DEVELOPING AN INTERVENTION TO REDUCE SEDENTARY BEHAVIOUR IN NON-AMBULANT YOUNG PEOPLE WITH LONG-TERM DISABILITIES (DOMORE).

by

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DOCTOR OF PHILOSOPHY

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Abstract

There is strong evidence that sedentary behaviour (> six - eight hours / day) increases risk of all-cause mortality, risk and incidence of cardiovascular disease mortality and incidence of type 2 diabetes in adults. Reducing children and young people's sedentary behaviour is also likely to positively impact health outcomes. Guidelines therefore advise children and adults to limit their sedentary time.

Children and young people with disabilities experience barriers to reducing sedentary behaviour. Non-ambulant young people (NAYP) with physical disabilities spend more time sedentary than able-bodied and ambulant young people with disabilities. No evidence-based interventions for NAYP specifically target sedentary behaviour.

The aim of this thesis was to co-design a digital behaviour change intervention (mobile application), which supports NAYP to reduce and break up sedentary behaviour by promoting light physical activity. The app was co-designed in partnership with stakeholders, using the Six Steps in Quality Intervention Development (6SQuID) model. Stakeholders included NAYP aged 12-25 years, family members of NAYP, health and educational professionals and experts in sedentary behaviour, disability and behaviour change / intervention development.

Step one of the 6SQuID, defining and understanding the problem and its causes, is reported in Chapters 2, 3 and 4. Undertaking a systematic search and review of the literature relating to sedentary behaviour and NAYP contributed to a defining of the problem and informed intervention development (Chapter 2). To understand the problem and its causes, a thematic analysis of data generated by stakeholders was undertaken to identify barriers and facilitators of sedentary behaviour of NAYP. Two

data collection methods were used: an innovative digital methodology (crowdsourcing) (Chapter 3) and virtual co-design workshops and interviews (Chapter 4). This was the first time crowdsourcing had been used to collect data as part of the 6SQuID. The Systems of Sedentary Behaviours (SOS) Framework describes six determinants of sedentary behaviour. The barriers and facilitators of sedentary time in NAYP identified by stakeholders were categorised into the six SOS Framework determinants of sedentary behaviour, prior to step two.

In step two (Chapter 5), stakeholders ranked the SOS Framework determinants of sedentary behaviour according to their potential for change. Three SOS Framework determinants which were amenable to change were selected. Fifteen barriers / facilitators to address within the intervention were chosen from these three determinants. The 15 barriers / facilitators were combined to formulate five intervention goals.

Step three (chapter 6) involved selection of a mid-range theory (Self-Determination Theory) to inform development of programme theory and production of a logic model for the intervention. Using the Behaviour Change Wheel (COM-B) approach, 11 mechanisms of action and 32 behaviour change techniques were selected from two taxonomies. Further data collection with stakeholders informed this decision making. Potential unintended outcomes of the intervention were discussed.

The thesis concludes at step four of the 6SQuID, delivering the change mechanisms. An implementation plan was formulated with stakeholders. A prototype app was produced and evaluated, using the Person-Based Approach to supplement the 6SQuID model. A table of changes prioritised modifications to be made in a first

iteration of optimisation prior to feasibility testing (step five). Strengths and limitations of this work and directions for future research are outlined in Chapter 8.

Dedication

I would like to dedicate this thesis to my husband Dale, who never doubted that this thesis would be submitted and to Lewis, my PhD dog, who patiently sat by my side for many hours, offering cuddles and kindness whenever it was needed.

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Publications and conference presentations

Publications

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Bradbury M. Getting sedentary young people with disabilities active. Frontline. 2020;26(2):45. ISSN: 2045-4910. URL: https://www.csp.org.uk/frontline/article/new-research-aims-get-sedentary-young-people-disabilities-active

Bradbury M, Bennison E, Mason H, Gregory J. Tools for participation: living aids and the F-words for childhood development. Paediatrics and Child Health. 2021;31(9):352-8. https://doi.org/10.1016/j.paed.2021.06.004

Bradbury M, O'Brien C, Giles N, Fenton S, Neilson S, Duda JL. Sedentary behaviour in non-ambulant children and young people with physical disabilities: a systematic search and review protocol. BMJ Open. 2021;11(12):e053077. https://doi.org/10.1136/bmjopen-2021-053077

Bradbury M, Tierney S. Perspectives of children with physical disabilities, parents and physiotherapists on use of walkers and their potential to increase physical activity. A qualitative exploration. Journal of Child Health Care. 2022;28(2):256-76. https://doi.org/10.1177/13674935221117868

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T Powell, M Bradbury, A Alayo, C Wood. Implementing Critically Appraised Topics (CATs) groups to embed evidence-based practice. Poster presentation. Research and Development Forum. 12th-14th May 2024. Cardiff, UK

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List of abbreviations

ANOVA: A one way analysis of variance

APEASE: Affordability, practicability, effectiveness/cost effectiveness, acceptability, side-effects/ safety, equity

AS: Adult Supporter

BCT: Behaviour change technique

BCW: Behaviour Change Wheel

BMI: Body mass index

CI: Confidence interval or chief investigator – context dependent

COM-B: Capability, opportunity, motivation – behaviour system

CP: Cerebral palsy

CPM: Counts per minute

DMD: Duchenne muscular dystrophy

GMFCS: Gross Motor Function Classification System

GMFM: Gross Motor Function Measure

HRQoL: Health-related quality of life

HPA: Habitual physical activity

HRR: Heart rate reserve

IQR: Interquartile range

LPA: Light physical activity

METS: Metabolic equivalents

MRC: Medical research council

MVPA: Moderate to vigorous physical activity

NAYP: Non-ambulant young people

NHS: National Health Service

PA: Physical activity

PARA-SCI: Physical Activity Recall Assessment for People with Spinal Cord Injury

PE: Physical Education

PEDI: Pediatric Evaluation of Disability Inventory

PPI: Public and patient involvement

RCT: Randomised control trial

SDT: Self - Determination Theory

SOS Framework: Systems of Sedentary Behaviours Framework

TD: typically developing / typical development

TDF: Theoretical Domains Framework

TV: Television

UK: United Kingdom

6SQuID: Six Steps in Quality Intervention Development

WHO: World Health Organisation

YP: Young people

1 Chapter 1: General introduction

1.1 Definitions

Throughout this thesis, the term non-ambulant young people (NAYP) is used to describe young people who do not walk, or only walk short distances indoors using a support walker due to long-term physical disabilities. NAYP may have conditions such as cerebral palsy (CP), spina bifida, muscular dystrophy, spinal / head injury or rare conditions. Support walkers (or gait trainers) have wheels and provide support for the trunk, pelvis or head (1). They are often used as part of physiotherapy programmes, in physical education or gross motor skills sessions at school or to participate in recreation and leisure activities such as disability sports. They are rarely used for mobility in the community.

Gross Motor Function Classification System (GMFCS) levels classify level of functional mobility for children and young people with CP (2), with level I being a mild mobility limitation and level V representing severely limited mobility. Those in levels IV-V are non-ambulant.

Sedentary Behaviour is defined as “any waking behaviour characterized by an energy expenditure ≤1.5 metabolic equivalent units (METs) while in a sitting or reclining posture” (3). Sedentary time is the total amount of time spent performing sedentary behaviours throughout the day (4).

1.2 Sedentary behaviour

In the field of physical activity research, sedentary behaviour is the lowest intensity of physical activity on the physical activity continuum (Figure 1). Adults and children

typically spend 55% of their waking hours being sedentary (5). World Health Organisation (WHO) guidelines on physical activity and sedentary behaviour advise that limiting sedentary time improves health and that everyone can benefit from reducing sedentary behaviour, including those with disabilities (6). These guidelines are based on strong evidence that high levels of sedentary behaviour, such as high total sitting or television (TV) viewing time, increases the risk of all-cause mortality, cardiovascular disease mortality and incidence of cardiovascular disease and type 2 diabetes, moderate evidence that it is associated with developing endometrial, colon or lung cancer and limited evidence suggesting it's associated with cancer mortality and weight status (7, 8). This increased risk is highest when total sitting volumes exceed eight hours per day (all-cause mortality) or six hours per day (cardiovascular disease) and TV viewing exceeds three-four hours / day (8). As international trends demonstrate increasing levels of sedentary behaviours associated with increases in screen time and prevalence of sedentary occupations (9-12), the associations between sedentary time and poor health are concerning. National Health Service (NHS) costs associated with sitting for ≥ six hours/day were estimated to be 0.8 billion in 2016-17 and 69,276 deaths might have been avoided if prolonged sitting was eliminated (13).

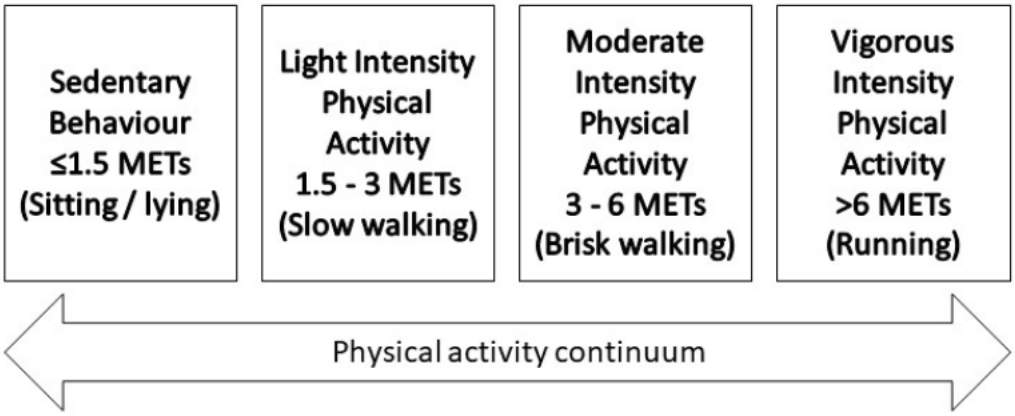


Figure 1 The four levels of the physical activity continuum. METs: metabolic equivalent units (14).

There is conflicting evidence in relation to whether long periods of uninterrupted sedentary time add to the negative effect total sedentary time has on all-cause mortality (7). In a study of adults in the US, a significant relationship between all-cause mortality and participants who had sedentary bout durations of ≥10 min and were sedentary for ≥12 hours / day was demonstrated ($p < 0.001$) (15). However, in older men in the United Kingdom (UK), breaks in sedentary behaviour and duration of bouts of sedentary time were not associated with all-cause mortality (16). There is evidence that the hazards of sedentary behaviour are magnified in physically inactive people (7).

In physical activity research, sedentary behaviour, physical inactivity and physical activity are clearly defined constructs which have independent associated health risks and benefits (3, 8). Being physically inactive is performing insufficient moderate to vigorous physical activity (MVPA) in comparison to recommendations given in physical activity guidelines (17). People who perform the recommended amount of MVPA are considered to be physically active (17). It is therefore possible to be highly

sedentary and physically active on the same day if the required amount of MVPA is undertaken, but the majority of the day is spent being sedentary. It is also possible to be inactive but not sedentary, if for example someone stands up for most of the day, but they do perform any moderate to vigorous physical activity.

1.2.1 Sedentary behaviour in children

In children, evidence suggests that sedentary time (particularly recreational screen time), is associated with poor health outcomes such as reduced fitness (18, 19), poor cardiometabolic health (18), spending less time sleeping (20), overweight / obesity , lower quality of life (21), higher depressive symptoms (22), unfavourable behavioural conduct (18) and low self esteem (18). Spending large amounts of time TV viewing and playing video games is associated with behavioural difficulties (23). High levels of screen time can be associated with poor mental health and anxiety (23, 24). However, there is evidence that sedentary behaviours such as reading and doing homework improve academic achievement (23). A relationship between children and adolescents bone health and sedentary time has not been demonstrated (25). It appears that spending less time sedentary improves health outcomes for children, however, a dose–response relationship cannot be demonstrated at present (23). As a result, it is not possible to provide evidence-based thresholds for how long can safely be spent doing activities such as recreational screen time (26).

In a study including children and adolescents in Europe, boys were less sedentary than girls, regardless of age group (27). Sedentary time was related to age, increasing progressively between four-five and 16-17 years, with a large increase observed between six-seven and eight-nine years (27). Adolescents are more

sedentary than younger children, spending 57% of their after-school time (end of school to 6pm) doing sedentary activities (28).

When impact of high levels of sedentary behaviour on adults and children are compared, there are some similarities, such as increased risk of poor cardiometabolic health and obesity. In children, alternative and additional outcomes such as sleep and mental health have been taken into account. Physical activity guidelines relating to sedentary behaviour are the same for adults and children and young people aged five-18 years in the UK (26). They state that individuals should "aim to minimise the amount of time spent being sedentary, and when physically possible should break up long periods of not moving with at least light physical activity" (26). The WHO guidelines for children and adolescents (five-17 years) recommend that "children and adolescents should limit the amount of time spent being sedentary, particularly the amount of recreational screen time." (23). It is important to consider that although the latter is a strong recommendation, the guidelines highlight that the evidence certainty is low. This is due to much of the evidence being from cross sectional studies, in which causality cannot be attributed. Also, many of the studies relied on retrospective self-reported or parent-reported measures that are prone to recall and social desirability bias (4).

1.2.2 Measurement of sedentary time

Measurement of sedentary time is a complex and rapidly evolving field. Objective, device-based measurement using accelerometers and / or inclinometers is considered more robust than self-reported measures; which introduce risk of recall and response bias (29). However, analysis of accelerometer / inclinometer data from free-living contexts is complex. Variation in devices, wear protocols, classification of

intensity of physical activity, data cleaning protocols and definitions of bouts and breaks in physical activity makes comparison of studies measuring sedentary time difficult (30). Measuring sedentary behaviours of people with physical disabilities who may use a wheelchair or have atypical movement patterns which are not recognised by existing algorithms adds additional challenges. Accelerometers worn on the hip or the centre of the lower back may not count activities such as self-propelling a wheelchair or cycling, and accelerometers may count movements that are not initiated by young person because they are being passively moved by a carer, during personal care for example (31, 32). Some device based and self-reported measures have been validated for adults who use a wheelchair and have CP, spina bifida, spinal cord injury and scoliosis, but no devices have been validated for NAYP at present (32). Sedentary time has been measured in non-ambulant participants with Duchenne Muscular Dystrophy using wrist and ankle accelerometers, however cut points for healthy children were employed and the variability and reliability of accelerometery as an outcome measure was not investigated (33). In adults who use a wheelchair, the self-reported Physical Activity Scale for Individuals with Disabilities and the Physical Activity Recall Assessment for People with Spinal Cord Injury were promising for physical activity intensity measurement (32). The GENEActiv, Actigraph GT3X+, Actiheart, or Physical Activity Monitor System devices showed moderate evidence of criterion validity for measuring physical activity intensity (32). The Physical Activity Monitor System and VitaMove have good evidence of criterion validity for measuring type of physical activity (32). The Physical Activity Monitor System uses a biaxial gyroscope placed between the spokes of the wheelchair, a triaxial accelerometer worn on the right wrist and / or a triaxial accelerometer placed

on the right upper arm (34, 35). The VitaMove has accelerometers on the sternum, both wrists and the lateral side of the mid-thighs bilaterally (36). The accelerometers on the lateral side of the mid-thigh were only worn by partially ambulant children. Only the Physical Activity Monitor System was valid to measure both intensity and type of physical activity (32). These complexities make it challenging to rigorously measure the impact interventions have on sedentary time of wheelchair users.

1.2.3 Sedentary behaviour and physical activity of people with physical disabilities

People with disabilities face environmental and social barriers that limit their opportunities to undertake physical activity (37). Children with physical disabilities spend more time sedentary than able-bodied children (38). As observed in able-bodied children and young people, older children and young people with disabilities are the most sedentary (39, 40), however no difference between boys and girls has been highlighted in this population (38). A recent rapid evidence review relating to physical activity for disabled children and young people concluded that the risks associated with a sedentary lifestyle outweighed any risks associated with participating in physical activity (41). This review acknowledged an evidence gap about the association of sedentary behaviour and health outcomes for this population, and therefore it is not possible to give more specific guidance than previously issued, to limit sedentary time, particularly recreational screen time (41). A similar rapid evidence review was undertaken for adults with disabilities (42) resulting in an infographic being co-produced with them (43). The infographic gives the following advice relating to sedentary behaviour; “don’t be still for too long” and “even a little movement is better than nothing”.

The WHO guidelines on physical activity and sedentary behaviour for children and adolescents with disabilities also highlighted the evidence gap in relation to sedentary time (44). In the absence of any evidence to suggest disability would alter the health outcomes associated with sedentary time in the general population, expert opinion agreed that the guidance for the general population could be extrapolated for children and adolescents with disabilities (44). The WHO acknowledge that more research to explore physical activity and sedentary time of people with disabilities is needed (37). It has been recommended that this future research explores types (for example physical / cognitive / sensory) and degrees of impairment (mild to severe) rather than specific conditions (37), which is in keeping with the population this thesis focuses on.

Sedentary lifestyles are associated with poorer physical components of health-related quality of life in young people with CP in comparison to the population norm (45). In young adults with CP, associations between fatigue and sedentary lifestyle have been demonstrated (45). A correlation between increased sedentary time and reduced sleep quality has also been demonstrated for children with CP, but is more evident in ambulant children (46). In children and young people with Duchenne Muscular Dystrophy, many of whom are non-ambulant, sedentary behaviour is negatively associated with lean body mass, (47) and is correlated with left ventricular ejection fraction and left ventricular cardiac index, indicating that it could contribute to the cardiomyopathy they develop (48). With the exception of these studies, research exploring associations between sedentary behaviour and health outcomes for children and young people with disabilities is minimal (41).

It is clear that NAYP with CP (GMFCS levels IV - V) are at higher risk of a number of non-communicable diseases and multimorbidity than both able-bodied young adults and ambulant young adults with CP (49, 50). Some of these diseases / conditions are commonly associated with high levels sedentary time. Young adults with CP (GMFCS I-V) have a higher prevalence of osteopenia, osteoporosis, hypertension, myocardial infarction, hyperlipidemia, asthma, and multimorbidity compared to young adults without CP, and are at higher risk of developing musculoskeletal morbidity, cardiometabolic morbidity, and multimorbidity (45). In comparison to those in GMFCS levels I-III (ambulant), those in levels IV-V (non-ambulant) have a greater risk of dysautonomia (high blood pressure, heart rate, respiratory rate and low blood oxygen saturation / body temperature) (50), a higher prevalence of osteopenia/osteoporosis, osteoarthritis, hypertension, other cardiovascular conditions, pulmonary embolism and multimorbidity, and higher risk of developing morbidity related to musculoskeletal, cardiometabolic or pulmonary conditions and multimorbidity (49). Although the link between sedentary time and increased prevalence of these conditions for young adults in GMFCS level IV-V is not clear, it seems likely that sedentary time could be a modifiable contributing factor. Indeed, an association between sedentary behaviour and elevated blood pressure has been demonstrated in ambulant children with CP (51).

There is some evidence relating to the metabolic effects of breaking up sedentary time for adults with physical disabilities. Bailey et al. found breaking up prolonged sedentary time attenuated postprandial glucose levels after a standardised test meal (lunch), however the same effect was not observed after a breakfast test meal (52). Breaking up sedentary time also improved mood. These findings may have clinical

relevance, as they suggest breaking up sedentary time may reduce the high risk of developing cardiovascular disease that adults with physical disabilities face and may improve their well-being (52).

Research exploring barriers and facilitators to physical activity for young people with CP has identified negative experiences of physical activity, environmental factors (physical / structural), negative attitudes, GMFCS level, policy barriers and lack of personal support from professionals, parents and friends as barriers (53, 54).

Support from healthcare professionals to encourage young people to participate in active leisure pursuits they enjoy has been highlighted as a facilitator of increased physical activity (55). Making friends and having fun was a motivating factor for young people with Duchenne muscular dystrophy and insufficient health was a barrier (56). Parents' of children with CP who were discussing their child's participation in physical activity identified the following themes: "belonging and taking space in the family", "important persons facilitating and hindering", "friends important but hard to get", "good for the body but challenging", "availability and opting out possibilities" and "protecting and pushing towards independence" (57). They wanted reassurance that there were competent people available to support their child. Family culture and attitudes affected their child's motivation for being physically active.

Another study exploring barriers / facilitators to participation in physical activity for youth with CP highlighted personal, family, and social level factors including self-confidence, persistence, athletic competence, parental participation in physical activity and close friendship experiences as modifiable factors to consider when designing interventions (58). These studies have focused on physical activity in

general. There is an evidence gap in relation to barriers and facilitators of reducing sedentary time.

1.2.4 Interventional studies for children and young people with physical disabilities in which sedentary behaviour has been measured

There are no interventions which are specifically designed to reduce sedentary behaviour of children / young people with physical disabilities, or that only aim to reduce sedentary behaviour. However, there are interventional studies that aim to increase physical activity (59, 60), increase physical activity and reduce sedentary time (61, 62), increase habitual physical activity (63) and increase aerobic capacity and activity levels (64) that have measured the impact their intervention had on sedentary time or behaviour.

Four of these studies included children with CP (59, 61, 63, 64), one was for children with Down's Syndrome (60) and one was for children with a range of physical disabilities (62). The studies for children with CP were 1) a randomised control trial (RCT) to determine the effectiveness of an internet based physical activity intervention for children in GMFCS levels I-III (ambulant children) (59), 2) evaluating feasibility of physical activity prescription for children in GMFCS levels I-V (ambulant and non-ambulant children) (61), 3) an RCT investigating the efficacy of an eight-week goal-directed, individualised, participation-focused therapy intervention for children in GMFCS levels I-III (ambulant children) (63) and 4) a 12 week RaceRunning intervention for young people in GMFCS levels III-IV (ambulant and non-ambulant children) (64). In both RCT's (59, 63) and the RaceRunning intervention (64), there was no significant change in sedentary time. Lauruschkus et al. (61) evaluated the feasibility and effectiveness of using face to face motivational

interviewing and production of a physical activity prescription to increase participation in physical activity and to reduce sedentary behaviour (61). Overall, sedentary time (measured by a validated physical activity questionnaire, a diary and via accelerometer) increased between baseline and follow up at 8 months (61). The study for ambulant children with Down's Syndrome investigated the effects of a bicycle riding program on physical activity and health related outcomes (60). This intervention reduced sedentary time at seven weeks and 12 months post intervention. Bedini et al. described a community based adaptive sports model (Bridge II sports) to increase physical activity and reduce sedentary time for children with a range of physical disabilities, however pre and post intervention outcomes were not reported (62). Interventions for NAYP that focus solely on reducing sedentary behaviour and are co-designed for this purpose may be more successful.

A number of studies that included non-ambulant children and young people have explored whether a specific intervention produced a physiological response which interrupted sedentary time. The first was to determine energy expenditure in lying, sitting and standing (including use of standing frames) for children with CP in GMFCS levels I-V (65). The results showed standing (with or without a standing frame) exceeded the threshold of 1.5 METS for sedentary time (65). A study exploring the effects of dynamic standing on blood glucose and blood lactate for NAYP with CP used a motorised device which enabled assisted passive movements in a weight bearing position as an exercise intervention (66). As there is evidence that use of standing frames interrupts sedentary time (65), it is likely that this similar intervention would also. The results showed elevated blood lactate at rest and after exercise in this group, with participants in GMFCS V having significantly higher blood lactate

than those in GMFCS level IV. Participants with higher resting blood lactate showed a significantly larger reduction in blood lactate after exercise than those with lower resting levels (66), suggesting that interrupting sedentary time with this intervention reduced blood lactate for participants with high resting levels. Another study found that both passive standing and repeated performance of the highest Gross Motor Function Measure (GMFM) assessment task individuals could perform significantly increased heart rate in GMFCS level IV participants, but not those in GMFCS level V (67). Asselin et al. (2015) found powered exoskeleton-assisted walking in NAYP with paraplegia interrupted sedentary time (68). Finally, an exploration of the physiological demands of therapeutic horseback riding for children with moderate to severe motor impairments showed that riding achieved both light (13.4% of riding time) and MVPA (21.8% of riding time) and therefore interrupted sedentary time, despite the rider remaining in a seated position or lying position (69).

The evidence relating to sedentary behaviour in non-ambulant children and young people is explored in depth in Chapter 2. Four questions relating to measurement and patterns of sedentary behaviour, risks associated with sedentary behaviour and interventions to reduce sedentary behaviour in this specific population are addressed.

1.2.5 Physical activity apps for adults who use a wheelchair

Adults with spinal cord injury who use a wheelchair have tested a just-in-time adaptive intervention delivered via an app to increase their physical activity in a pilot study (70). Although sedentary time was not measured, this intervention, which provided real-time feedback about physical activity from an activity monitor, showed an increase in light and moderate physical activity for 69% of the participants. It is

therefore likely that sedentary time reduced as light and moderate activity increased for these participants.

1.2.6 Rationale for developing a new intervention

The need for effective interventions to be developed that reduce sedentary time for underserved groups in addition to the general population has been highlighted (71), inclusive of children and young people with physical disabilities specifically (72). There are no evidence-based interventions that specifically aim to reduce sedentary behaviours for NAYP (38). The behaviour change intervention co-designed in this thesis aims to address this.

1.3 Complex intervention development methods

Interventions are deemed to be complex when they involve properties such as: multiple components, targeting a range of behaviours, expertise and skills being required to deliver / receive the intervention, targeting a number of groups / settings / levels, or some flexibility of the intervention or its components being required (73).There is a large, rapidly growing evidence base relating to complex intervention development. Recent developments in this field (including a paradigm shift from the key outcome being demonstration of effectiveness to a more pluralistic approach (73)) have resulted in a requirement to update the Medical Research Council's (MRC's) 2006 guidance for developing and evaluating complex interventions (74). The new guidance (2021), describes four research perspectives which can be applied during complex intervention design (efficacy, effectiveness, theory based and systems). These perspectives are overlapping and can be combined (73). In the new framework, four phases of research design are described: development / identification of an intervention, feasibility, evaluation and implementation (Figure 2)

(73). There are six core elements which should be considered in every phase: context, programme theory, stakeholders, key uncertainties, refinement and economic considerations.

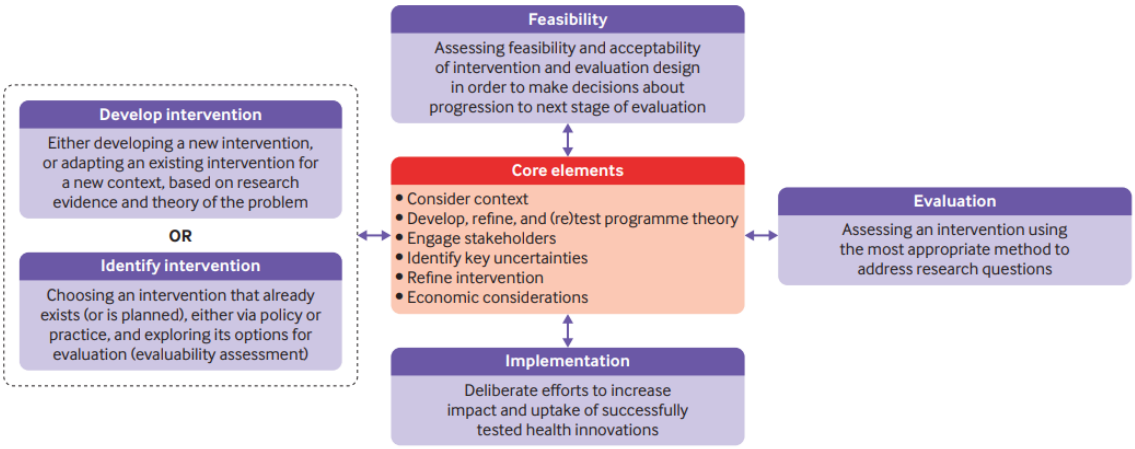


Figure 2 MRC framework for developing and evaluating complex interventions. Reproduced with permission from Skivington et al.(73). This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) license. See: https://creativecommons.org/licenses/by/4.0/. No changes have been made to the original figure.

This thesis focuses on the first of the four phases described in the MRC guidance, intervention development. This phase covers all the processes involved from initial conception to the beginning of phase two, feasibility. This phase is described in 11 key actions in the INDEX study guidance (75). These key actions were formulated and described based on expert opinion, because it remains unclear which key actions during the process result in production of effective health interventions (75). A rigorous process of 1) reviewing published intervention development approaches (76), 2) undertaking qualitative interviews with stakeholders, 3) undertaking a Delphi study, then 4) undertaking a consensus workshop was followed.

The review of published approaches (76) identified 21 different approaches to intervention development, which are listed below.

- Co-design
- User driven
- Experience based co-design
- Person-based
- User-centred
- Human-centred design
- MRC Framework for developing and evaluating complex interventions
- Behaviour change wheel
- Intervention mapping
- Matrix Assisting Practitioner's Intervention Planning Tool
- Normalisation process theory
- Theoretical domains framework
- Reach, Effectiveness, Adoption, Implementation, Maintenance
- Multiphase optimization strategy
- Multi-level and fractional factorial experiments
- Micro-randomisation trials
- Six essential Steps for Quality Intervention Development
- Five actions model
- Obesity-Related Behavioural Intervention Trials
- Digital (e.g. Integrate, Design, Assess and Share)
- Patient decision support or aids
- Group interventions
- Participatory Action Research based on theories of Behaviour Change and Persuasive Technology

These approaches were condensed into eight intervention development categories:

1) Partnership (with stakeholders)

2) Target-population centred

3) Theory and evidence-based

4) Implementation-based

5) Efficiency-based

6) Stepped or phased based

7) Intervention-specific

8) Combination.

Consideration of existing theory during intervention development is strongly advocated (73, 77-80) to: 1) inform the intended goals of the intervention by identifying what is important, relevant and feasible, 2) enable developers to explicitly state the intended mechanisms of action of the intervention, 3) inform the content and delivery of the intervention and 4) make it more likely that the intervention will be effective (75, 76). However, a recent review of reviews concluded that there is no evidence that theory-based interventions are more effective than non-theory based interventions (81). The review included nine systematic reviews which included RCTs of health behaviour change interventions for adults and were published between 2007 and 2017. The RCTs in the reviews included individuals with type 2 diabetes, cardiovascular disease, obesity, healthy adults and individuals of retirement age. The reviews included interventions for: diet and physical activity, multiple behaviour changes; diabetes self-management, cardiac rehabilitation and smoking behaviours. Theory-based interventions were no more effective than non-theory based interventions in eight/nine of the reviews. There was some evidence suggesting that interventions based on control theory, motivational interviewing, and self-determination theory in particular were associated with greater effectiveness for physical activity and/or dietary interventions and outcomes.

This review of reviews does not indicate that utilising theory is not beneficial with certainty, as methodological and reporting issues in the RCTs and the reviews were identified (81). Reporting of theory use lacked detail, with use of dichotomous reporting of use of theory versus no use of theory in eight/nine reviews. Methodological limitations identified by the review included failure to include tables of excluded studies, not stating conflict of interests and funding sources for review authors and their included studies, not including grey literature or stating language criteria in the inclusion criteria and pooling data from RCT's without consideration of their differing follow up lengths. Overall, quality of the nine included reviews was very low to moderate when appraised using the AMSTAR (A Measurement Tool to Assess Reviews) instrument (82). Many of the RCTs in the reviews had high / unclear risks of bias which could have reduced reliability of the results.

Despite these limitations, this review of reviews (81) and the evidence gap relating to which intervention development processes result in development of effective interventions (75) raises questions about our understanding of how to develop an effective intervention. To address this, the INDEX study produced guidance to summarise the 11 key actions and eight intervention development categories (listed above) identified in their Delphi study and consensus workshop (75). The 11 key actions are listed below.

1. Plan the development process
2. Involve stakeholders
3. Identify a team and decision making process
4. Review the published evidence
5. Draw on existing theory

6. Develop and describe and refine the programme theory
7. Undertake primary data collection
8. Understand context
9. Consider future implementation of the intervention realistically
10. Design and refine the intervention
11. End the development phase

In the absence of research to demonstrate whether any of the eight categories of intervention development are more successful than the others (76), combining them creates an opportunity to provide additional strength and rigor to the process. The approach taken in this PhD is the eighth category; combining published approaches. This intervention development combines the following intervention development categories:

1) Partnership (co-design and community-based participatory research, person-based approach (83))

3) Theory and evidence-based (behaviour change wheel (77), theoretical domains framework (84), self-determination theory (85))

6) Stepped or phased based (Six Steps in Quality Intervention Development (86))

7) Intervention-specific (digital delivery)

These approaches and how they have been used in development of this behaviour change intervention are described in the following sections of the introduction.

1.3.1 The Six Steps in Quality Intervention Development model

The Six Steps in Quality Intervention Development (6SQuID) (86) is a stepped based approach (76). It draws on strengths of frameworks such as intervention mapping (79), and the Medical Research Council guidance for the development and evaluation of complex health interventions (73). It also simplifies the complexities of intervention mapping and provides guidance relating to the early stages of intervention development. The six steps of the model are shown in Figure 3.

The 6SQuID model has been used to develop digital interventions (87), interventions for adolescents (88) and interventions to address sedentary behaviour (89) previously. Pringle et al. described how they operationalised the 6SQuID model to develop an intervention to support positive health related behaviours for adolescents (88). Sinclair et al. concluded that following the model had made the digital intervention they developed to support women with breast cancer to monitor and reduce their alcohol intake where necessary more acceptable and feasible. The model was used to develop the “Stand up for Health” intervention to reduce sedentary time of workers in contact centres (89). The intervention was acceptable and feasible, however a larger RCT identified that the stepped wedge research design selected was not feasible and that more hybrid activities that applied to those working at home and in an office were needed (90). Although there are no examples of the 6SQuID being used to develop interventions for people with disabilities, these examples demonstrate why it is an appropriate model for designing this intervention.

The 6SQuID model has provided an overarching structure for the intervention development process described in this thesis (86). The work included in this PhD thesis ends at step four with the production and evaluation of a prototype mobile application (app).

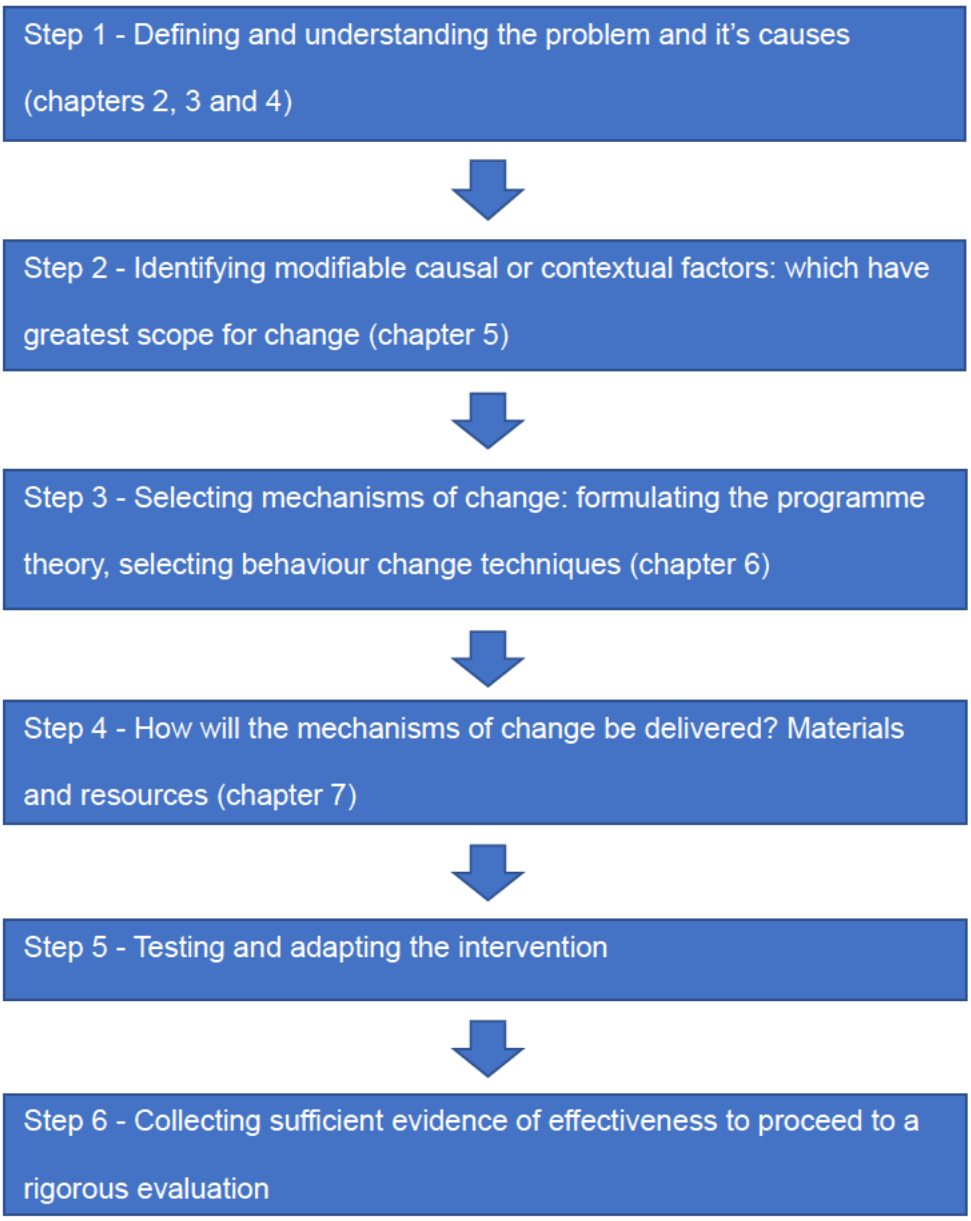


Figure 3 The Six Steps in Quality Intervention Development and how they relate to the thesis chapters (86).

1.3.2 Partnership approach

Meaningful engagement of key stakeholders is a core element of complex intervention development (73). NHS England's Ladder of Engagement and Participation (91) (Figure 4), which is based on Arnstein's Ladder of Citizen Participation (92), assists with understanding the term meaningful engagement. The rungs of informing and consulting can both be considered to include a degree of tokenism, because stakeholders do not necessarily have any influence over the decisions being made (92) and therefore their participation may not be meaningful. Co-design operates at the rung of collaborating and occasionally at the level of devolving, when decision making is placed in the hands of the stakeholders (91). Frauenberger et al. have adapted Arnstein's Ladder of participation to describe three levels of participation found in design work involving children with disabilities (93). They describe non-participatory approaches, participation via proxy (where parents or teachers describe children's needs) and full participation, where children with disabilities themselves have a direct impact on decision making. Throughout the complex intervention development in this thesis, the aim has been for stakeholders (our participants) to be collaborating with the research team as equal partners or decision makers, adopting this full participation approach.

Devolving	Placing decision-making in the hands of the community and individuals. For example, Personal Health Budgets or a community development approach.
Collaborating	Working in partnership with communities and patients in each aspect of the decision, including the development of alternatives and the identification of the preferred solution.
Involving	Working directly with communities and patients to ensure that concerns and aspirations are consistently understood and considered. For example, partnership boards, reference groups and service users participating in policy groups.
Consulting	Obtaining community and individual feedback on analysis, alternatives and / or decisions. For example, surveys, door knocking, citizens' panels and focus groups.
Informing	Providing communities and individuals with balanced and objective information to assist them in understanding problems, alternatives, opportunities, solutions. For example, websites, newsletters and press releases.



Figure 4 NHS England: Ladder of Engagement and Participation (91). Permission is granted by NHS England for this image, which is in the public domain, to be used as a best practice tool by NHS England staff. No changes have been made to the original figure.

Co-design and participatory research are both co-creation models (94, 95) which have been utilised in this complex intervention development. They have differing origins, but share similar key principles:

- a systems perspective of multiple and complex interacting factors that generate unpredictable outcomes,
- research is creative and human experience is at its core,
- when working in partnership with stakeholders, the quality of the relationships is important. Facilitation techniques that promote power sharing and utilise conflict positively are needed (94, 95).

Design is a human centred approach to problem solving that is collaborative, but does not necessarily involve the end user (95). The terms co-design and participatory design can be used interchangeably and mean that the end user is an active participant in the design process (96).

Community-based participatory research is defined as “an orientation to research that emphasizes ‘equitable’ engagement of partners throughout the research process, from problem definition, through data collection and analysis, to dissemination and use of findings to help effect change.” (97). This model recognises the power imbalance between researchers and stakeholders and that mutual trust, built over time to work towards a shared goal, is required (94).

1.3.2.1 Involving children and young people with disabilities in partnership approaches

It is acknowledged that children with disabilities have had fewer opportunities to influence technology design than typically developing children (98). Often, parents and professionals are involved in co-design of interventions for children and young people with disabilities, but not the child / young person themselves (99-102). However, children with physical disabilities such as cerebral palsy, spina bifida, neuromuscular conditions and multiple / complex needs have previously participated in technology design (98). They have been involved in designing upper limb rehabilitation equipment (103), communication devices and methods (104, 105), a mixed-reality game (106), educational apps and software (107, 108), exergames (109), personas for health based games (102) and seating systems (110).

Some conference proceedings have been published exploring engagement of children with severe disabilities (including being limited to non-verbal communication), in co-design (111, 112). They highlighted 1) the need for additional time, 2) a lack of familiarity with being an active decision maker and not a recipient and 3) the use of proxies to facilitate communication (who may misinterpret the

child's communication), as tensions when co-designing with this group (111). Guidelines for managing the co-design process with them included accepting awkwardness, advocating for the child's self-expression, using low tech interactions, interacting with multiple care givers, learning how the child indicates that they want to stop, working with other teams involved in caring for the child, breaking work down into small tasks and working in small groups (112).

How children's ideas have been incorporated into final intervention designs is often not clear or transparent in co-designs involving children with disabilities (98). This makes it difficult to evaluate the impact of their participation. There are examples where children's feedback about initial prototypes has directly informed subsequent versions, for example: 1) including different versions of a magic wand in a digital photographic tool (105) 2) incorporating children's game and character ideas into an exergaming intervention and 3) adapting games based on feedback provided after an eight week home trial (109). One barrier to clearly reporting how children's participation has influenced the intervention being designed is the level of adult help required (98). Often children will contribute in a 1:1 environment with the researcher and a supporting carer / parent / guardian present, due to the need for support with communication. This results in multiple differing ideas being suggested, which the designers then need to reconcile into one solution (98). Due to these complexities, the impact that contributions from children with disabilities have on effectiveness of interventions has not been explored (93).

Despite a lack of evidence of the impact co-designing with young people with disabilities has on effectiveness of intervention; there is qualitative evidence from multiple sources that the participants themselves benefit from involvement in early

design activities and feeding back on initial protocols (98). Benefits observed include: enjoyment, empowerment, improved engagement, ownership or pride, increased confidence, taking more responsibility, better behaviour, feeling competent, development of creativity, development of team work and social skills (98).

Throughout the stepwise progression of this intervention development, engagement of participants in the co-design as equal partners has been central to the selection of research methods and decision making. Participants were invited and encouraged to contribute at each 6SQuID step. Their contributions determined the direction of the subsequent steps.

1.3.2.2 Crowdsourcing

In the first step of the co-design (Chapter 3), a novel co-design methodology was explored. Crowdsourcing involves inviting a defined group of volunteers “the crowd”, via an open advertisement, to undertake a task with a clear goal via a participative online process (113). Using crowdsourcing to undertake the 6SQuID intervention development steps was proposed. Questions were posted by the researchers, with the intention of creating an interactive online dialogue between the contributors. It was proposed that collecting data in this way would overcome barriers to participation that young people with disabilities and their parents may face, by allowing plenty of time for people with varying physical, communication and learning abilities to communicate their responses, eliminating the need for travel and offering flexibility, as participants could contribute at a convenient time for them.

1.3.2.3 The Person-Based Approach

In step four of the co-design (delivering the change mechanism), an additional intervention development approach was drawn upon. This fourth step involved production and evaluation of a prototype app. Methods and resources described in the Person-Based Approach to intervention development were employed (83). The Person-Based Approach was developed specifically for co-designing digital behaviour change interventions which aim to improve health outcomes. It's focus on implementation of behaviour change techniques via digital delivery and compatibility with human-centred and user-centred design disciplines (114, 115) made it particularly useful to this step of the intervention development. The three common intervention design objectives described in the Person-Based Approach, (1) promoting user autonomy, 2) promoting user competence and 3) promoting a positive experience and sense of relatedness) were based on the three constructs of Self - Determination Theory (SDT) (85). SDT is also informs the intervention being co-designed in this thesis. The person-based approach has two key elements, 1) a developmental process involving in depth qualitative research with stakeholders, 2) identification of guiding principles that highlight how the intervention will address context-specific behavioural targets (83). Think-aloud qualitative methods (116) and the table of changes (117) template form the Person-Based Approach were particularly relevant to this work.

1.3.2.4 Public and Patient involvement

Involvement and engagement of the public and patients in the design and delivery of this research has also been central to the partnership approach. There has been meaningful public and patient involvement at every stage from developing a grant

application to dissemination of results. Contributions of public and patient involvement representatives are described in each chapter.

1.3.3 Theory and evidence-based approach

Use of evidence and theory has been integrated throughout the intervention development. The 6SQuID model (86) has been used to structure this intervention development. This is an evidence-based model, developed using existing frameworks in addition to drawing upon its author's extensive intervention development experiences. To ensure the intervention development is evidence-based, a systematic search and review (Chapter 2) was used to define the problem the intervention would address and to inform the focus of the subsequent steps.

Existing frameworks and models which have guided and informed the intervention development include the Systems of Sedentary Behaviours Framework (118) (Chapter 4), the Behaviour Change Wheel (77), Theoretical Domains Framework (TDF) (84), and SDT (85) (Chapter 6).

1.3.3.1 Systems of Sedentary Behaviours Framework

The Systems of Sedentary Behaviours Framework (118) is an international transdisciplinary consensus framework which maps determinants of sedentary behaviour across the life course. The rigorous development process and its focus on sedentary behaviour make it an ideal framework for categorising barriers and facilitators to moving participant's identified in step one of the 6SQUiD. The framework is presented as a systems-based map (118) (Figure 8, Chapter 4). This map overcomes limitations of the ecological model of sedentary behaviour, by capturing the complex interplay between determinants. It broadens a single

theoretical ontological position by including multidisciplinary perspectives, accounting for social and ethnic diversity and removing the epistemological assumption that spheres of influence are hierarchical (118). An intended use of the framework was to engage stakeholders in co-design of complex interventions by identifying which group of determining factors could influence sedentary behaviour for their specific population. In this thesis it has been used in this way. It has also been used to identify methods of influencing sedentary behaviours of patients who have suffered a stroke at a UK stroke forum (118) and by Bianco et al. to categorise 79 possible determinants of physical fitness level of adolescents (identified via a survey) into three broad dimensions (119). Lepson et al. referred to this framework in step three of their 6SQuID intervention development, to ensure that interactions between various levels of the socioecological model were considered in addition to the multiple levels the intervention was acting at (90).

1.3.3.2 The Behaviour Change Wheel and COM-B

The behaviour change wheel (BCW) is a theory and evidence-based tool which facilitates both design and characterisation of behaviour change interventions (77). It was developed in consultation with behaviour change experts. A systematic search and evaluation of existing behaviour change frameworks was undertaken, which identified 19 frameworks that matched the inclusion criteria (120). Nine intervention functions and seven policy categories that could enable interventions were identified from the 19 frameworks. The creators of the BCW proposed a behaviour system which makes the hub of the wheel. The system has three components, capability, opportunity and motivation (COM). The behaviour system was therefore abbreviated to COM-B (120). The wheel hub is surrounded by two rings which contain the

intervention functions and policy categories (Figure 5) (120). The COM-B components are linked to specific intervention functions, and the intervention functions are linked to specific policy categories to guide intervention development (77). The BCW tool encourages intervention designers to 1) define the problem the intervention will address in behavioural terms, 2) select a target behaviour and 3) gain a theoretical understanding of it in order to identify the mechanisms that need to change to achieve the target behaviour (77). These mechanisms are known as mechanisms of action (121) and many are described in the TDF (84). The TDF simplifies psychological theories relevant to behaviour change by bringing together 84 constructs from 33 behaviour change theories and dividing them into 14 domains, or mechanisms of action. When the mechanisms of action are decided, it is possible to identify which intervention functions are likely to be most effective and select behaviour change techniques (122) that are linked to the intervention functions and mechanisms of action.

An example of a behaviour change intervention for children with physical disabilities which has utilised COM-B is ParticiPAte CP (63). The intervention is for ambulant children with CP (GMFCS levels I-III) aged eight-12 years. The BCW and the TDF form its theoretical basis. The intervention effectively increases perceived performance of physical activity participation goals (63). A detailed content analysis of the intervention has been published, which identified barriers to participation in all TDF domains (123). The TDF domains targeted in the intervention were social influences, environmental context and resources, intentions, skills, knowledge, and beliefs about capabilities. Six of the nine intervention functions of the BCW were employed, and 32 behaviour change techniques (123).

1.3.3.3 Intervention functions and behaviour change techniques used to reduce sedentary time

In adults, education, persuasion, environmental restructuring, and training are promising intervention functions in interventions to reduce sedentary behaviours (124). The following behaviour change techniques are promising to reduce sedentary time in adults: self-monitoring, problem solving, restructuring the social environment, providing information on health consequences, behaviour substitution, unspecified social support, providing feedback on behaviour, setting outcome goals, reviewing behavioural goals, using prompts or cues, providing practical social support, restructuring the physical environment, behavioural practice or rehearsal, pros and cons, social rewards, habit formation, commitment and discrepancy between current behaviour and goals (124).

Tracking / self-monitoring is the most frequently used and most effective strategy in persuasive technologies to increase physical activity or reduce sedentary behaviour (125). Aldenaini et al. found it was used in 90% of persuasive technology studies and 79% of the studies employing it were effective or partially effective (125).

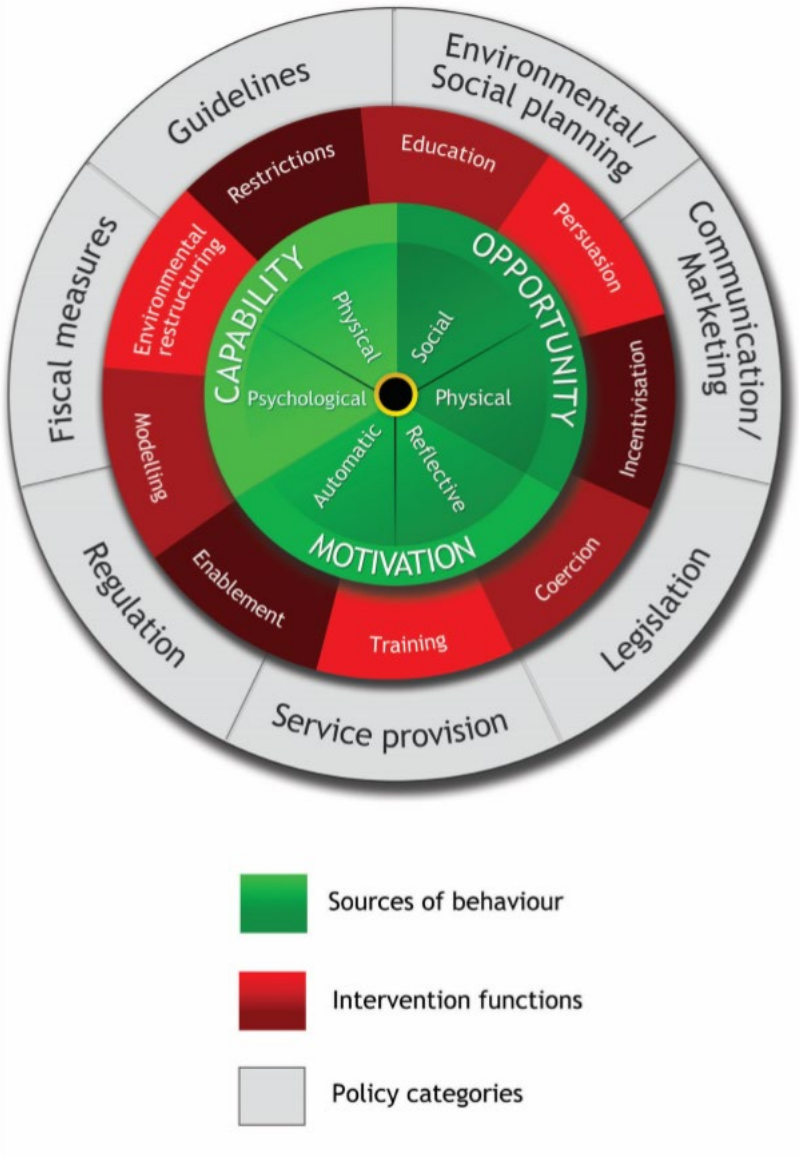


Figure 5 The Behaviour Change Wheel. Michie et al. (2011) (120). Reproduced without amendment under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0).

1.3.3.4 Self - Determination Theory

SDT is a broad theory of motivation, comprised of six mini-theories (cognitive evaluation theory, organismic integration theory, basic psychological needs theory, causality orientations theory, goal content theory and relationship motivation theory)

(126). It seeks to deepen understanding of the processes that motivate an individual to initiate and maintain a new health related behaviour. SDT has three core constructs, autonomy, competence and relatedness. It proposes that when an individual has a sense of all three constructs (or basic psychological needs), in relation to the health behaviour in question, they are more likely to undertake an internalisation and integration process which results in self-regulation and maintenance of the behaviour (85). The constructs / basic psychological needs of SDT are also considered to be potential mechanisms of action for interventions (123, 127).

Autonomy relates to whether individuals are intrinsically motivated, or whether their motivation is controlled via an external influence. Enjoying a behaviour results in intrinsic motivation to engage in it, and therefore the behaviour is autonomous because the individual is sufficiently motivated to choose to do it. Often, positive health behaviours such as drinking less alcohol or adhering to recommended medication regimes are not enjoyable. For an individual to be intrinsically motivated to carry out these behaviours, they need to personally value them or consider them important. In SDT, this is known as identified regulation (85). Providing information and a rationale for carrying out a behaviour can result in identified regulation. To achieve integrated regulation, which is a higher level of autonomy than identified regulation, the individual also needs to incorporate the behaviour into their lifestyle and associate it with their central values (85).

External influences which control motivation include acting to receive a reward, to achieve social acceptance or to avoid a negative consequence. In SDT, these influences are forms of external regulation. Acting to avoid guilt or disapproval, or to

gain approval or praise from someone else is another form of controlled motivation, which is known as introjection. Controlled motivation is not autonomous. According to SDT, when a behaviour is autonomous, it is more likely to be sustained, resulting in long term behaviour change (85).

Competence involves having the skills and tools needed for change and having the confidence and ability to apply them. Health professionals can support competence by providing tools and teaching skills. In addition to this they need to support the service user to apply the tools and skills when they experience barriers. To achieve internalisation of a behaviour, both autonomy and competence are required (85).

Relatedness requires the individual to feel understood, respected and cared for. This results in a trusting relationship between the service user and those supporting them. When a trusting relationship is established, the individual is more open to receiving information from the people supporting them and is more likely to comply with their recommendations (85).

The ParticiPAte CP intervention described above was underpinned by SDT (63). The intervention involved a self-determined process of collaborative goal setting, participation-based therapy and motivational interviewing, which supports autonomy and is consistent with SDT (128). Effective digital interventions to reduce sedentary time that are underpinned by SDT include a web-based personalised intervention to reduce and interrupt sitting time in office workers (129) and a classroom media intervention for girls from ethnic minorities which increased intrinsic motivation (130). A study involving able-bodied adolescent boys found that an intervention to reduce

screen-time enhanced autonomous motivation and significantly reduced screen time at 18 month follow up (131).

Detailed information about how the frameworks and theories described above have been applied in this co-design of a digital behaviour change intervention is provided in the relevant chapters.

1.3.3.5 Logic model

Step three of the 6SQUiD recommends diagrammatic representation of an intervention's programme theory. In this thesis, a logic model has been employed to achieve this. The logic model is an adaptation of an existing template designed for interventions which will be used in multiple contexts (132). This template was appropriate as the digital intervention developed in this thesis will be deployed remotely via an app in multiple settings. Each setting will have unique environmental and contextual influences on sedentary time.

1.3.4 Intervention based approach (digitally enabled delivery)

The NHS long term plan sets out an intention for digital tools, including apps and wearable devices, to empower people to manage their health and improve efficiency (133). Currently NHS services are struggling to manage a backlog of work created by the Covid-19 pandemic (134). Waiting times for routine care are higher than ever and clinicians are leaving in large numbers (134). Digital technologies that reduce the demand for face-to-face contact with clinicians can reduce the pressure on an overstretched workforce (135), who have limited time to engage with training about new interventions or delivery of them. The plan for digital health and social care (135) describes how appropriate digital health solutions have the potential to: 1) prevent

escalation of health and social care needs, 2) personalise health and social care so digital tools are tailored to individual's needs, 3) reduce health inequalities, 4) improve the experience of those providing care, 5) increase the impact professionals have and 6) improve performance of health and social care organisations.

Prior to commencing the intervention development described in this thesis, the author undertook research to explore the perspectives of children with physical disabilities, parents and physiotherapists on use of walkers and their potential to increase physical activity (1). One of the three themes identified was acceptance of technology within walkers. Children were motivated and excited by the concept of adding technology to walkers which allowed them to play games that would incentivise them to use their walker. Alongside positive comments relating to more inclusive digital interventions for physical activity, parents and physiotherapists also expressed reservations about safety and a self-monitoring culture. Overall, improving the manoeuvrability, safety, ease of use and comfort of walkers was more important than adding new technology. This conclusion prompted a shift away from plans to modify walkers by adding technology that monitored physical activity and onto physical activity monitoring via wearable devices that monitor the movement of the individual throughout their day, not only when using their equipment.

Further previous work that inspired the digital direction of this research was undertaking co-design workshops to facilitate modification of an existing active video gaming system for use by young people with limited mobility (136). Following optimisation of the system, a small feasibility study was undertaken to assess its use in the community to increase physical activity, as an adjunct to routine physiotherapy

programs. A model was produced which described factors influencing young people's engagement with active video gaming.

The author's interest in digital health and the current focus on using digital tools to improve health and social care services (135) lead to the decision that this intervention would be digitally enabled. This was specified prior to commencement of the co-design, but the digital delivery method was not stipulated.

Use of technology to enhance delivery of health care (133, 137, 138), deliver interventions to reduce sedentary behaviours (71, 139, 140) and for delivery of research (141) is a rapid growth area. There is a considerable body of evidence exploring using persuasive technology to tackle sedentary behaviour (125). Persuasive technologies have been defined as "interactive systems designed to aid and motivate people to adopt behaviours that are beneficial to them and their community while avoiding harmful ones" (142). Research indicates that using persuasive technology to reduce sedentary behaviour is an effective approach, however the majority of studies focus on adults (125). Aldenaini et al. found that only 5% of studies using persuasive technology to increase physical activity and reduce sedentary time included teenagers (13-17 years), and 12% included young adults (18-30 years) (125). In 62% of the studies involving teenagers and 76% of the studies involving young adults persuasive technologies were fully or partially effective, in comparison to 86% for adult studies (125). These figures indicate that persuasive technologies to reduce sedentary time for teenagers and young adults are less effective than those for adults.

Two reviews have explored quality, features, behaviour change techniques (139) and efficacy (143) of apps (or interventions including apps) to improve diet, physical activity and sedentary behaviour. The first review, which focussed on children and adolescents, included 25 apps in total. Seven apps aimed to reduce sedentary behaviour. This review concluded that children's and adolescent's engagement with the apps was low (139), and an improved understanding of factors that promote engagement is likely to improve their effectiveness (139). Information quality within the apps was also low, highlighting a need for future apps to be evidence-based. The most frequently used behaviour change techniques were providing instructions, providing general encouragement, providing contingent rewards and providing feedback on performance. The most frequently used behaviour change techniques in apps for adults which aim to improve diet, physical activity and reduce sedentary behaviour are goal-setting, self-monitoring and performance feedback (144-146). Therefore, the behaviour change techniques differed between apps targeting adults or the general population and those designed for children and young people, which may explain Aldenaini et al.'s results showing that they are less effective in this group than in adults. The lack of apps employing self-monitoring in this review is striking, as Aldenaini et al. identified this technique as the most frequently used and most effective strategy in persuasive technologies to increase physical activity or reduce sedentary behaviour (125). Social support, modelling, consequences for behaviour, other's approval, self-monitoring, intention formation and behavioural contracting have been advocated as the most effective behaviour change techniques to use in apps to reduce increase physical activity and improve diet in adolescents (147). These techniques were not well represented in the apps included in this review.

As highlighted above (theory and evidence-based approach section), self-monitoring is the most frequent and effective behaviour change technique used in persuasive technologies which aim to reduce sedentary time (125). In such technologies, this self-monitoring is frequently achieved via a wearable device. Wearables were used in eight/25 of the apps in Schoeppe et al.'s review (139) and linking wearable devices with the NHS app and online NHS profiles forms part of the UK plan for digital health and social care (135). In Aldenaini et al.'s review, activity trackers and sensors were used in 29% of the studies, making them the second of the most popularly used technology platforms in physical activity and sedentary behaviour persuasive technologies, after mobile and handheld devices (125). As 40/42 of the studies using wearables were successful, this review advocated use of wearables in persuasive technologies to increase physical activity and reduce sedentary time, proposing that the accurate feedback they provide about activity progress motivates users to change their behaviour. In light of this evidence, a decision to include a wearable device in this intervention was made early in the intervention development.

In the second review (exploring efficacy) (143), one of three studies which specifically related to children and adolescents and aimed to reduce sedentary behaviour showed a significant between group improvement in sedentary behaviour (measuring screen time). However, the app was part of a multi component intervention including face to face activities and provision of fitness equipment (148). One of two studies aiming to reduce sedentary behaviour in adults showed a significant reduction (143). In that study, a collection of three behaviour change apps were used over an eight week period by adults aged 45 and over and a significant reduction in leisure time sitting was achieved (149).

There is some literature exploring use of behaviour change apps to increase physical activity or reduce sedentary time for people with physical disabilities. A pilot study was published exploring use of an app to provide physical activity feedback and a just in time adaptive intervention to people with spinal cord injury (70). The results showed 69% of participants increased their light or moderate physical activity during the intervention period in comparison to baseline levels, suggesting this digital intervention for non-ambulant people had potential to increase physical activity. In contrast, a study comparing the effects of a mobile app with supervised training on cardiorespiratory fitness and health related quality of life in young adults with self-perceived mobility disability did not find significant differences between the two delivery models (150). Hoevenaars et al. tested usability and feasibility of an app designed to improve health behaviours of wheelchair users with spinal cord injury or lower limb amputation, including their physical activity (138). Participants were adults. There was no significant change in physical activity (measured using a self-reported tool), however, there were significant favourable changes in relation to body composition.

Another study compared usability and feasibility of a web-based and telecoaching intervention to improve physical activity and nutrition behaviours of children and young people with physical disabilities (lower extremity mobility disabilities) to telecoaching only (151). Again, no significant changes in diet or physical activity were demonstrated, but engagement was good and results were promising. Key lessons highlighted were that it was important that the intervention targeted the child primarily, not the parent and that schools needed to be involved in the intervention. Parents

valued the telecoaching calls over the website. Participants fed back that they would be more likely to use the online component if it was an app rather than a website.

This previous work suggests delivering a behaviour change intervention via an app has potential to reduce sedentary behaviours for non-ambulant young people. There is an appetite amongst people with disabilities for fitness apps that are relevant to and meet the needs of people with disabilities (152, 153). Adolescents with a diagnosed physical and/or developmental disability have endorsed the potential apps have to enhance their health via empowerment and provision of a virtual support system (154), but it is critical that they are designed with high usability, accessibility and engagement in mind (155, 156). Parents and healthcare professionals advised that apps which are co-designed with a range of stakeholders could assist with the complex and wide-ranging support needs of this group by offering individualised support. Current resources do not appropriately meet their needs (154).

This chapter has introduced the key definitions, guidance, models, frameworks and theories that this thesis draws upon. Chapter 2 reports the first part of step one of the 6SQuID (86), defining the problem. This was achieved by undertaking a systematic search and review of literature relating to sedentary behaviour in NAYP, to gain a comprehensive understanding of existing evidence relating to this topic and the strengths and weaknesses of that evidence.

2 Chapter 2: Step one of the Six Steps in Quality Intervention Development (6SQuID). Defining the problem.

Note: Elements of the introduction and methods section of this chapter have been reproduced from a publication for which I am the primary author. The publication was the protocol for this review. The reference is below:

Bradbury M, O'Brien C, Giles N, Fenton S, Neilson S, Duda JL. Sedentary behaviour in non-ambulant children and young people with physical disabilities: a systematic search and review protocol. BMJ Open. 2021;11(12):e053077

Use of the past tense and amendments to the methodology have resulted in the majority of the text being modified. Author contributions published in the article are copied verbatim below:

"Contributors MB helped in conceptualisation, methodology, writing the original draft, writing review and editing, visualisation, project administration and funding acquisition. CO'B helped in methodology, writing review and editing and project administration. NG helped in writing review and editing and project administration. SF and SN was responsible for conceptualisation, methodology, writing review and editing and visualisation. JLD helped in conceptualisation, methodology, writing review and editing and visualisation. Public and patient involvement representatives, Roger Leek and Jacqueline Hawkins helped in writing review and editing."

2.1 Title: A systematic search and review exploring sedentary behaviour in non-ambulant children and young people with physical disabilities: measurement, patterns, risks and interventions.

2.2 Introduction

Sedentary behaviour is defined as “any waking behaviour characterised by an energy expenditure ≤1.5 metabolic equivalents (METs) while in a sitting or reclining posture” (3). Examples of sedentary behaviours include activities such as watching television, playing video games or reading. Sedentary time is considered the sum of all sedentary behaviours (4). Sedentary behaviour is the lowest level of a broader physical activity continuum, incorporating light (LPA) and moderate to vigorous physical activity (MVPA). It is important to acknowledge that sedentary behaviour differs from physical inactivity, which is defined as a lack of MVPA (17). Sedentary behaviour can be measured using validated self or proxy-reported tools. Sedentary time can be measured using wearable devices containing accelerometers and / or inclinometers or by calculating energy expenditure from gas analysis or monitoring heart rate whilst also collecting postural data.

Negative health consequences associated with sedentary time include increased risk of all-cause mortality, cardiovascular disease mortality and incidence of type 2 diabetes, cardiovascular disease, and endometrial, colon or lung cancer (7, 8). It is estimated that television viewing is associated with 8% of deaths (all-cause mortality) and 29% of type 2 diabetes incidence in England (8). The World Health Organisation (WHO) and United Kingdom (UK) physical activity guidelines for adults, children and young people therefore advise limiting sedentary time (6, 23, 26).

2.2.1 Sedentary time in non-ambulant young people (NAYP)

There is consensus across a large body of evidence that children and young people with physical disabilities are more sedentary than their able-bodied peers (38, 157). In recognition of the additional challenges people with disabilities face in relation to physical activity and sedentary behaviour, the WHO published additional guidelines specifically for children and adolescents with disabilities (44). These guidelines recommend limiting sedentary and recreational screen time, in line with the guidelines for the general population. However, this guidance and other recent reviews (38, 41) highlight the significant evidence gaps in relation to sedentary behaviour of children and young people with disabilities. There is a lack of research relating to valid measurement of sedentary time, health outcomes associated with high levels of sedentary time and interventions to address sedentary behaviour in children and young people with disabilities (41, 44). It is currently assumed that risks related to sedentary behaviour are likely to be similar to those experienced by the general population (44).

In this review, non-ambulant young people (NAYP) are defined as those aged 0-25 years, who are unable to walk, or only walk short distances using a walker that supports their body (not handheld walkers). NAYP with any diagnosis are incorporated, including (but not limited to) cerebral palsy (CP), muscular dystrophies, spina bifida, spinal cord injury and metabolic / rare conditions. NAYP with CP are those in Gross Motor Function Classification Scale (GMFCS) levels IV-V.

Within the broader population of children and young people with physical disabilities, NAYP represent a population who may be at significantly increased risk of the adverse consequences of sedentary time, owing to the amount of time spent sitting.

Previous research has demonstrated that NAYP spend more time sedentary than ambulant children and young people with physical disabilities (39, 158, 159), and that their sedentary time increases with age (39, 40). Due to this, this review includes a broad age range extending into young adulthood, allowing impact of transition into higher education or work and adult health services to be evaluated. A previous scoping review exploring sedentary behaviour in children with physical disabilities highlighted that the majority of research on this topic has focused on ambulant children (38). NAYP are therefore an underserved population from a research perspective, resulting in considerable evidence gaps. Ganz et al.'s review highlighted the challenges of measuring sedentary time in NAYP and the need for additional research to develop validated measurement methods (38). Indeed, accurate measurement of sedentary time is critical to better understand the health consequences of this behaviour for this population.

2.2.2 Review typology

The systematic search and review typology (160) was selected rather than undertaking a systematic review because systematic reviews are expected to have one specific question. This review has an overarching question and four sub-questions. In addition, in contrast to scoping reviews, the systematic search and review typology allows for appraisal quality of evidence, which informs a best evidence synthesis. The best evidence synthesis allows conclusions to be drawn or hypotheses to be proposed about a body of evidence that cannot be quantitatively synthesised, as would be expected in a traditional systematic review.

2.2.3 Aims and objectives

The aim of this review is to provide an overview of the literature concerning sedentary time in NAYP, to improve our understanding of; 1) methods currently used to measure sedentary time in NAYP, 2) characteristic patterns of sedentary time observed using these measures, 3) associated health consequences, and 4) the design and content of existing interventions to decrease sedentary time in this population.

To date, reviews which have included evidence relating to sedentary behaviour of NAYP have not evaluated the quality of the evidence. This review builds on previous work by focussing specifically on NAYP, adding critical appraisal of the included papers, addition of a sub-question exploring risks associated with sedentary time in this population and having a broader search strategy including additional databases across a range of disciplines.

The overarching research question and sub-questions for this review are;

Overarching question: “What is the quality of the evidence relating to sedentary behaviour in NAYP?” (161)

Sub-questions:

1. Do validated measures of sedentary time or behaviour of NAYP exist?
2. Have patterns of sedentary time or behaviour of NAYP been described?
3. Have risks associated with sedentary time or behaviour been explored or quantified for NAYP?

4. What evidence-based interventions to reduce sedentary behaviour or decrease and break up sedentary time in this population have been evaluated and what is the strength of this evidence? (161)

The objectives of this review are outlined in the previously published protocol (161). These are;

“1. Identify all peer-reviewed journal articles relating to measurement of sedentary time, patterns of sedentary behaviour and interventions to decrease sedentary time or behaviours for non-ambulant children and young people.

2. Categorise the articles according to study design and four sub-questions relating to (1) measurement, (2) patterns, (3) associated risks and (4) interventions to reduce sedentary time or behaviour for non-ambulant children and young people.

3. Critically appraise the quality of the articles using appropriate tools to evaluate the study design.

4. Produce a best evidence synthesis (162), which summarises the evidence for each sub-question and describes its cumulative strength, based on the hierarchy of evidence and the quality ratings assigned following critical appraisal. Identify knowledge gaps for this specific population.”

2.3 Methods

This review has been written following the PRISMA reporting guidelines (163). However, as an alternative typology to a pure systematic review has been used, there is some variation in synthesis elements, which are described throughout where relevant.

2.3.1 Protocol and registration.

The review protocol was published prior to data collection (161). The review was registered on the Open Science Framework database 29/03/2021 (https://osf.io/sqxjb).

2.3.2 Eligibility criteria

The inclusion and exclusion criteria were determined using the Population, Concept and Context (PCC) framework (164) and are re-produced from the review protocol (161) in Table 1. The publication date range has been extended due to a refresh of the original searches being undertaken in September 2023.

Table 1 Inclusion and exclusion criteria for the systematic search and review relating to sedentary behaviour of non-ambulant young people. Reproduced from study protocol (161).

PCC framework element	**Inclusion**	**Exclusion**
Population	Participants with long-term physical disabilities or long-term physical and intellectual disabilities / sensory impairments. AND A proportion of the participants are non-ambulant. The proportion of non-ambulant participants is clear. For participants with cerebral palsy, children and young people in GMFCS levels IV–V are considered non-ambulant. AND Article includes participants under 25 years.	Participants with intellectual disabilities, visual or hearing impairments and no physical disability. OR Participants with a temporary lack of ambulation due to injury or short-term illness. OR The article includes ambulant participants only, or the proportion of non-ambulant participants is unclear. For participants with cerebral palsy, children and young people in GMFCS levels I—III are considered ambulant. OR All participants in the article are 25 and over
Concept	Article explores measurement of, patterns of or risks related to sedentary behaviour. OR Article evaluates feasibility or effectiveness of an intervention to decrease or break up sedentary time. Any outcome measured in studies matching the inclusion criteria will be accepted.	Papers relating to physical activity that have not measured or explored patterns or correlates of sedentary time or behaviour specifically.
Context	Peer reviewed journal articles (quantitative, qualitative, mixed methods), scoping reviews, systematic reviews, theses / dissertations AND Published in the English language. AND Published between January 1996 and September 2023.	Grey literature, abstracts, conference proceedings, conference papers, conference review, protocols, commentaries, opinion articles, literature reviews (not systematic), narrative reviews, books or chapters. OR Published in languages other than English. OR Published before 1996 or after September 2023.

Note: GMFCS: Gross Motor Function Classification System, PCC: Population, Concept, Context.

2.3.3 Search strategy

The following electronic databases were searched: The Allied and Complementary Medicine Database (AMED), APA PsycINFO, Applied Social Sciences Index & Abstracts, Child development and adolescent studies, CINAHL Plus, Cochrane Library, EMBASE: Excerpta, ERIC, MEDLINE (R), Nursing and Allied Health Database, Scopus, SPORTDiscus and Web of Science. Initial searches were undertaken between October – November 2021 and updated in September 2023. Reference lists of included articles were hand searched in January 2024.

See Table 2 for an example search strategy. The full search strategy for all databases is available in the supplementary material of the review protocol (161).

Table 2 Search strategy for the systematic search and review, using the Population, Concept, Context framework.

Database	Population	Concept	Context
AMED—The Allied and Complementary Medicine Database Via EBSCOhost	'physical disabilit*' (KW) OR 'physically disabled' (KW) OR 'non-ambulant' (KW) OR 'non-ambulatory' (KW) OR wheelchair* (KW) OR 'limited mobility' (KW) OR 'immobil*' (KW) OR 'mobility impairment' (KW) OR 'neuromusculoskeletal disabilit*' (KW) OR amputee* (KW) OR 'cerebral pals*' OR diplegi* (KW) OR quadripleg* (KW) OR tetrapleg* (KW) OR 'muscular dystroph*' OR 'spina bifida' (KW) OR 'spinal dysraphism' (KW) OR 'neural tube defect*' (KW) OR parapleg* (KW) paralys* (KW) OR 'spinal cord injur*' OR handicap* (KW) OR 'hereditary motor sensory neuropath*' (KW) OR 'charcot-marie-tooth' (KW) OR 'spinal muscular atroph*' (KW) AND minors (KW) OR pediatric (KW) OR paediatrics (KW) OR pediatric (KW) OR paediatric (KW) OR child (KW) OR children (KW) OR baby (KW) OR childhood (KW) OR babies (KW) OR infant (KW) OR infants (KW) OR infancy (KW) OR school (KW) OR preschool (KW) OR adolescen*	sedentary (KW) OR 'screen time' (KW) OR screentime (KW) OR 'screen-time' (KW) OR 'screen use' (KW) OR 'screen exposure' (KW) OR (television or TV) NEAR/3 watch* OR 'physical inactivity' (KW) OR 'physically inactive' (KW) OR sitting (KW)	Published date: 1996–2023 Language: English

Database	Population	Concept	Context
	(KW) OR teen* (KW) OR youth (KW) OR 'young adult*' (KW) OR 'young person*' (KW) OR 'young people' (KW) OR toddler* (KW) OR juvenile* (KW)		

Note: KW, keyword in title or abstract.

The results from the population and concept columns in Table 2 were combined using AND prior to limits being applied. Records were exported to Endnote referencing software (165) for storage. They were transferred to Microsoft excel for manual deduplication and screening. Once searches were completed, articles were screened prior to quality appraisal of articles meeting the inclusion criteria. Poor quality articles were excluded prior to data extraction and best-evidence synthesis. These processes are described in detail below.

2.3.4 Article screening

Title and abstract screening was completed by two independent reviewers, who rated records as relevant, not relevant or not known. Discrepancies were resolved through discussion. Full text articles were obtained for all records rated as relevant or not known. For articles rated "not known", the full text was independently reviewed to establish relevance prior to critical appraisal. Discrepancies were discussed and a third reviewer was available if agreement could not be reached.

Corresponding authors were contacted if additional information was required to decide whether an article was relevant, or if further information was required during data extraction.

2.3.5 Assessing quality of the evidence

The reviewers collaboratively categorised the articles for critical appraisal into one of the four sub-questions to be addressed. As articles were not excluded on the basis of

study designs, several critical appraisal tools were used, which are listed in Table 3. To ensure quality ratings were uniform despite using multiple tools, reviewers agreed articles would be rated poor if fatal flaws were identified, fair if no fatal flaws were identified but there were methodological weaknesses and good if there were no or only minor weaknesses.

Table 3 Critical appraisal tools used for each study design.

Study Design	**Critical appraisal tool**
Observational and cross-sectional studies	The Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (166)
Qualitative studies	The CASP Qualitative Checklist (167)
Validity studies	QUADAS-2 (168)
Interventional studies with crossover designs	Revised Cochrane risk of bias tool for randomized trials (RoB 2). Additional considerations for crossover trials (169)
Scoping review	PRISMA Extension for Scoping Reviews (PRISMA-ScR) (170)
Systematic review	The CASP Systematic Review Checklist (167)
Case control study	The CASP Case Control Checklist (167)
Evaluation	Checklist for Evaluative Studies in Visual Analytics (171)
Survey	Survey (Including pre-test probabilities) Checklist (172)
Single armed interventional study	Quality Assessment Tool for Before-After (Pre-Post) Studies With No Control Group (166)

Table 3 Footnote: The following tools were not included in the review protocol: QUADAS-2 (168), Revised Cochrane risk of bias tool for randomized trials (RoB 2), Additional considerations for crossover trials (169), PRISMA Extension for Scoping Reviews (PRISMA-ScR) (170), The CASP Systematic Review Checklist (167), The CASP Case Control Checklist (167), Checklist for Evaluative Studies in Visual Analytics (171) and the Survey (Including pre-test probabilities) Checklist (172). These tools were used because they were deemed more appropriate for appraising the study designs of some articles than the pre-specified tools.

2.3.6 Data extraction

Items for data extraction were decided a priori and were published in the study protocol (161). Briefly these are: author, year of publication, country of origin,

participant characteristics, study objectives and design, intervention (if applicable), methods, results, critical appraisal tool used and quality rating (good / fair / poor). An additional column has been added to the summary tables to separate details of statistical analysis from the rest of the methods. It was decided this would be added during writing of the manuscript to improve presentation of the methods. Results relating to physical activity in general, or LPA / MVPA were not extracted. The sub-question the article was categorised to did not influence data extraction (i.e. all data relating to sedentary behaviour or time was extracted) even if it aligned with a different sub-question. One reviewer undertook data extraction; the second checked its accuracy.

Corresponding authors were contacted if further information was required during data extraction.

2.3.7 Synthesis methods

The best evidence synthesis (162) involved producing a table for each sub-question summarising study characteristics and results, critical appraisal tools used, quality ratings and reasoning for the quality ratings for each included article. The cumulative evidence is then narratively described; including consideration of whether there was consensus or lack of consensus across articles and how the quality of the evidence and risks of bias identified may have influenced this.

The best evidence synthesis is used to: 1) draw conclusions about the certainty of evidence for each sub-question, 2) understand the level of heterogeneity across articles addressing each sub-question and the potential for quantitative synthesis of evidence, and 3) identify knowledge gaps.

2.3.8 Public and patient involvement

Three public and patient involvement representatives reviewed the study protocol and provided feedback which was incorporated prior to publication. One of these representatives has also acted as a third reviewer where discrepancies between reviewers one and two were raised, and provided feedback on manuscript drafts and revisions.

2.4 Results

2.4.1 Article screening

Results of database searches, subsequent screening of records and reasons articles were excluded at full text screening are outlined in Figure 6. Following removal of duplicates, 3620 records were screened. Fifty-one articles were deemed relevant for critical appraisal. Two additional relevant articles were identified via screening of reference lists of included articles (61, 173), increasing the number of critically appraised articles to 53. The most frequent reason for exclusion at full text screening was all participants being ambulant, or the proportion of non-ambulant participants being unclear. Articles studying the general population were excluded at title and abstract screening. Articles excluded at full text review tended to study clinical populations with disabilities, but participants were ambulant. Examples include articles involving young people with CP in GMFCS levels I-III only (174-178), young people with sensory or learning disabilities (179, 180), ambulant young people with physical disabilities (excluding CP) (181, 182) or articles which did not describe their participant's level of mobility impairment in sufficient detail to ascertain the proportion of non-ambulant participants (183-185). Many references were found to be conference abstracts at full text review, which were excluded publication types (186-

189). Articles exploring physical activity but not sedentary behaviour were excluded (190-192).

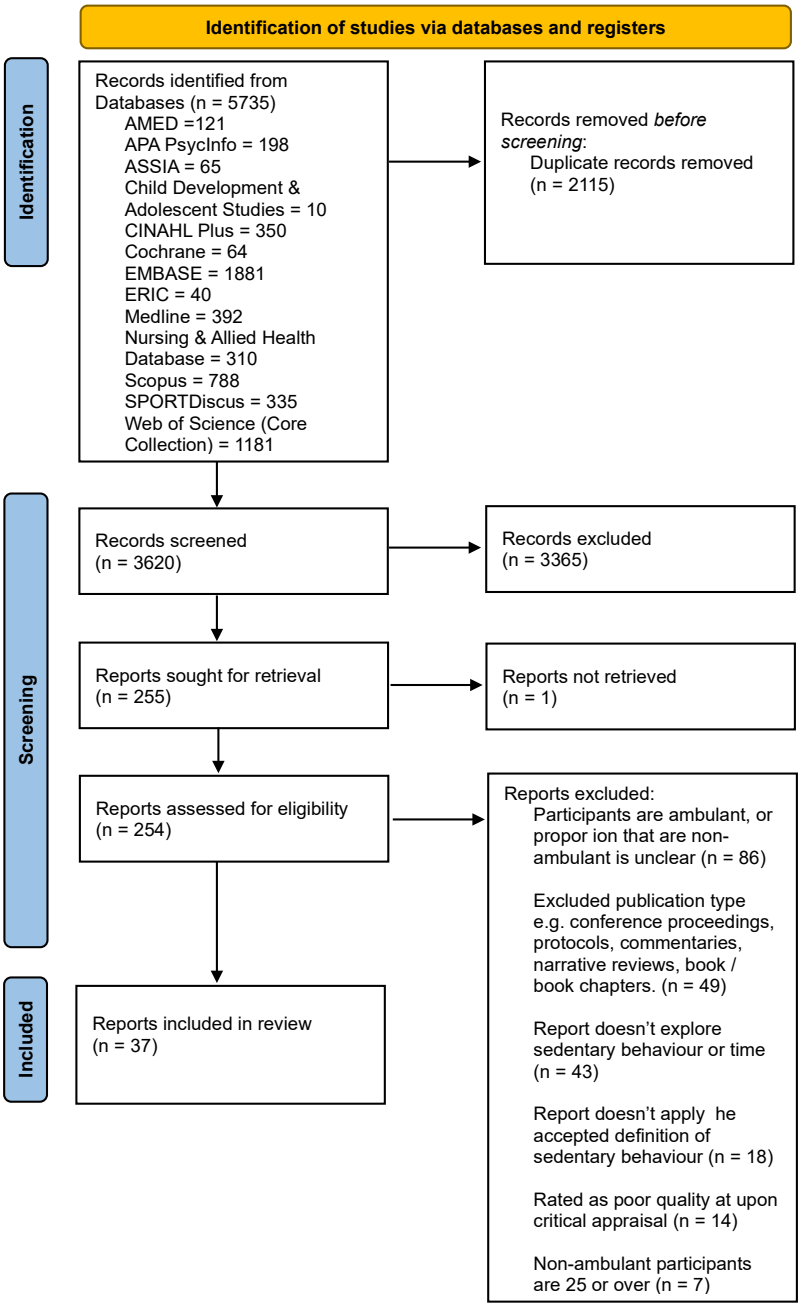


Figure 6 PRISMA flow chart showing results of database searches, screening of records and reasons articles were excluded. Allied and Complementary Medicine (AMED), Applied Social Scienced Inex and Abstracts (ASSIA), American Psychological Association (APA), Cumulative Index to Nursing and

Allied Health Literature (CINAHL), Excerpta Medica database (EMBASE), Educational Resources Information Center (ERIC)

© 2020 PRISMA. Adapted from: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71 For more information, visit: http://www.prisma-statement.org/

2.4.2 Quality assessment

From the 53 articles that were critically appraised, five were rated as being good quality, 33 were fair quality and 15 were poor quality. Those rated as being poor quality were excluded. A total of 38 articles were therefore included in this review for subsequent data extraction and best-evidence synthesis. There is a discrepancy with Figure 6 (which shows 37 included articles), because an additional article identified in hand searching of reference lists was included (173).

Reasons articles were rated as poor quality were: using unvalidated self / proxy-reported measures of sedentary behaviour / time (56, 193-195), or self-reported measures that have been modified but not validated for NAYP (196), validity of self-reported measure of sedentary behaviour was questionable (197), small sample size (61, 69, 198, 199), sedentary time estimate was based on heart rate or heart rate and unvalidated self-report alone (67, 200, 201), choice of study design did not match research objectives (55), risk of selection bias (61), lack of statistical testing (61) and lack of reliability / validity of measurement methods employed to measure other outcomes (for example sleep quantity and quality, pain and fatigue) whose relationship with sedentary behaviour was being investigated (46, 200).

2.4.3 Characteristics, critical appraisal and best evidence synthesis of included articles

For studies included, eight addressed measurement of sedentary time or behaviour for NAYP (sub-question 1), 20 addressed patterns of sedentary time or behaviour observed in NAYP (sub-question 2), six explored risks associated with sedentary time or behaviour (sub-question 3) and two evaluated interventions with potential to reduce sedentary behaviour or decrease and break up sedentary time for this population (sub-question 4). Two scoping reviews (38, 157) span multiple sub-questions.

The scoping reviews are summarised in Table 4. All articles including NAYP that featured in the scoping reviews (38, 157) have been individually screened as part of this review. Therefore, scoping review findings have not been incorporated into the best evidence synthesis which follows, as they include a considerable body of evidence that is not applicable to NAYP.

Table 4 Study characteristics, results and quality assessment for scoping reviews.

Author (year) Country of origin	Participants	Objectives	Design	Intervention	Methods	Results (specific to sedentary behaviour)	Critical appraisal tool	Quality of article (good / fair)	Reasoning for Quality Rating
Ganz et al., (2021) (38) Canada	Total included papers: 36 Papers involving non-amb. participants: 14 Diagnosis: CP, Down syndrome, Prader–Willi syndrome, acquired brain injury, myelomeningocele, confirmed or suspected Developmental Coordination Disorder, juvenile idiopathic arthritis, Rett	Summarise research relating to 1) sedentary behaviour patterns, (2) measurement of sedentary behaviour (3) current evidence regarding effectiveness of interventions to reduce sedentary behaviour in children with physical disabilities.	Scoping review	One intervention including non-amb. young people. Face-to-face physiotherapist administered motivational interviewing and PA prescription (3–6 m)(61)	Search terms: (sedentary and child* or school-aged or kindergarten* or pediatric* or peadiatric* or youth* or adolescen* or teen*) AND (disab*or special needs or motor impair* or physical impair*or physical* limitation* or cerebral palsy or wheelchair* or muscular dystroph* or spina bifida or neural tube defect* or epilep* or arthritis* or traumatic brain injur* or parapleg* or quadripleg* or spinal cord injur*)	Children with CP under 5 y, GMFCS III–V spend more time sedentary than peers without disabilities and more time sedentary than children in GMFCS I-II. Time spent sedentary increased with age. In GMFCS IV-V, mean duration of sedentary bouts (>10 min) and number of sedentary breaks lower than for children with TD and children in GMFCS I-II. Sedentary time negatively associated with motor skills and	1	Good	Protocol not registered. Full electronic search strategy for one database not published. No contact with authors of included papers reported. Funding sources for included articles not listed.

Author (year) Country of origin	Participants	Objectives	Design	Intervention	Methods	Results (specific to sedentary behaviour)	Critical appraisal tool	Quality of article (good / fair)	Reasoning for Quality Rating
	syndrome, a sample of heterogeneous physical disabilities. Age range: 0-18 y Mean age (y) (SD): Not reported				Databases: CINAHL, MEDLINE, ERIC, EMBASE, SPORTDiscus up to and including articles published in November 2018. Screened reference lists of included articles. Inclusion criteria: participants 0–18 y and had physical disabilities, focus of research was on sedentary behaviour patterns, measurement of sedentary behaviour or evaluation of interventions to decrease sedentary behaviour. Studies including individuals over 18 y included if data for those under 18	functional mobility. Further research needed to investigate validity of accelerometers with children who are non-amb. Intervention study including non-amb. young people: changes in sedentary time were variable (pre-post differences not analysed). Existing evidence does not support effectiveness of strategies to reduce sedentary behaviour in children with physical disabilities. Few studies addressed sedentary behaviour in younger children or			

Author (year) Country of origin	Participants	Objectives	Design	Intervention	Methods	Results (specific to sedentary behaviour)	Critical appraisal tool	Quality of article (good / fair)	Reasoning for Quality Rating
					y presented separately. Exclusion criteria: focused on PA not sedentary behaviour, focused on children and youth with intellectual, visual, or hearing impairments without physical disabilities, study protocols, conference abstracts, books, theses, studies published in languages other than English. Independent full text screening of papers and data extraction 2 reviewers. 3rd reviewer available to discuss discrepancies.	children who use wheelchairs.			

Author (year) Country of origin	Participants	Objectives	Design	Intervention	Methods	Results (specific to sedentary behaviour)	Critical appraisal tool	Quality of article (good / fair)	Reasoning for Quality Rating
Xiong et al., (2021) (157) Canada / Australia / Netherlands	Total included papers: 47 Papers involving non-amb. participants: 16 Diagnosis: CP Total participants: 1958 Age range: Under 4 y to 65+ y Mean age (y) (SD): Not reported	1) What is documented about sedentary behaviour in individuals with CP, including operationalisation / activities that constitute sedentary behaviour. 2) How is operationalisation of sedentary behaviour in this population measured? Are valid and reliable tools used? 3) What is the	Scoping review	NA	Followed Joanna Briggs Institute manual for conduction scoping reviews. Inclusion criteria: published 2011-2020. Measured sedentary behaviour or sitting / reclining / lying postures. >50% of participants in the study had CP. Primary studies only. Experimental / qualitative / longitudinal / observational study designs. Exclusion criteria: Studies not written in English. Studies measuring physiological indicators in sedentary postures but not measuring sedentary	Sedentary behaviour operationalized through muscle activation /energy expenditure / oxygen consumption in typically sedentary postures (9 studies), thresholds and postures using accelerometers, activity monitors, and a questionnaire to measure sedentary time (25 studies). 7/8 studies measuring energy expenditure found ≤ 1.5 METs for sitting and lying. Different accelerometer thresholds used across studies. Sedentary behaviour was consistently	1	Good	Protocol not registered. Search dates not specified. Funding sources for included articles not listed.

Author (year) Country of origin	Participants	Objectives	Design	Intervention	Methods	Results (specific to sedentary behaviour)	Critical appraisal tool	Quality of article (good / fair)	Reasoning for Quality Rating
		relationship between sedentary behaviour and health in people with CP?			behaviour. Not peer reviewed. Reviews. Databases searched: OVID Medline, CINAHL, Excerpta Medica database, OVID psycINFO, Physiotherapy Evidence Database. Search terms: “sedentary behaviour”, “cerebral palsy” and their synonyms. 2 independent reviewers screened title, abstract, full text. Consensus or referral to 3rd reviewer for discrepancies. Screened reference lists of included articles. 2 independent reviewers extracted	operationalized as sitting and lying. Minimal consistency existed in the subpopulation, instruments and cut-points for studies on validity or reliability of tools for measuring sedentary behaviour (19 studies).. No significant associations between sedentary behaviour and: waist circumference, height, height-for age z-score, C-reactive protein levels, metabolic syndrome, cardiorespiratory fitness, BMI z-score, % body fat, fatigue (adults only,			

Author (year) Country of origin	Participants	Objectives	Design	Intervention	Methods	Results (specific to sedentary behaviour)	Critical appraisal tool	Quality of article (good / fair)	Reasoning for Quality Rating
					data for 19% of studies. 1 reviewer extracted remaining data.	all GMFCS levels for the latter). Significant positive correlations for children in all GMFCS levels with % body fat and negative correlations for fat free mass (controlled for height), no longer present when GMFCS was adjusted for. No positive correlation between sedentary behaviour and BMI for adults with CP at all GMFCS levels. Children with CP and chronic pain across all GMFCS levels spent significantly less time sedentary than TD peers with chronic pain. Significant negative			

Author (year) Country of origin	Participants	Objectives	Design	Intervention	Methods	Results (specific to sedentary behaviour)	Critical appraisal tool	Quality of article (good / fair)	Reasoning for Quality Rating
						correlations between sedentary behaviour and sleep quality and quantity in children (GMFCS I-IV).			

Note: Non-amb.: non-ambulant, y: years, m: months, min: minutes, CP: Cerebral Palsy, GMFCS: Gross Motor Function Classification Scale Level, METS: Metabolic equivalents, PA: physical activity, TD: typically developing / typical development, CI: confidence interval. Critical appraisal tool key: 1 = PRISMA Extension for Scoping Reviews

Table 5, Table 6, Table 7 and Table 8 summarise study characteristics and results of included studies for each sub-question. The tables also indicate which critical appraisal tool was used to assess quality, quality rating assigned and reasoning for the quality rating assigned. The latter was not included in the data items table of the study protocol (161). The additional information provided in this column provides a succinct justification for the assigned quality rating. The best evidence synthesis for each sub-question follows the relevant table.

2.4.4 Sub-question one. Do validated measures of sedentary time or behaviour of NAYP exist?

Table 5 Study characteristics, results and quality assessment for sub-question one - do validated measures of sedentary time or behaviour of NAYP exist?

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
Claridge et al., (2015) (202) Canada	Total: 42 Non-amb. participants: 18 Diagnosis: CP Age range: 18-75 y Mean age (SD): 33.5 y (12.3) GMFCS: I-V	1) Investigate quantification of HPA and sedentary time in adults with CP using accelerometers. 2) Evaluate interpretation and categorisation of activity counts into PA levels. 3) Assess concurrent	Cross sectional validity study	Hip and wrist worn ActiGraph GT3X accelerometers. 3 s epochs. Minimum wear time = 5 hrs on 4 consecutive days. Sedentary time = <100 cpm, (with reference to 3 sets of cut points; 1) Freedson, 2) Evenson, 3) Swartz). Breaks from sedentary time and number of breaks from sedentary time relative to total sedentary time	Shapiro–Wilk test for normality. ANOVA to compare differences between GMFCS levels for outcomes. Tukey honestly significant differences test for post hoc analysis (homogeneity of variances assumed). Dunnett	Non-amb. adults had greater sedentary time and fewer breaks interrupting sedentary time than amb. adults ($P<0.05$). Sedentary time (mins/hr): GMFCS IV = 58.61 (SD 0.96), GMFCS V = 59.19 (SD 0.49). Breaks from sedentary time (breaks/day): GMFCS IV = 3.25 (SD 1.57), GMFCS V = 2.39 (SD 1.39).	1, 2	Fair	Uncertainty whether accelerometery is a validated measure of sedentary time in this population. Sampling not random or consecutive.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
		validity of the PARA-SCI by comparing to accelerometer data.		calculated. Concurrent validity of self-reported PARA-SCI assessed for LPA and MVPA intensities. PARA-SCI completed after 7 days of wearing accelerometer.	T3 test (homogeneity of variances not assumed). Nonparametric ANOVA where appropriate.	PARA-SCI and accelerometer data not compared for sedentary time. PARA-SCI not a valid measure of LPA.			
Goodlich et al., (2020) (173) Australia	Total number: 11 Number of non-ambulant participants: 6 Diagnosis: CP Age range: Not reported Mean age yrs (SD): 11 (3) GMFCS level: III-IV	Can activity-monitors and machine learning models provide accurate information about PA of children and adolescents with CP who use	Validity study	Activities completed wearing ActiGraph GTX3+ accelerometers on wrist, hip, mid-thigh of least affected or dominant side at 30Hz sampling frequency. Activities were: supine rest, colouring in supported sitting, ball throwing and	Model performance evaluated using leave-one-subject-out cross-validation accuracy.	Random forest classifier using wrist features was best performing single device model = 79% classification accuracy. Same model with hip and wrist best performing 2 device model = 92% accuracy. Support vector machine classifier for hip, wrist and thigh = 90% accuracy.	2	Fair	Not a consecutive or random sample of patients. No blinding reported.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
		mobility aids.		catching in sitting, brisk walking with an aid, wheelchair propulsion, cycling on an adapted tricycle. 5 mins per activity. Direct observation and video footage of activities. 40 features extracted in 5 s epochs. 3 supervised learning algorithms (decision tree, support vector machine, random forest) trained using features in the raw-acceleration signal.		Combining features from 2 or more device placements significantly improved classification accuracy in comparison to 1 device ($p<0.05$). No difference between 2 and 3 devices. Activity recognition good - excellent for sedentary activities; supine rest (80–100%), seated upper limb tasks (88–94%). Wheelchair propulsion (seated non-sedentary) 77–85% accurate.			
Jakobsson et al., (2023)	Total: 33 Non-amb. participants: 33	Evaluate settings during processing	Evaluation	ActiGraph GT3X accelerometer worn above the iliac crest for 7	To compare mins / day sedentary, LPA, MVPA	Measuring vector magnitude and non-wear time of at least 90 mins	3	Fair	Well conducted study but results not

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
(203) Sweden	Diagnosis: CP Age range: 4-17 y Mean age: 12.36 ± 3.43 y GMFCS: IV-V	of accelerometer data in non-amb. children with CP, comparing: 1) vertical acceleration vs vector magnitude, 2) 60 vs 90 consecutive mins of non-wear time, 3) 300, 500 or 600 mins/day or more to classify the day as valid, 4) 3 vs 4 valid days to classify a		consecutive days during waking hrs (excluding water based activities) up to 4 times/year. Sampling frequency = 30Hz. 10 s epochs. Used Evenson et al. cut points.	VA vs VM and 60 vs 90 mins of non-wear time: Friedman test with post hoc Wilcoxon signed-rank test. Difference in valid days and valid periods using different settings compared with Cochran's Q test with post hoc pairwise comparisons using Dunn's procedure with Bonferroni correction for multiple	increased mins recorded/day, especially for sedentary time ($p<0.0125$). Significant difference in numbers of valid days depending on time criteria set to determine a valid day ($p<0.0001$). No significant difference in valid periods using 3 vs 4 days. Using vector magnitude, non-wear time of 90 mins, 500 min recorded/day for periods of at least 3 valid days was recommended.			as externally valid / generalisable as is implied.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
		period as valid.			comparisons. Kruskal–Wallis H test with post hoc pairwise comparisons using Dunn's procedure with Bonferroni correction for multiple comparisons to determine statistical differences in sedentary time, LPA and MVPA for valid days in valid periods using VA or VM and 60 or 90 mins of non-wear time.				

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
Keawutan et al., (2016) (204) Australia	Total: 84 Non-amb. participants: 23 Diagnosis: CP Age range: 4-5 y Mean age (SD): 4 y 8 m (6 m) GMFCS: I-V	1) Identify triaxial accelerometer cut-points in children with CP aged 4-5 against direct observation. 2) Validate these cut-points in an independent sample in the same population. 3) Validate previously established cut-points in children with TD with children	Cross sectional validity study	Random allocation to calibration or validation group. Videoed doing GMFM-66 assessment wearing ActiGraph GT3X / GT3X+ accelerometer aligned with the lumbar spine. Data collected at 30Hz in 5 s epochs. Observed activities categorized as sedentary or active using Behavioural Evaluation Strategy and Taxonomy, in epochs synchronized with accelerometer.	Receiver operating characteristic analysis used to determine classification accuracy of cut-points in the calibration work. Used Bland-Altman plots to validate developed cut-points and Butte cut-points for TD children. For area under the curve in receiver operating characteristic analysis,	No significant differences between calibration / validation groups. Calibration cut-points (counts per 5 s), % sensitivity and specificity, area under curve, CI and classification accuracy: GMFCS IV = 60 (65% sensitivity, 63% specificity), 0.70 CI = 0.67-0.73, fair GMFCS V = 16 (81% sensitivity, 80% specificity), 0.84 CI = 0.78-0.89, good No significant differences in sedentary time between observed and predicted	2	Fair	Static standing misclassified as sedentary time. Not reported how sample were selected. No blinding reported.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
		with CP and compare them with the new cut-points for CP.		Sedentary = child stationary with or without limb movement. Active = child moved their centre of mass. Epochs excluded if an adult moved the child or child moved out of view. 1 observer scored videos. Intrarater reliability: excellent agreement achieved, 0.81 κ score (P<.001). Different cut-points established for each GMFCS level.	≥0.9 = excellent accuracy; 0.80 to 0.90 = good; 0.70 to 0.80 = fair; and < 0.7 = poor	values for GMFCS levels IV and V. Results support use of Butte cut-points for sedentary time (820 cpm) in children with CP aged 4 to 5 y in all GMFCS levels. The cut-point can be applied to group data, but not individuals, due to wide 95% CIs.			
McPhee at al., (2022)	Total: 83 (survey) 67 (Feasibility study)	1) Investigate importance of specific	Cross sectional survey and	Survey: importance of the following health outcomes:	Descriptive summary statistics (means,	66% participants rated physical behaviour as very important, 24%	1	Fair	Cross sectional data so temporal

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
(205) Canada	Non-amb. participants: 23 Diagnosis: CP Age range: 14-68 y Mean age: 30 y (SD 15 y 1 month) GMFCS: I-V	outcome measures within a core outcome set for multimorbidity risk in adolescents and adults with CP. 2) Assess feasibility of these outcome measures in international clinical research settings. 3) Describe associations between the core outcome	feasibility study	physical behaviour, nutrition, sleep, cardiorespiratory endurance, body composition, blood pressure, blood lipids, and glucose. Feasibility study: collecting the most important self-reported outcomes. Prevalence of multimorbidity risk and associations of risks with GMFCS level described. Physical behaviour (including sedentary time) measured using Activ8 device worn on right or	SDs, median, IQR, percentages. Associations between each outcome measures and GMFCS levels: Spearman's ρ).	somewhat important. 39 (58.2%) participants agreed to wear the Activ8 device. 11 did not meet the minimum wear time criteria. Physical behaviour data was not collected for any GMFCS IV-V participants, so sedentary time results are not reported. Measuring physical behaviour resulted in additional participant burden, time and personnel required in comparison to other outcomes. Barriers included inconvenience of wearing the device			relationships can't be explored. Risk of selection bias in feasibility section as was a convenience sample. No sample size justification.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
		set data and GMFCS levels.		least affected upper thigh for 7 days. Minimum wear time = 5 days of 11 hrs/day. Device detects: lying, sitting, standing, walking, running, cycling. Sedentary behaviour was time spent lying and sitting. Activity diary kept.		for 7 days and arranging its return. Additional research personnel were needed to distribute, collect, curate, and analyse accelerometer data.			
Oftedal et al., (2014) (206) Australia	Total: 103 Non-amb. participants: 25 Diagnosis: CP or no diagnosis (TD) Age range: 1 y 6 m - 3 y Mean age, y	Validate uni- and triaxial ActiGraph cut points for sedentary time in toddlers with CP and TD children.	Cross sectional validity study	Participants divided into calibration / validation samples. TD, amb. and non-amb. children with CP analysed separately. ActiGraph (GT1M / GT3X / GT3x+) accelerometer	Receiver operating characteristic – area under the curve analysis determined classification accuracy of accelerometer data. Predictive	Cut point for: uniaxial accelerometers = 2 counts per 5s epoch for all GMFCS levels, triaxial accelerometers = 10 counts per 5s epoch for GMFCS levels IV-V.	2	Fair	Observed static standing miscoded as sedentary time. Not described how sample were

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
	(SD): 2 (6 m) GMFCS: I-V			worn during videotaped assessment. Accelerometers positioned centrally on the back at waist height. Observed behaviour coded as sedentary or non-sedentary. Static standing and sitting or lying without limb movement coded as sedentary. Data analysed in 5 s epochs. Any accelerometer activity in the epoch resulted in epoch being classed as non-sedentary.	validity determined using Bland–Altman analysis.	Classification accuracy for established cut points: Uniaxial GMFCS levels IV = 0.72 Uniaxial GMFCS level V = 0.61 Triaxial GMFCS level IV = 0.86 Triaxial GMFCS level V = 0.71. Triaxial cut points provided accurate group-level measures of sedentary time (bias = 2.1%, 95% limits of agreement = -17.3% to 21.5%;) for non-amb. toddlers. The difference between observed and predicted time spent sedentary			selected from existing cohort. No blinding reported.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
						was not significant (p>0.05).			
Rast et al., (2022) (207) Switzerland	Total: 87 Non-amb. participants: NA. Participants were health professionals. Discipline: Therapists (62), doctors (16), nurses (9). Y of clinical experience (SD): 13 (10)	Identify clinically relevant outcomes that could be gathered from wearable inertial devices for children and adolescents with neuromotor impairments; to inform development of new algorithms.	Mixed methods survey	Anonymous survey of paediatric health professionals from 23 neurorehabilitation centres in German speaking countries of Europe. Participants rated clinical relevance of 34 existing outcomes which measure quality or quantity of motor activities using a 4-point Likert scale (very relevant, relevant, hardly relevant, not relevant or no response). Outcomes were grouped into	Median response and mean rank to determine clinical relevance for each outcome. Confounders: Kruskal-Wallis test: differences between health professions. Tukey's range test: profession-wise comparisons where significant differences	70% response rate. 2% of outcomes not ranked. All outcomes had median rating of "very relevant" or "relevant". 11% of open-ended questions answered. Outcomes relating to sedentary time: Duration of lying, sitting, standing was the most relevant outcome overall (mean rank 12.1), followed by amount of active propulsion during wheeling periods (mean rank 13.1). Number of sit to stand transitions was quite central in	4	Fair	Convenience sample introducing selection bias. Not a validated survey.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
				categories. For each category, an open-ended question asked for any unlisted relevant outcomes. Confounders accounted for: discipline, y of clinical experience, workplace. Results combined with a survey of family priorities to produce a list of relevant clinical outcomes to monitor motor activities using device-based wearables.	identified. Spearman rank correlation coefficient: relationship between work experience and the responses. Wilcoxon rank sum test: place of work. Alpha level = 0.05. No correction for multiple testing to avoid overlooking influences of confounders.	the rankings (mean rank 17). Energy expenditure had lower clinical relevance (mean rank 18.7). Discipline, clinical experience, and workplace had minimal impact on priorities. From sedentary time related outcomes, only sit to stand transitions were influenced by y of clinical experience. More experienced professionals ranked this as significantly more relevant. Outcomes suggested in open-ended questions did not relate to sedentary time.			

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
						Duration of sitting, lying and standing was a priority for families also. Active and passive wheeling was less relevant to families than professionals. Families were interested in number of transfers, which could indicate interruption of sedentary time.			
Rast et al., (2024) (208) Switzerland	Total: 31 Non-amb. participants: 11 Diagnosis: Neuromotor impairments (CP, traumatic brain injury, DMD, epilepsy,	Validate accuracy of 3 sensor configurations and their corresponding algorithms to measure motor activities in children	Validity study. Comparison of algorithm output to video.	Participants completed an activity circuit at inpatient rehabilitation centres: watching a film, playing a game seated, cycling, drinking, playing outdoors, moving between activities in a self-	Measured classification accuracy, sensitivity and precision of each algorithm. >90% for all 3 elements = excellent, 80%-90% good, 70%-	Some participants did not complete every activity. Classification accuracy: 1) posture algorithm = 97%, 2) wheeling algorithm = 96% . Results relevant to distinguishing lying, sitting and standing activities only are	2	Fair	Convenience sample introducing selection bias. No blinding of those undertaking analysis, however 2 independent

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
	cerebrovascular disease and other) Age range: 4-20 Mean age (SD): 11.8 y (3.2 y) GMFCS: I-IV	having rehabilitation. The sensor configurations and algorithms measure: 1) Time spent sitting, lying and standing and number of sit to stand transitions (trunk and thigh sensor) 2) Active and passive wheelchair propulsion (wrist and		selected way. Self-selection of games and how to do activities to replicate real life. Wore ZurichMOVE sensor modules (3-axis accelerometer, 3-axis gyroscope, and altimeter) on both wrists, sternum, thigh and shin of less-affected side, walking aids and wheelchairs. Sampling rates = 50Hz. Reference standard = video recordings for 3 sensor and algorithm configurations [(1) posture, 2) wheeling, 3)	80% moderate, and < 70% weak. Relative measurement error of activity-specific outcome measures was estimated. Spearman's rank correlation co-efficients described between participant variability to determine whether algorithms could discriminate	summarised. Posture algorithm: Sensitivity and precision to detect lying, sitting, and standing were > 93%. In cases of misclassification, lying, sitting and standing were confused with each other, but not with other activities, with the exception of cycling. Wheeling algorithm had good-excellent performance. Identification of active wheeling was more sensitive and precise than passive wheeling. Wheeling was misclassified as sitting and assisted walking but not any			reviewers labelled videos.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
		wheelchair sensors) 3) Time spent walking (independently or assisted) and altitude change (ankle sensor, sensor on walking aid).		walking]. Devices synchronized. 2 independent researchers labelled videos as lying, sitting (including sitting, kneeling, being carried, active wheeling, passive wheeling, cycling, swinging, sliding), standing (including standing, free walking, assisted walking, going upstairs, going downstairs, jumping), and unknown when not visible. Time periods excluded from analysis were: unknown time (0.4%), disagreement in	between participants.	other activities. Relative measurement error medians (IQR) were: Lying duration 0% (3%), sitting duration 0% (5%), standing duration 0% (6%), active wheeling duration 0% (5%), passive wheeling duration 2% (19%), sit to stand transitions -20%, (32%).			

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for quality rating
				video labelling (4.2%) and incorrect sensor placement (1.9%).					

Note: ref.: reference, non-amb.: non-ambulant, amb.: ambulant y: years, m: months, hr: hour, hrs: hours, mins: minutes, s: second, CP: Cerebral Palsy, DMD: Duchenne muscular dystrophy, GMFCS: Gross Motor Function Classification Scale Level, HPA: habitual physical activity, LPA: light physical activity, MVPA: moderate to vigorous physical activity, cpm: counts per minute, TD: typically developing / typical development, IQR: Interquartile range, CI: confidence interval, ANOVA: a one way analysis of variance, SD: standard deviation. Critical appraisal tool key: 1 = The Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies, 2 = QUADAS-2, 3 = Checklist for Evaluative Studies in Visual Analytics 4= Survey (including pre-test probabilities) checklist

Eight articles rated as fair quality and published between 2014 and 2024 were relevant to measurement of sedentary behaviour in NAYP (Table 5). Articles included participants with a range of physical abilities, with the exception of Rast et al.(207) (survey of health professionals) and Jakobsson et al. (203) (all participants were NAYP). A minimum of 24% of the sample were non-ambulant in the remaining articles. Participants had CP in the majority of the articles, with the exception of Rast et al. (207) (survey of health professionals), and Rast et al. (208). The latter included participants with a variety of neuromotor impairments. Two articles included adults over 25 years (202, 205).

Four articles have validated device-based measures of sedentary time in NAYP using accelerometers by comparing data with videotaped direct observations (173, 204, 206, 208). Two of these articles examined the validity of count-based accelerometer cut-points among participants ≤ five years of age (204, 206). Specifically, ActiGraph accelerometers were placed in the centre of the back on a neoprene belt whilst participants carried out a Gross Motor Function Measure 66 play-based assessment. Keawutan et al. (204) used triaxial accelerometers to establish cut points for each GMFCS level, then compared the established cut points to Butte cut points (68 counts per five second epoch) for sedentary time, developed for typically developing children. The sedentary time cut points established for GMFCS levels IV and V were 60 and 16 counts per five second epoch respectively. Classification accuracy (receiver operator characteristic – area under the curve analysis) for established cut points was 0.70 and 0.84 for GMFCS levels IV and V respectively. Classification accuracy was not calculated for Butte cut points, as these were only used in the validation phase. Validation of Butte cut points showed no significant difference

between observed and predicted sedentary time for GMFCS levels IV and V. Results supported use of Butte cut points for NAYP, but only for group data. The 95% confidence intervals were too wide for them to be used for individuals.

Oftedal et al. (206) established cut points for children in GMFCS levels I-III and IV-V for both uniaxial and triaxial accelerometers. The cut point for uniaxial accelerometers was two counts per five second epoch for all GMFCS levels. For triaxial accelerometers it was 10 counts per five second epoch for GMFCS levels IV-V. Classification accuracy (receiver operator characteristic – area under the curve analysis) for established cut points was 0.72 and 0.61 for GMFCS levels IV and V respectively for uniaxial accelerometers and 0.86 and 0.71 for triaxial accelerometers.

Both articles acknowledged that back-worn accelerometers could not distinguish standing from lying or sitting and recognised this as limitation. They managed this by coding observed static standing on the videotapes as sedentary behaviour. This is not in keeping with the accepted definition of sedentary behaviour (3), because only sitting and lying postures are sedentary. This is a weakness of these studies. As the articles acknowledged, the back-worn accelerometer would have classified the standing as sedentary time, which should have been coded as non-sedentary behaviour if the accepted definition was applied. It is therefore likely that the accelerometer classification accuracies reported would be lower if observed static standing had been coded as non-sedentary behaviour.

Two articles explored the validity of using multiple sensors attached to different sites for classifying sedentary time and other activities in a laboratory setting (173, 208).

Goodlich et al. (173) used three supervised machine learning models (random forest, decision tree, support vector machine) to classify activities from raw accelerometer data, including supine rest, colouring in supported sitting, ball throwing and catching in sitting, self-propelling and cycling. Triaxial accelerometers were worn on the wrist, hip and mid-thigh. The reference standard was observation from videotapes. Results suggested 79% classification accuracy across all activities could be achieved with a single wrist sensor, increasing to 92% where individuals wear both a hip and wrist sensor (random forest model). Analysis indicated addition of data collected from a third sensor site (the mid-thigh) was not beneficial.

Rast et al. (208) used an algorithm to combine data from trunk and thigh sensors (ZurichMOVE sensor modules) to measure lying, sitting and standing duration with excellent accuracy. The sensor modules contained a triaxial accelerometer and gyroscope and a barometric pressure sensor. Again, the reference standard was observation from videotapes. Rast et al. (208) also combined raw data from sensor modules on the wrist and spokes of the wheelchair to detect self-propelling with good-excellent classification accuracy (90%). Results suggested that placement of a single accelerometer in the centre of the back (204, 206) introduces potential for self-propelling / cycling to be misclassified as static sitting. These recently published articles using multiple devices (173, 208) currently present the most valid measures of sedentary time in NAYP. However, some risks of bias were identified on quality assessment and validity (and feasibility) of using multiple sensors placed at different sites to measure sedentary time in free-living environments has not been evaluated (Table 5).

Claridge et al (202) aimed to validated the self-reported Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI) against device-based measurement of physical activity (PA) and sedentary time. Estimates of sedentary time from the PARA-SCI questionnaires were correlated with estimates from hip and wrist worn accelerometers (i.e. criterion standards) with reference to three sets of cut points; 1) Freedson, 2) Evenson,3) Swartz (sedentary / LPA cut point was 100 counts per minute). Appraisal of this article identified that correlation between estimated sedentary time from the PARA-SCI and the accelerometer was not reported, only correlations with MVPA and LPA. The article was categorised to this sub-question due to its reported aims, however it would have been more relevant to sub-question two. There was poor correlation between self-reported and accelerometer - assessed LPA. Given the lack of validation of using single accelerometers for measuring sedentary time in NAYP, it is not appropriate to use them as the criterion standard for establishing the validity of other measures.

Three articles categorised to this sub-question did not assess validity of sedentary time / behaviour measures (203, 205, 207). These articles explored importance and feasibility of measuring sedentary time in NAYP and processing of data collected by accelerometers. They have been included in this review because they meet the inclusion criteria of “exploring measurement of sedentary behaviour in NAYP” and are relevant to the overarching question. This was the most appropriate sub-question to categorise these articles to, as they relate to measurement of sedentary time / behaviour.

The first of these three articles involved a survey of people with CP to investigate the importance of specific outcome measures within a core outcome set and to assess

feasibility of these outcome measures (205). The second was a survey of health professionals aiming to identify clinically relevant outcomes for children and adolescents with neuromotor impairments that could be collected by wearable inertial sensors (207). Survey respondents with CP and clinicians agreed upon the importance of measuring physical behaviours (including sedentary time) (205, 207). Measurement of physical behaviour was very or somewhat important to 90% of participants with CP (205). Health professionals indicated that measurement of lying, sitting and standing duration was the most clinically relevant of 34 possible outcomes which could be collected by wearable movement sensors (207). McPhee et al. (205) assessed feasibility of measuring physical behaviour using a thigh worn device and completing an activity diary for seven days. No participants in GMFCS levels IV-V successfully collected this data, suggesting it was not feasible for them. Barriers included meeting the minimum wear time and returning the device.

In conflict with McPhee et al. (205), Jakobsson et al. (203) successfully collected data from participants in GMFCS levels IV-V for a maximum of seven days using a single hip worn accelerometer. Participants in this study were younger, so may have had parents / guardians supporting them. In this third article that did not assess validity of a measure, Jakobsson et al. (203) evaluated different settings during processing of accelerometer data in non-ambulant children with CP, comparing: vertical acceleration versus vector magnitude, 60 versus 90 consecutive mins of non-wear time, 300, 500 or 600 mins/day or more to classify the day as valid, three versus four valid days to classify a period (a set number of days meeting the specified number of minutes) as valid. Using a variety of non-parametric statistical tests, they compared minutes recorded per day, number of valid days and number of

valid periods using different processing settings. From these comparisons, they recommended minimum wear time of 500 minutes / day and having three valid days of data is sufficient in this population, which could improve feasibility of data collection.

Concerns over potential misclassification of accelerometer data in single device studies and the differing study designs, wear protocols, devices and age groups studied in these articles make synthesis via metanalysis inappropriate for this sub-question.

In conclusion, there is a lack of good quality evidence relating to measurement of sedentary time in NAYP. Device-based measures may be valid for measuring sedentary time in NAYP when used at multiple placements sites (i.e. wrist and hip, or wrist and wheelchair). Further research is required to establish validity of these measurement methods in free-living environments. There are weaknesses in the limited existing evidence which uses count-based cut-points (204, 206), rather than analysis of raw accelerometer data (173, 208). Studies using count-based cut-points focused on pre-school children. There is a gap in relation to older age groups. In future, it is important that researchers consider both the postural and energy expenditure components of the definition of sedentary time. For NAYP, using a single accelerometer which is proximally placed on the trunk or hip cannot accurately measure either component. If researchers wish to pursue using count-based cut-points for sedentary time measurement in NAYP, more high quality research is needed.

2.4.5 Sub-question two. Have patterns of sedentary time or behaviour of NAYP been described?

Table 6 Study characteristics, results and quality assessment for sub-question two - Have patterns of sedentary time or behaviour of NAYP been described?

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
Arteaga et al., (2020) (33) USA	Total: 64 (49 with DMD, 15 healthy controls) Non-amb. participants: 33/49 (67%) participants with DMD Diagnosis: DMD Age range: 8.4 - 24.3 y (participants with DMD), 11.5 - 18.4 y (healthy controls) Mean age (y) (SD): 13.6 (4.0)	1) Assess total amounts and patterns of PA in people with DMD using accelerometery in a home environment. 2) Compare PA meaures between patients with DMD / age and sex	Cross sectional observational study	ActiGraph GT3X accelerometer worn on dominant wrist and ankle for 7 days (24 hrs/day) in home environment. Healthy controls only had 1 wrist worn accelerometer. Accelerometers recorded at 30 Hz in 15 s epochs. Recordings converted into omnidirectional acceleration estimates (vector magnitude) in counts/min. Wear	Shapiro-Wilk test for normality. Depending on results, two-sample independent t t-test or Mann-Whitney U test to compare anthropometric measures, adherence, PA measures (wrist-worn and ankle	Non-amb. participants with DMD sedentary for 91.0% ± 7.7% of the day. Non-amb. participants spent significantly more of their sedentary time in the sedentary 1 subcategory and less time in sedentary 3 than amb. participants with DMD ($p<0.001$). Non-amb. people with DMD had a lower wrist VM/min wear and VM/min ankle ($p<0.001$) than amb. participants	1	Fair	Sedentary 3 category above 1.5 MET threshold. No sample size justification. Not reported participation rate of eligible participants. Dates of recruitment and data collection not stated.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
	(participants with DMD) 14.0 (2.3) (healthy controls)	matched healthy controls and between amb. / non-amb. patients with DMD. 3) Examine the effect of ambulation status, age, corticosteroid use on PA measures in people with DMD.		and non-wear periods identified with Choi's algorithm. Activity divided into time spent in sedentary, LPA and MVPA categories. Cut points were for healthy youth and adolescents from "Youth Compendium of Physical Activities". Sedentary category divided into 3 subcategories and LPA into 2 subcategories by dividing the range of corresponding VM/min into equal parts. Sedentary 1 = lowest	worn accelerometers) and wrist-to-ankle ratios between groups. Compared distribution of PA across intensity categories between study groups using non-parametric Kolmogorov-Smirnov test. Two-sample independent t t-tests with Bonferroni	with DMD and healthy controls. Activity measures in participants with DMD were significantly affected by age and ambulation status ($p<0.05$) but not corticosteroid use. Adjusting for age and corticosteroid use, being amb. vs non-amb. predicted an approximately 60% increase in wrist VM/min wear of the DMD group's average. Non-amb. participants with DMD had lower ankle VM/min wear and VM/min awake ($p < 0.001$), but greater wrist-to-ankle ratios of VM total, VM/min wear,			

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				sedentary category, sedentary 3 = highest. Highest sedentary 3 VM/min was equivalent of 2.0 METS.	correction to compare distribution of PA across sedentary and LPA, and % mins awake in sedentary behaviours and LPA between study groups. Multiple regression to assess impact of confounders.	and VM/min awake than amb. participants with DMD ($p < 0.001$).			
Bloemen et al., (2019) (209)	Total: 53 Non-amb. participants (including	1) Quantify PA and sedentary time in	Cross sectional observational study	Participants all used manual wheelchairs. VitaMove	Shapiro-Wilk test for normality. Wilcoxon	Participants more sedentary than typically developing peers (94.3%	1	Fair	Dates of recruitment and data collection

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
Netherlands	therapeutic amb.): Vitamove 29/34, Actiheart 26/36, vitamove and actiheart 20/25 Diagnosis: Spina Bifida Age range: 5-19 y Mean age (y) (SD): Vitamove 13.7 (3.2), Actiheart 13.5 (3.6), Vitamove and Actiheart 13.4 (3.3)	youth with spina bifida who use a wheelchair, 2) evaluate intensity of activities and compliance with American College of Sports Medicine (ACSM) PA guidelines		(multiple wireless body fixed accelerometers, sternum and both wrists for non-amb. participants) data presented as time spent sedentary and time spent physically active (34 participants) was compared to reference data of typically developing youth. Vitamove records at 128 Hz. Sitting and lying were considered time spent sedentary. Walking, running, wheeling, (hand) biking and non-cyclic moving were clustered as time spent	Signed Rank tests to compare differences between school days and school and weekend days. Differences in age and gender between participants and those in TD reference data accounted for using linear regression.	versus 78.0% per 24 h, $p < 0.000$). Participants spent 90% of wear time (IQR 7%) sitting or lying during school days compared to 96% (IQR 10%) on weekend days, which is significantly different ($p = 0.007$). Lying was 22% HRR (SD 9, range 0-76%), sitting was 22% HRR (SD 10, range 0-99%) and non-cyclic moving was 29% HRR (SD 9, range 5-71%) which are all classified as a very light intensity level (<30% HRR). The intensities per activity varied			not stated. Not reported participation rate of eligible participants. No sample size justification.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				physically active. Standing was clustered separately. Actiheart data was used to measure time spent at different intensities of PA (36 participants) in 30 s epochs. HRR was calculated. Intensities categorised according to the ACSM (very light intensity to near to maximal intensity). 0-30% of HRR was classed as very light activity. Wore both devices in waking hrs on 2 school days and 1 weekend day.		extensively between participants, e.g. a HRR of 99% was reached in sitting.			

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				Type of activity and intensity was combined (25 participants). Vitamove data was compared with reference data of 20 typically developing age and gender matched youth, collected on school days.					
Bloemen et al., (2020) (210) Netherlands	Total: 53 Non-amb. participants (including therapeutic amb.): 29/34 Vitamove, 27/30 Vitamove and peak oxygen uptake measured,	Explored relationships between PA and peak oxygen uptake, age, sex and severity of disability (Hoffer	Cross sectional observational study	Sedentary time, time spent being physically active, and time in MVPA (dependent variables) were measured using Vitamove (34 participants) and Actiheart (36 participants). Peak oxygen uptake measured	Univariate and multivariate regression analyses performed to identify associations with independent variables (peak oxygen	Sedentary time during school days was influenced by age (β=0.326/β=–0.320) and Hoffer classification (β=0.409/β=–0.534). On weekend days, sedentary time was influenced by Hoffer classification	1	Fair	Dates of recruitment and data collection not stated. Not reported participation rate of eligible participants.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
	26/36 Actiheart, 24/30 Actiheart and peak oxygen uptake. Diagnosis: Spina Bifida Age range: 5-19 y Mean age (y) (SD): 13.7 (3.2) Vitamove, 14 (3.0) Vitamove and peak oxygen uptake measured, 13.5 (3.6) Actiheart, 14.2 (3.1) Actiheart and peak oxygen uptake.	classification)		using wheelchair shuttle test.	uptake, sex, age, Hoffer classification)	(β=0.617/β=–0.428), but not age.			No sample size justification.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
Carlon et al., (2013) (211) Australia	Total number of included papers: 6 Papers involving non-amb. participants and measuring sedentary time: 1 Non-amb. participants whose sedentary time was measured: 32 Diagnosis: CP Age range in paper: 11-17 Mean age (y) (SD): Not reported GMFCS: I-V	Systematically review and compare daily habitual PA levels and sedentary time of young people with CP to typically developing peers and PA guidelines.	Systematic review	Databases searched: AMED, AMI, CINAHL, Cochrane Library, EMBASE, ERIC, Medline, PEDro, PsychINFO, ProQuest. Search Date: earliest available evidence - September 2011 Key search terms: “cerebral palsy,” “physical activity,” and “exercise,” plus synonyms and MeSH terms. Citation tracking of included papers and screening of reference lists. Inclusion criteria: Written in English, quantitative measurement of	Standardized mean differences calculated. Meta-analysis not performed due to heterogeneity of groups and outcome measures.	1 included study (Maher et al., 2007) measured sedentary time in non-amb. young people via a self / proxy reported survey, including hrs / week of screen time. This study was rated 8/10 in the risk of bias assessment. Young people with CP had an average of 28.5 (14.8) hrs of screen time / week, in comparison to a PA guideline recommending a maximum of 14 hrs / week.	2	Fair	Sedentary time in purpose of the study but not listed as a search term. No contact with authors of included papers reported. Inclusion of unpublished evidence not reported. Excluded non-English studies.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				habitual PA or sedentary behaviour, participants had CP, population had a mean age of 18 y or less and compared their habitual PA data to normative data or to matched TD peers. Exclusion criteria: qualitative measurement, raw data not provided. Independent screening by 2 reviewers Data extraction by 1 reviewer and independently verified by 2nd reviewer. Risk of bias in					

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				individual studies assessed using a quality assessment checklist for observational studies. Quality assessment undertaken by 2 independent reviewers.					
Chunxiao and Shihui, (2012) (53) China (Hong Kong)	Total: 8 Non-amb. participants: 2 Diagnosis: CP Age range: 11-16 Mean age (SD): 14.4 (1.9) GMFCS: I-V	Gain insight into the PA experiences of special school students with CP in Hong Kong.	Qualitative	Semi structured interviews. Content analysis of transcripts.	NA	Participants preferred sedentary activities (reading, watching TV, surfing the internet) to PA and had low levels of PA.	3	Fair	Purposeful selection introducing risk of selection bias. Researchers had existing relationship with participants. No discussion of reflexivity.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
Claridge (2019) (212) Canada / Netherlands	Total: 35 Non-amb. participants (including therapeutic ambulatory): 4 Diagnosis: Spina Bifida Age range: 5-18 y Mean age (SD): 10 y 11 m (3 y 6 m)	1) Describe active and sedentary time in children with spina bifida. 2) Compare their PA on weekdays vs weekend days.	Cross sectional observational study	PA and sedentary time measured using ActiGraph GT3X or Actiheart monitors. ActiGraph monitors worn on right waist in waking hrs for 7 consecutive days (excluding water-based activities). Data stored in 3 s epochs and compared with TD age- and sex-matched controls. Used Evenson et al. cut points, validated for amb. children with CP. Measured total, weekday, and weekend average time by activity intensity and average vertical	Independent samples t-tests to compare actigraph data with TD age- and sex-matched controls. HRR categories compared between weekdays vs weekend days using Wilcoxon signed-rank tests.	ActiGraph data showed children with spina bifida spent more time sedentary (mean [SD] 49.5min/h [5.78]) in comparison to TD controls (mean [SD] 41.0min/h [5.76], p=0.001). ActiGraph- and Actiheart data showed no significant difference in sedentary time for weekdays vs weekends. Increased sedentary time in children with spina bifida vs TD controls was consistent on weekdays and weekends.	1	Fair	Single sensor or heart rate only sedentary time measure. Not reported participation rate of eligible participants. Data collection at different timepoints in different countries. No sample size justification. Confounders not explored.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				axis activity cpm. Did exercise testing wearing Actiheart (2 standardised electrodes on chest) and polar accurex monitor to establish resting and maximal heart rate. HRR used to calculate time spent in very light, light, moderate, vigorous, and near-maximal to maximal PA intensity zones using ACSM guidelines for PA intensity in 30 s epochs. Time spent in each HRR zone calculated in total mins and % daily					

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				monitoring time. Actiheart devices worn for 3 days (2 weekdays, 1 weekend day) in waking hrs and night time. Minimum 8 hrs of monitoring on at least 1 day required for inclusion (both devices).					
Houston et al., (2018) (213) USA	Total: 15. (10 with disabilities, 5 TD age matched children.) Non-amb. participants: 8 Diagnosis: CP, traumatic brain injury, severely low muscle tone.	1) Measure PA levels during inclusive physical education and recess. 2) Assess lesson context to determine its influence on	Systematic observational study	Direct observation: System for Observing Fitness Instruction Time instrument. Codes for PA, lesson context, and teacher behaviour are recorded every 20 s. 5 codes for PA: 1) lying down, 2) sitting, 3) standing	One-way ANOVAs to test differences between amb. vs non-amb. students for each PA level during physical education, recess, lesson	Time spent sitting / lying down during PE for amb. and non-amb. participants with disabilities: lying down 0.71% SD 1.33, sitting 65.42%, SD 36.25. Classes involving high levels of fitness work, sitting for students with disabilities =	1	Fair	A priori Inclusion / exclusion criteria not reported. Not reported participation rate of eligible participants. Data collection dates not

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
	Age range: 6-11 y Mean age (SD): Not stated	participating students.		/ intermittent self-propelling / throwing a ball / turning a skipping rope, 4) walking / continuous self-propelling/ push up from chair, 5) vigorous / self-propelling across grass / pull up from chair using a rope. Students observed in PE an average of 6 times over 3 m.	context, teacher behaviour.	85.53%. When fitness work was low sitting = 45.32%. In highly managed classes, students with disabilities moved more to reach a position or do an alternative activity, sitting = 48.65%. When management activities were low, sitting = 76.6%. Sitting time in recess not reported. Support staff observed pushing student's wheelchairs so they could keep up with peers instead of allowing them to self-propel. Students were not typically taken out of wheelchair.			stated. No sample size justification. Confounders not explored.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
						Students in wheelchairs were helped to throw a ball on their behalf rather than throwing it themselves.			
Keawutan et al., (2017) (214) Australia	Total: 95 Non-amb. participants: 20 Diagnosis: CP Age range: 18 m - 5 y Mean age (y) (SD): NA - longitudinal study GMFCS: I-V	Investigate longitudinal changes in HPA and sedentary time in children with CP aged 1 y 6 m - 5 y.	Cohort study	HPA measured using ActiGraph GT3X and GT3X+ accelerometer worn in the centre of the lower back for waking hrs (excluding water-based activities) for 3 days (2 weekdays, 1 weekend day) for at least 1 time point and a maximum of 3 time points between 18 m - 5 y. Used 5 s epochs. Cut-points used:	Linear mixed-effects regression models used for analyses.	46 participants only assessed at 1 time point. Children in GMFCS I-II had significantly lower sedentary time than those in GMFCS III-V at all time points. A significant increase in sedentary time was seen at 4 and 5 y. Annual sedentary time significantly increased (GMFCS III–V: 6.9%, 95% CI 4.6–9.2). Sedentary time (% wear time) in GMFCS III-V	1	Fair	Single sensor sedentary time measure. No blinding reported. Approx half of sample had data collected at more than 1 time point.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				GMFCS IV-V, aged 1 year 6 m - 3 y: 10 counts per 5 s GMFCS I-V, aged 4 - 5 y: 68 counts per 5 s Activity diaries completed including waking and bed times, when monitor was on/off, reasons for removing monitor and when the child was being carried / pushed in a mobility aid.		increased 68.4% (SD=7.0) at 18 m – 2 y to 85.2% (SD=13.3) at 5 y.			
Keawutan et al., (2017) (215) Australia	Total: 67 Non-amb. participants: 14 Diagnosis: CP Age range: 4-5	1) Objectively investigate habitual PA and sedentary behaviour in children	Cross sectional observational study	ActiGraph GT3X / GT3X+ accelerometers worn on lower back for 3 days (2 weekdays, 1 weekend day). Removed for	Linear / logistic regression to compare characteristics of participants, activity	Non-amb. participants sedentary for 92.7% (SD 6.4) of waking hrs. This was significantly higher than sedentary time of	1	Fair	Single sensor sedentary time measure. Less than 50% of eligible

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
	Mean age (y) (SD): 4 y 10 m (4 m) GMFCS: I-V	with CP aged 4 to 5 y across all functional abilities. 2) Compare data to the Australian Physical Activity Guidelines		water-based activities. 5 s epochs. Sedentary time cut-point of 68 counts per 5 s (based on children with TD, validated in preschool children with CP). Activity diary kept.	data boys vs girls and amb vs marginally amb vs non-amb, number meeting activity guidelines (amb vs marginally amb vs non-amb), relationship between %TSS, activity counts, and GMFM-66 Paired t test to compare activity data weekdays vs weekend days.	amb. and marginally amb. participants. 50% of non-amb. participants did not meet recommendations of being sedentary for ≤ 60 mins at a time on any day. 21% achieved this on 1 day, 21% on 2 days and 7% on all 3 days. The proportion of participants who were sedentary for ≤60 mins at a time on at least 1 day was significantly higher in the independently amb. group than in the non-amb. group ($p<.001$). % time spent sedentary was			participants took part. No blinding reported.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
						significantly higher on weekdays vs weekend days (all participants). % time spent sedentary was significantly associated with GMFM-66 (β=−0.61, 95% CI=−0.69 to −0.53, R2=0.74, (p<.001).			
Keawutan et al., (2018) (216) Australia	Total: 67 Non-amb. participants: 18 Diagnosis: CP Age range: 4-5 y Mean age (y) (SD): 4.9 GMFCS: I-V	Investigate relationships between HPA, sedentary time, motor capacity and capability in 4-5 year olds with CP	Cross sectional observational study	Assessed motor capacity using GMFM-66. Wore ActiGraph GT3X or GT3X+ accelerometer for 3 days (2 weekdays and 1 weekend day) in centre of the lower back for waking hrs. Removed for water-based activities. 5 s	Analysis used mixed-effects regression models.	Participants in GMFCS III-V had significantly higher sedentary time than those in GMFCS I (p<0.001). Sedentary time in GMFCS IV=85.4% (SD 5.2) of wear time, GMFCS V=94.5% (SD 5.4). GMFM was negatively associated with sedentary time (MD	1	Fair	Single sensor sedentary time measure. No blinding reported.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				epochs. 820 cpm cut-point for sedentary time. Activity diaries completed including waking time / bed time, when the monitor was on/off, reasons for taking monitor off and when child was being carried or pushed in a mobility aid. Motor capability assessed using functional skills of mobility domain from 59 item PEDI.		= -0.6%; 95% CI=-0.7 to -0.5, p<0.001). PEDI was negatively associated with sedentary time (MD=-0.5%; 95% CI=-0.6 to -0.4, p<0.001). Following stratification for ambulatory status, GMFM and PEDI were associated with sedentary time in amb. participants, but not non-amb. participants.			
Laurusch kus et al., (2017) (57) Sweden	Total: 25 parents (of 16 children) Non-amb. children: 3 Child's	1) Explore how parents of children with CP experience	Qualitativ e	Semi structured focus groups or 1:1 interviews. Inductive approach. Content analysis.	NA	Main category: ‘‘Protecting and pushing towards independence’’, expressed challenges parents	3	Good	Self-selecting sample but all eligible invited. Reflexivity

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
	diagnosis: CP Age range: 8-11 Child's mean age (y) (SD): 9 (1.14) Child's GMFCS: I-V	their child's participation in physical activities. 2) Identify facilitators and barriers for being physically active and reducing sedentary behaviour				experienced when their child wanted to be physically active. Subcategories: "Belonging and taking space in the family", ‘‘Important persons facilitating and hindering’’, ‘‘Friends important but hard to get’’, ‘‘Good for the body but challenging’’, ‘‘Availability and opting out possibilities’’. Availability of competent people to support in participation in physical activities and support in finding friends for their child to be active with is important.			discussed. Multiple analysers. Sufficient quotes to evidence results. Existing relationships not reported.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
						Family culture and attitudes affect children's motivation for being physically active.			
Luther, (2010) (40) USA	Total: 12 parents (of 12 children) Non-amb. children: 6 Child's diagnosis: Meningocele / myelomening ocele spina bifida Age range: 7 y 6 m - 11 y 11 m Child's mean age (y) (SD): 10 (1.5) Child's level of impairment: L3-L5 lesion	Explore how parents form and direct PA choices for their children in prevention of overweight and obesity	Qualitativ e	Semi structured interviews. Open coding, axial coding and selective coding were used during analysis. Constant-comparative analysis used.	NA	Encouraging PA was 1 of 3 key themes that described parents' perceptions of promoting health. Children became more sedentary as they reached puberty. Increased sedentary behaviours of watching TV, playing video games, being in their wheelchair were noted by parents of older children. Parents needed to enforce selection of active activities. Parents	3	Good	Reflective field notes considerin g researcher s role and potential bias. Member validation and multiple researcher s involved in analysis.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
						predicted a change in functional ability but not children's choice making. Change in choices occurred when environmental and social barriers to PA increased and parents were battling weight gain. Healthcare providers did not prepare parents by discussing increased desire to be sedentary with age. Parents adapted PA to child's functional ability, such as transfers to / from their wheelchair, moving about their home, school and neighbourhood. Matching functional			

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
						abilities to physical activities their child could do safely was a priority. Parents of older children observed developmental and physical changes that reduced their child's desire and ability to be active, alongside children's growing resistance. Finding appropriate group activities, providing peer socialisation, having skilled helpers available and time for parent involvement were facilitators of activity. Cost, time, travel, child's interest and fatigue were barriers. Participation in			

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
						community activities could be harmful when adaptations were insufficient, there was a lack of skilled helpers or children did not achieve compared to able-bodied peers. Participation reduced as children grew more aware of their differences to peers. Younger children's desire to be active outweighed fear or embarrassment of physical differences. Older children were less likely to do physical activities when parents did not participate with them. Parents			

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
						assisted with their comfort and desire to hide their need for help from peers. Older children were more fearful of falls and injuries. Some children attained skills allowing them to engage adults and friends to help them do physical activities; others chose not participating above asking for help.			
McPherson et al., (2013) (217) Canada	Total: 180 Non-amb. participants (non-functional ambulatory and non-ambulatory): 52 Diagnosis: Spina Bifida	Explore how weight is assessed and discussed in an outpatient clinic for children with spina bifida.	Retrospective medical records review (qualitative)	Standardised data extraction form. Height / weight extracted from records of children who attended clinic between 2009 - 2011. BMI was calculated and classified using	NA	Sedentary behaviour history recorded in 30 records (16.7%). Sedentary activities e.g. playing video games / computer use were often recorded. Advice about reducing sedentary	3	Good	All eligible records reviewed. Retrospective review eliminated potential for change of practise in response

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
	Age range: 2-18 y Mean age (SD): 12.39 (4.79)			Centers for Disease Control and Prevention cut offs. Data extraction undertaken by 1 author. 10% was checked by 2nd author. Notes around weight, diet and physical / sedentary activities transcribed verbatim. Descriptive thematic analysis. Authors extracted the same excerpts 84.7% of the time. Independent inductive coding and suggestion of themes prior to comparing and contrasting,		behaviours did not appear in any records. No discussions about appropriate levels of sedentary behaviours (e.g. screen time) were recorded. 1 of 4 themes identified was "Physical and sedentary activities: friend or foe".			to the review. Multiple researchers involved in analysis. Sufficient quotes to evidence results. Influence of own role not reflected on.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				merging, re-labelling or splitting codes / themes. Negative cases and similarities and differences between codes discussed.					
Njoki et al., (2007) (218) South Africa	Total: 10 Non-amb. participants: 10 Diagnosis: Spinal cord injury Age range: 15-21 y Mean age (SD): 16.5 (SD not reported)	Explore health-related behaviours and factors that influence behaviour of physically disabled youth with spinal cord injury to determine their health promotion needs.	Descriptive qualitative study	Purposeful selection. Inclusion criteria = English speaking, 15-29 y old, sustained traumatic spinal cord injury >6 m prior to recruitment, discharged from inpatient rehab, living in the community. Individual face-to-face semi structured interviews	NA	10/11 people approached participated. Primary themes: personal influences, perceived needs, support and barriers to positive health related behaviours. Involvement in risky health behaviours (including sedentary lifestyles) reported. >50% of participants reported resorting	3	Fair	No ethics approval documented or details about information provided to participants prior to consent. Reflexivity not discussed. Existing relationships not reported.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				followed by focus group discussions to gain a phenomenological understanding of health promotion needs. Audio recorded and transcribed verbatim. Content analysis. 2nd researcher independently coded transcripts. Consensus reached with emerging themes. Transcriptions shared with 5 participants to validate categories and themes, check accuracy of transcripts.		to sedentary activities e.g.: watching television, listening to music, sitting and chatting with friends, playing cards and computer games during leisure time. Personal struggles with identity and adjustment post injury influenced participation in these behaviours. Barriers to positive health behaviours (including being less sedentary) were: transport, lack of facilities, information and self-confidence, uncertainty about abilities and negative perceptions in			

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
						society. Contact with a support group was a facilitator.			
Oftedal et al., (2015) (159) Australia	Total: 78 (58 had CP, 20 children with TD) Non-amb. participants: 12 Diagnosis: CP / children with TD Age range: Not reported Mean age (y) (SD): 2.4 (0.5 y) GMFCS: I-V	1) Compare PA and sedentary behaviour between toddlers with CP according to GMFCS level, age-matched children with TD and Australian PA recommendations 2) Evaluate differences in sedentary time and	Cross sectional observational study	ActiGraph GT3X worn at centre of lower back for 3 days (2 weekdays, 1 weekend day) during waking hrs (excluding water based activities). Sedentary time measured as % wear time. Wear time diary completed. 5 s epochs. Identified active and sedentary periods using cut points validated by Oftedal et al. (2014), for children with CP. Number and	One-way ANOVA with post hoc testing (continuous data) or Fisher exact test (categorical variables) to test differences between groups (TD vs GMFCS I-II vs GMFCS III vs GMFCS IV-V). Stepwise multiple linear regression	GMFCS IV–V group was most sedentary of all groups (74%, $p<0.05$) and were more likely to have sedentary bouts ≥60 min than any other group ($p>0.05$). Age, sex, height, weight, and wear time did not influence sedentary time. Ambulatory status was the only significant contributor to the regression model ($r2=0.56$, $df=76$, $p=0.001$). No difference in sedentary time between weekdays	1	Fair	Single sensor sedentary time measure. Not clear whether data for control group and those with CP collected simultaneously. No sample size justification. No blinding reported.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
		duration of bouts and number of breaks in sedentary time between these groups.		duration (< 60 s; 1–5 min; 5 min 1 s - 10 min; > 10 min) of sedentary bouts and breaks calculated for each group.	used to account for age, sex, height, weight, wear time, ambulatory status. Reliability of 3 day average to measure sedentary time assessed using one-way random ICC analysis. Significance = 0.05 for a priori analysis and 0.016 for post hoc analysis.	and weekend days for any group (p=0.480).			

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
Rabani et al. (2014) (39) Israel, Jordan and Palestine	Total: 222 (for whom data was analysed) Non-amb. participants: 25 Diagnosis: CP Age range: 13-22 y Mean age (SD): 16 y 9 m (2 y) GMFCS: II-IV	1) Capture HPA in adolescents and young adults with CP in Jordan, Israel and Palestine, including duration and frequency of sedentary behaviour and active events 2) Compare this across GMFCS levels and compare those in educational institutions	Cross sectional observational study.	ActivPAL3 triaxial accelerometer worn for 4 consecutive days (excluding water based activities). Placed midline of anterior thigh on less affected leg. Usually included 2 weekend days, 4 weekdays for some participants. Wheelchair mobility classified as sedentary for GMFCS IV participants. Standing recorded if participants stood stationary for > 20 s. <20 s was included in walking events. Activity diary kept.	Non-parametric outlier tests conducted for each GMFCS level to identify outlying results. Mann–Whitney U tests identified differences between GMFCS levels and other variables ($p<0.05$).	Data removed for 10 outliers and lost for 2 participants. 222 remaining participants. Significant differences ($p<0.001$) between all GMFCS levels for duration of sedentary and standing activity, apart from standing time between GMFCS II and III ($p=0.07$). Sedentary durations significantly longer and standing duration significantly shorter in higher GMFCS levels. Sedentary time measured as % of 24 hrs: GMFCS IV Mean	1	Fair	Single sensor sedentary time measure. Wheelchair mobility classed as sedentary. Dates of recruitment and data collection not stated. No sample size justification. No blinding reported. No comparison of characteristics of outliers / those with

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
		to those who are homebound.				(SD) = 95.7 (5.4) Median (IQR) = 97.7 (4.9). Number of sedentary, standing, and walking events reduced as GMFCS level increased. Duration of sedentary events longest (median=100 mins) at GMFCS IV. Duration of standing events not significantly different between GMFCSs II and IV (approx. 49 s). Participants attending school were less sedentary than homebound participants ($p<0.05$) across			lost data to included participants. Confounders not explored.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
						combined GMFCS levels.			
Salie et el., (2021) (158) South Africa	Total: 103 (48 with CP, 55 TD) Non-amb. participants: 16 Diagnosis: CP Median age yrs) (IQR): Adolescents with CP: 17.8 (16.8-18.5) Adolescents TD: 17.3 (16.9-18) Adults with CP: 34.9 (30.9-36.3) Adults TD: 34 (29.3-35.6) GMFCS: I-V	1) Determine step count/day and PA levels in adolescents and adults with CP living in urban South Africa, 2) Compare this with TD peers 3) Explore relationships between sex, GMFCS, BMI and socio-economic status and	Case control study	Convenience sample recruited from schools for pupils with special educational needs / mainstream schools. Adults with CP had been involved in previous studies or heard about the study via social media / word of mouth. Recruitment of TD adults not described. Participants matched for age, sex and socioeconomic status. Wore triaxial ActiGraph GT3X accelerometer on	Kruskal-Wallis tests used to examine differences between GMFCS groups and TD peers. Spearman rho correlations used to explore associations between PA levels and sex, GMFCS, BMI and socio-economic status. Bonferroni correction	73 (adults with CP) -100 (TD adults) % of each group were included. Sedentary time, (% of the day) was: Adolescents with CP (GMFCS I-V)=74% Adolescents with CP (GMFCSs IV-V)=84% Adults with CP (GMFCS I-V)=75% Adults with CP (GMFCSs IV-V)=84% For sedentary time calculated as mins/hr, adolescents in GMFCSs IV and V were significantly more sedentary	4	Fair	Single sensor sedentary time measure. Convenience sample subject to potential selection bias. Recruitment / selection process not clear for control group. No sample size justification. No blinding reported. Result only

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
		step count/day / PA levels		non-dominant hip for 7 consecutive days (excluding water-based activities) to determine step count/day and time spent sedentary and in LPA / MVPA (mins per hr). Evenson cut points for children and Freedson cut points for adults, (≤100 cpm for children, ≤99 cpm for adults). 5 s epochs recorded at 30Hz. Transformed to 1 min epochs on analysis. Minimum 5 hrs of waking wear time/day. 3 valid week days and 1	applied to allow for multiple analyses	than those in GMFCSs I-II and TD peers. Adults in GMFCSs IV-V were significantly more sedentary than typically developing adults only. Higher GMFCS was associated with higher sedentary time in adolescents and adults (p=0.002, p=0.005 respectively). Sex, BMI, socioeconomic status and week vs weekend day did not influence sedentary time.			generalisable to low socioeconomic countries.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				valid weekend day required for inclusion.					
Sienko (2019) (54) USA	Total: 97 Non-amb. participants: 34 Diagnosis: CP Age range: 18-30 y Mean age (y) (SD): 23.83 (3.58) GMFCS: I-V	Examine the role functional motor level and environmental barriers have on participation in PA and recreation.	Cross sectional survey	Respondents self-reported: GMFCS level, The Physical Activity Scale for Individuals with Physical Disabilities (physical activity participation), The Assessment of Life Habits (recreation), The Craig Hospital Inventory of Environmental Factors (environmental barriers). Only leisure activities in the Physical Activity Scale for Individuals with Physical	Normality testing undertaken. ANOVA's used to test differences between GMFCS levels, for PA and recreation. Pearson product moment correlations used to analyse associations between GMFCS level, Craig Hospital Inventory of Environme	22% response rate. 79% did stationary leisure activities on 5-7 days/week, 7% on 3-4 days/week and 4% on 1-2 days/week. 10% >4 hrs/day doing stationary leisure activities, 80% spent 2-4 hrs and 10% spent between 1-2 hrs/day.	1	Fair	Dates of recruitment and data collection not stated. Low response rate. No sample size justification.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				Disabilities were assessed (household / work activities excluded). Questions about frequency and length of time spent doing sedentary activities (reading, watching TV, computer games, doing handcrafts), which were described as stationary activities were included.	ntal Factors subscales of services/assistance, attitudes/support, policies and physical structure and participation in recreational activities. Linear regression examined relationships between functional motor ability and environmental barriers and participatio				

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
					n in recreational activities. Significance: p<.0125 (Bonferroni corrections for multiple comparisons).				
Sonenblum et al., (2016) (219) USA	Total: 28 (was 37. 9 excluded for incomplete data) Non-amb. participants: 28 (100%) Diagnosis: Spinal Cord Injury Age range: 21-66 y Mean age (y) (SD): 41 (12)	Describe in-seat movement and weight-shifting behaviour of full-time wheelchair users.	Descriptive observational study	Pressure relief monitoring mat including 8 sensors placed underneath wheelchair cushion to measure pressure. Pressure continuously sampled at 1 Hz with 8-bit resolution for 1-2 weeks. Total load = sum of all eight sensor	Coefficient of variation calculated across subject days (across-subject variation), and individually (within-subject variation). Individual coefficients	192 days of data collected. 50% of days included a segment of upright sitting lasting at least 2 h without a weight shift. Participants spent mean 10.6 h (SD 3h) per day sitting in their wheelchair. On an average day, subjects sat without transferring out of the chair or performing a weight shift or pressure	1	Fair	Dates of recruitment and data collection not stated. Not reported participation rate of eligible participants. No comparison of characteristics of those with

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				measurements. Used to determine wheelchair occupancy and complete off-loading. Movements classified as weight shift if pressure was reduced by > 30%. Reported wheelchair occupancy, transfers out of the chair (off-loading for 2 mins or more), pressure relieving frequency (off-loading for 15 - 120 s), weight shift frequency (pressure reduction on one area for at least	of variation averaged to calculate overall within-subject variation.	relieving movement for 140 min ± 84 min. High variability across and within subjects.			incomplete data to included participants. No sample size justification.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				15 s), and in-seat activity frequency (in-plane motion of centre of pressure or total load reduced by 30%), upright sitting time (longest duration without pressure relief or weight shift) for each day.					
Zijlstra and Vlaskamp (2005) (220) Netherlands	Total: 196 Non-amb. participants: 196 Diagnosis: Profound intellectual and multiple disabilities (PIMD) Age range: 18 and over. Mean age (y)	1) Describe duration, frequency, location and content of leisure activities in residential facilities at weekends 2) Investigate relationships between	Cross sectional observational study	Direct support professionals in 112 living units interviewed to complete a questionnaire. Actual leisure provision of 196 people with PIMD recorded over 4 weekends via a diary containing a semi-structured questionnaire and	ANOVA used to test effect of gender and age on frequency, variety and duration of leisure activities. Post hoc comparison tests undertaken	Level of agreement of categories allocated between regular observer and the blinded reliability observer=91.1% (SD=10.1). 'Audio-visual media' was most frequently recorded activity. Included listening to music and watching television or videos.	1	Fair	Carer report from direct observation. Age of participants not reported. Dates of recruitment and data collection not stated. No sample

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
	(SD): Not reported	age and sex and frequency, duration and variety of leisure time activities.		a questionnaire. Reported activities categorised according to an existing system that was modified to improve its relevance. 13 activity categories. Reliability of categorisation checked using a blinded assessor on a sample of approx. 1/3 of the data.	where there were significant differences. ANCOVA with age and gender of the participant as the covariates undertaken to test the effect different facilities had on frequency, variety and duration of leisure activities.	Accounted for 37.3% of time spent doing a leisure activity and 7.9% of total leisure time available. Across 4 weekends, participants spent mean 360 mins doing audio-visual media activities (median 255 mins).			size justification.

Note: Ref.: reference, non-amb.: non-ambulant, amb.: ambulant y: years, m: months, hr: hour, hrs: hours, mins: minutes, s: second, CP: Cerebral Palsy, DMD: Duchenne muscular dystrophy, GMFCS: Gross Motor Function Classification Scale Level, GMFM: Gross motor function measure, PEDI: Pediatric Evaluation of Disability Inventory, HPA: habitual physical activity, METS: Metabolic equivalents, PA: physical activity, LPA: light physical activity, MVPA:

moderate to vigorous physical activity, cpm: counts per minute, TD: typically developing / typical development, HRR: Heart rate reserve, BMI: body mass index, IQR: Interquartile range, CI: confidence interval, MD: mean difference, TV: television. Critical appraisal tool key: 1 = The Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies, 2 = The CASP Systematic Review Checklist., 3 = CASP Qualitative studies checklist 4= CASP Case-control Study Checklist

Twenty studies published between 2005 and 2021 were described patterns of sedentary time / behaviour in NAYP (Table 6). Three studies were rated as good quality (40, 57, 217). The remainder were fair quality. Studies included both quantitative (i.e. systematic review (211), cohort study (214), case control study (158), systematic observational study (213), cross sectional observational studies (33, 39, 159, 209, 210, 212, 215, 216, 220), descriptive observational study (219) cross sectional survey (54)), and qualitative study designs (i.e., interviews (40, 53, 57, 218), focus groups (57, 218) and review of medical records (217)). The systematic review results (211) have not been reported in this evidence synthesis because only one study within it included NAYP and that study has been excluded from this review due to poor quality (197). The rest of the studies in the review are not relevant to NAYP so it is not appropriate to discuss them.

Three studies focussed exclusively on NAYP as participants (218-220). Less than 25% of participants were non-ambulant in a number of studies (39, 57, 158, 159, 212, 214, 215). Several studies included typically developing participants, comparing their sedentary time to participants with varying physical disabilities (33, 158, 159, 212, 213). Parents of NAYP participated in two studies (40, 57). The majority of articles included participants with CP (11) or spina bifida (5). Other diagnoses included spinal cord injury (218, 219), Duchenne muscular dystrophy (DMD) (33) and profound intellectual and multiple disabilities (220). Four articles included adults over 25 years (54, 158, 219, 220).

2.4.5.1 Quantitative studies measuring sedentary time:

The evidence provided some consensus to suggest that NAYP spend more time sedentary compared to both young people with typical development (33, 158, 159, 209, 212) and ambulant young people with disabilities (33, 158, 159, 210, 215). All of these studies (which used device-based measures of sedentary time and / or bouts), were rated fair because some risks of bias were identified. Regardless of wear protocol, device used or diagnosis of participants, there was consistent reporting of NAYP spending ≥74% (159) of their time sedentary, with several studies reporting ≥90% (33, 39, 209, 215). Data from cushions containing pressure sensors in the wheelchairs of adult patients with spinal cord injuries (aged 21 to 66 years) showed that participants sat in their wheelchair for an average of 10.6 hours/day (219). Participants sat without performing a pressure reliving movement or weight shift for an average of 140 minutes ± 84 minutes (219). One study identified that non-ambulant toddlers are also more likely to have sedentary bouts lasting ≥60 min (measured with an accelerometer worn at the centre of lower back), compared to ambulant toddlers with or without disabilities (159). In a study that did not include participants in GMFCS level V, participants in GMFCS level IV had the longest duration of accelerometer-assessed sedentary bouts (median 100 minutes) (39). Studies categorised to sub-question three also found that NAYP spend more time sedentary compared to both young people with typical development and ambulant young people with disabilities (47, 221). One study categorised to sub-question three contradicted this, in which children in GMFCS levels I-III had similar sedentary time to those in GMFCS levels IV-V (p=0.21) (222). This study included young children (aged two-10 years) which may be why their findings were different.

The consensus across papers strengthens the likelihood that their conclusions about high levels and uninterrupted bouts of sedentary time in NAYP is accurate. However, considering our findings in sub-question one, there are risks that sedentary time may be overestimated in NAYP where protocols employ a single accelerometer. More recent studies reporting on patterns of sedentary time that have used multiple device locations or accelerometers combined with heart rate monitoring (i.e. including accelerometers on the wrist and ankle (33), accelerometers on the sternum and both wrists and an Actiheart device (209, 210) and accelerometers on the waist plus an Actiheart (212)) are likely to provide more valid estimates of sedentary time. These studies included participants with DMD (33) and spina bifida (209, 210, 212), aged five-25 years, and estimated sedentary time to be ≥82% in NAYP. However, they did not investigate the duration of sedentary bouts.

2.4.5.2 Factors associated with patterns of sedentary time

Physical function (quantitative studies): Effects of participant's level of physical impairment or functional mobility on sedentary time were explored in six studies (39, 158, 159, 210, 214, 216). These articles were rated fair quality. ActiGraph GT3X (158, 159, 214, 216), ActivPAL (39) or a combination of Vitamove and Actiheart devices (210) were used to measure sedentary time. The consensus that there is a significant positive correlation between sedentary time and increasing levels of physical or mobility impairment is therefore likely to be robust. Interestingly, a study categorised to sub-question three found that amongst participants with CP, those with dyskinesia were significantly more sedentary than those with spasticity (222). No other studies in this review explored whether there was a relationship between having spastic or dystonic CP and sedentary time.

Age (quantitative and qualitative studies): Effects of age were explored in five studies. Four studies were quantitative and measured sedentary time with single (159, 214) or multiple (33) ActiGraph GT3X accelerometers, or a combination of Vitamove and Actiheart devices (210). One study was qualitative, in which parents of children with spina bifida described an increase in sedentary activities as their children reached puberty (40). Two devise-based studies demonstrated a significant positive association between age and sedentary time (33, 214). However interestingly, Oftedal et al. (159) (measured sedentary time with a single ActiGraph GT3X accelerometer placed in the centre of the lower back) found age was not associated with sedentary time and Bloemen et al. (210) (measured sedentary time with a combination of Vitamove and Actiheart devices) found age was only associated with sedentary time on weekdays and not at the weekend. Participants in Oftedal et al.'s study had a mean age of 2.4 years (SD 0.5 years) (159), so it is possible that they were too young for a relationship between sedentary time and age to be demonstrated. This potential positive relationship between age and sedentary time in NAYP may also be why Arruda et al. (222) found sedentary time was similar in their young (under 10 years) ambulant and non-ambulant participants with CP and Oftedal et al. (223) reported relatively low levels of sedentary time in NAYP aged ≤ five years (55-56% across all GMFCS levels). Arruda et al. (222) measured sedentary time with a single ActiGraph GT3X accelerometer placed on the right hip. Oftedal et al. (223) measured sedentary time with a single ActiGraph GT3X accelerometer. Both of these studies were categorised to sub question three. From this evidence, it is likely but not certain that sedentary time increases with age in NAYP. Further exploration of how sedentary time varies with age across a broad

spectrum of age groups, as well as investigation of the factors influencing this variation is required.

Day of the week (quantitative studies): The lack of consensus in relation to whether sedentary time differed between weekdays and weekend days was striking. Seven studies included this in their analysis, which measured sedentary time using a single ActiGraph GT3X accelerometer (158, 159, 215), ActivPAL devices (39) or a combination of Vitamove and Actiheart (209, 210) or ActiGraph GT3X and Actiheart devices (212). Considering the heterogeneity in relation to age, diagnosis, culture and socioeconomic status of participants across studies, perhaps a lack of consensus should be expected. It may be that age and level of school attendance / differing school environments affect whether a difference in sedentary time exists, depending on week versus weekend days.

Physical characteristics and socioeconomic status (quantitative studies): Three studies investigated whether sex influenced sedentary time for NAYP, and there was consensus that it did not (158, 159, 210). Body Mass Index and socioeconomic status also had no association with sedentary time of NAYP (158).

2.4.5.3 Qualitative studies:

The qualitative work of Lauruschkus et al .(57), McPherson et al. (217) and Luther et al. (40) was rated good, suggesting their findings are trustworthy. Njoki et al.'s (218) study was rated fair. In these qualitative studies, children and young people with physical disabilities and their parents reported a preference for sedentary activities such as reading, watching television (TV), listening to music, chatting with friends, surfing the internet or playing computer / video games, in comparison to undertaking

PA (40, 53, 217, 218). This is in keeping with Zijlstra and Vlaskamp's direct observation of leisure time activities in participants with profound intellectual and multiple disabilities (220). Zijlstra and Vlaskamp found audiovisual media was the most frequently observed leisure activity, accounting for 37.3% of time spent doing a leisure activity. This preference for sedentary activities increased in puberty (40).

Lauruschkus et al. concluded that cultural background, parental attitudes and previous experiences were barriers / facilitators that needed to be taken into account when designing interventions to reduce sedentary behaviour of NAYP (57). Finding friends to be active with and adults who are trained to support safe participation in physical activity was important for reducing sedentary behaviour (40, 57, 218). Luther et al described how social isolation and stigmatisation of NAYP and fewer opportunities for development of self-regulation (due to protected environments where choices are limited) promotes sedentary lifestyles (40). Cost, time, travel / transport, lack of facilities, fatigue, young people's interest in activities, self-confidence and negative perceptions of society were barriers to reducing sedentary time (40, 218). Parents reported that as young people matured they were more aware of their differences to their peers and more fearful of injury (40). This provides a possible explanation for the relationship between sedentary time and age demonstrated by some of the quantitative studies. Most young people then relied on parents to help them overcome these barriers. However, some parents of children with spina bifida observed that their child developed skills to engage friends or adults outside their family in helping them to move as a method of overcoming the barriers they experienced (40).

Parents' reported that health professionals did not prepare them for their child's increasingly strong desire to do sedentary activities and their resistance to pursuits involving physical activity (40). This was supported by McPherson et al.'s findings (217). They found professionals only documented sedentary behaviour history in 16.7% of medical records from an outpatient spina bifida clinic. They did not document conversations about appropriate levels of sedentary time or any attempts they made to influence patterns of sedentary behaviour (217), which highlights a missed opportunity for behaviour change.

2.4.5.4 Summary

Validity concerns associated with single sensor studies and the differing study designs, diagnoses of participants, wear protocols, devices used and age groups studied within these articles make synthesis via meta-analysis inappropriate for this sub-question.

NAYP spent ≥ 74% of the day sedentary, however, this is likely to be closer to 82% when we look at studies using the most valid assessments of sedentary time (33, 209, 210, 212). There are many factors that may influence sedentary time, including physical function, age, sex, day of the week and socioeconomic status. More research into how sedentary time varies according to these factors is required, to better understand groups of NAYP, who might be most at risk for negative health outcomes associated with the highest levels of sedentary time.

There are multiple complex social, environment and cultural influences on sedentary behaviour of NAYP which also require more in-depth exploration. A preference for sedentary activities appears to strengthen as children go through puberty. This

evidence suggests health professionals miss opportunities to raise awareness of these patterns with families and therefore do not discuss potential behaviour change strategies.

2.4.6 Sub-question three. Have risks associated with sedentary time or behaviour been explored or quantified for NAYP?

Table 7 Study characteristics, results and quality assessment for sub-question three – Have risks associated with sedentary time or behaviour been explored or quantified for NAYP?

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
Arruda et al., (2022) (222) Brazil	Total: 53 (after 19 excluded for incomplete data) Non-amb. participants: 36 Diagnosis: CP Age range: 2-10 y Median age: 6.2 y (IQR 4.5-8.6) GMFCS: I-V	Describe PA and sedentary time of children with CP and its association with body composition	Cross sectional observational study	Compared GMFCSs I-III with IV-V. Wore ActiGraph GTX3 accelerometer on right hip for 7 days (excluding water-based activities). Minimum wear time= ≥5 hrs/day for ≥ 3 days (including weekend day). Non-wear time=no activity for 60 mins. 15s epochs with Evenson et al. cut points (for TD	Tested for normality using Kolmogorov-Smirnov test. Hypothesis testing with Student's t-test (normal data), Mann-Whitney U test (non-parametric data). Categorical variables expressed as percentiles and compared using chi-squared test	16/17 dyskinetic participants were in GMFCSs IV-V. Groups were similar in relation to age, sex, and family income. Sedentary time similar in those GMFCSs I-III and GMFCS IV-V (p=0.21). Children with dyskinesia spent longer sedentary	1	Fair	Single sensor sedentary time measure. Not reported participation rate of eligible participants. Just below required sample size. No blinding reported.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				children). Sedentary time < 100 cpm. Bouts of uninterrupted sedentary time classified as 1 - 4 , 5 - 9, 10 -14, 15 - 30 min, and ≥31 min and expressed as frequency/day. Activity diary kept. Body composition assessed using anthropometry and electrical bioimpedance (Maltron BF-906). Food intake estimated using 24 hr diet recall. Carers interviewed re: clinical and sociodemographic issues.	or Fisher's exact test. Logarithmic regression to explore associations of PA, sedentary time, sleep and body composition.	=927.6 mins (SD 367) than those with spasticity=771 mins (SD 200) p=0.049. No associations between sedentary time and weight, BMI, lean mass, body fat.			No comparison of characteristics of those excluded compared to included participants.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
Jacobson et al., (2020) (45) Sweden	Total: 61 Non-amb. participants: 21 Diagnosis: CP Age range: 20-22 Mean age (SD): 21 y 2 m (8 m) GMFCS: I-V	1) Describe health-related quality of life, pain, fatigue, and other health variables in young adults with CP 2) Explore associations with the GMFCS level and PA.	Cross - sectional, with population based recruitment	Clinic visit. Interview, clinical history, questionnaires, physical examination, medical chart review. Remote appointments for n=12 who were unable to attend clinic (physical examination data from recent clinical visits used). Data collected: Short Form 36 version 2 for Health-related Quality of Life (HRQoL), Brief Pain Inventory – Short Form, Fatigue Severity Scale, level of PA, medical history, and physical	2-sample t-test with unequal variance to test differences across GMFCS level groups. 1-sample t-test to test differences with the norm mean. Non-parametric test for trends used to test trends across groups. Spearman's correlation coefficient used for correlations with Short Form 36 version 2 and Bodily Pain Inventory. For binary variables the point-biserial	Participants with sedentary lifestyle: GMFCS IV=4/9 (44%), GMFCS V=9/12 (75%). Across GMFCS levels: sedentary lifestyle associated with poorer physical component score (PCS) in Short Form 36 version 2 for HRQoL in comparison to population norm (PCS=50), (for CP, PCS=37.5, 95% CI 32.2–42.3 p=0.001). Mean Fatigue Severity Scale=4.2 for	1	Fair	Validated self-report measure. < 50% eligible participants took part, however population based rather than convenience sampling was a strength. Small sample size acknowledged. No blinding reported.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				examination. Used Saltin-Grimby Physical Activity Level Scale to report physical activity. Level 1 (sedentary) = being almost completely inactive: reading, TV watching, movies, using computers or doing other sedentary activities during leisure time.	correlation coefficient was used. Correlations = negligible (0.0–0.3), low (0.3–0.5), moderate (0.5–0.7), or high (0.7–0.9). Binary regression model to explore confounders.	participants with sedentary lifestyle, 3.6 for light-moderate physical activity, 3.2 for regular strenuous physical activity (statistically significant trend p=0.035). No significant correlation between PA level and pain or the mental component score for HRQoL.			
Jacques et al., (2018) (47) UK	Total: 76 Non-amb. participants: 36 Diagnosis (number of participants):	Investigate: 1) relationship between muscle strength and size	Cross sectional observational study	Measured: Body fat (%) & lean body mass using bioelectrical-impedance. Gastrocnemius medialis anatomical	Normality testing. Kruskal–Wallis test to compare groups, with post hoc Mann–Whitney U (least	Participants with DMD sedentary for 97.1% (SD 3.3) of waking hrs (100% non-amb.), participants with	1	Fair	Single sensor sedentary time measure. No a priori inclusion /

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
	Able-bodied (16), DMD (15), Becker's MD (18), Limb-girdle MD (13), Facioscapulohumeral MD (14) Age range: Not reported Mean age (y) (SD): DMD: 24.2 (6.1) Becker's MD: 42.4 (13.5) Limb-girdle MD: 43.1 (12.4) Facioscapulohumeral MD: 47.1 (11.1) Able-bodied: 35.4 (12.7)	2) relationship between muscle size and strength and PA		cross-sectional area using B-mode ultrasound. Isometric maximal voluntary contraction during plantar flexion and knee extension. PA for 7 continuous days wearing a GENEActiv accelerometer (for 24 hrs) on dominant arm / preferred wrist collecting data at 100 Hz. 60 s epochs. Used cut-points for the general population, therefore only divided into sedentary / physically active time. Reported mean daily mins	significant difference or LSD) pairwise comparisons where appropriate. Height and lean body mass compared between groups using one-way ANOVA with Tukey's for post hoc comparison. Kendall Tau correlations used to identify associations of anthropometric variables, muscle size, muscle strength, and PA. ANCOVA performed	Becker's MD for 83.8 % (SD 8.8) (56% non-amb.), participants with Limb-Girdle MD 88.9% (SD 5.4) (31% non-amb.), participants with Facioscapulohumeral MD 83.1% (SD 6.4) (29% non-amb.). Participants with DMD more sedentary than participants with Becker's MD (14%, p<0.001), Limb-Girdle MD (8%, p=0.016), Facioscapulohumeral MD (14%, p<0.001) and			exclusion criteria reported. No sample size justification. Not reported participation rate of eligible participants. Dates of recruitment and data collection not stated.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				being physically active or mean daily % of waking hrs being sedentary.	where significant associations identified. Bivariate / multiple linear regressions where associations between variables identified. Post hoc effect sizes determined.	able-bodied (39%, p<0.001) participants. Able-bodied participants less sedentary than participants with Becker's MD (29%, p<0.001), Limb-Girdle MD (33%, p<0.001), and Facioscapulohumeral MD (29%, p=0.004). Sedentary time negatively associated with lean body mass in participants with DMD only (=- 0.446, p=0.021). Sedentary behaviour negatively			

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
						associated with knee extension isometric maximal voluntary contraction (R=-0.477, p= 0.006) and knee extension isometric maximal voluntary contraction / body mass (R =-0.487, p=0.005) in Becker's MD.			
Leb et al., (2022) (221) USA	Total: 38 (after 9 excluded for incomplete data) Non-amb. participants: 19 Diagnosis: CP	1) Describe relationship between PA level and cardiovascular risk measures 2) Describe general PA patterns of	Cross sectional observational study	ActivPAL worn on anterior thigh for 6 days. Sitting / lying time and number of transitions per 24 hr period recorded. Measured weight, BMI and waist to hip ratio. Relationship	Kruskal-Wallis tests to compare mean activity measurements between GMFCS levels. Dunn tests with Bonferroni adjustments used for	Participants in GMFCSs IV-V spent more time sitting / lying than those in GMFCSs I-II (p=0.007) and GMFCS III (p<0.001). Those in	1	Fair	Single sensor sedentary time measure. Not reported participation rate of eligible

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
	Age range: 18-77 y Median age: 28.5 y (IQR 24.25 - 47.00) GMFCS: I-V	adults with CP.		between these measures and PA assessed.	pairwise comparisons of activity by GMFCS level. Bivariate relationships between anthropomorphic and PA measures assessed with Spearman's rank correlations	GMFCS IV spent 23.04 hrs (IQR 20.39-23.74) sitting / lying and those in GMFCS V 23.43 hrs (IQR 22.31 - 23.92). Sitting / lying time was not associated with weight, BMI, or waist to hip ratio for those in GMFCSs IV-V.			participants. Reported that study is underpowered. No comparison of characteristics of those excluded compared to included participants. No blinding reported. Confounders not explored.
McPhee et al., (2017) (224) Canada	Total: 41 Non-amb. participants: 17 Diagnosis:	1) Describe experiences of fatigue in adults with CP	Cross sectional observational study	Fatigue measured using Fatigue Impact and Severity Self-Assessment questionnaire.	Normality testing using Shapiro–Wilk descriptive	Mean sedentary time/hr (all participants)=55.7 mins (SD 4.29), Median=	1	Fair	Single sensor measurement of sedentary

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
	CP Age range: 18-75 y Mean age (y) (SD): 33.7 (12.3) GMFCS: I-V	2) Determine if PA level, sedentary time, age, or body compositio n can predict fatigue in these adults.		Measured HPA and sedentary time using hip worn ActiGraph GT3X accelerometer for 7 consecutive days. Minimum wear time: 5 hrs, 4 consecutive days. Freedson cut-points used for differing intensity levels of PA (general population). Consecutive epochs of 0 counts/any activity <100 cpm during wear time classed as sedentary time. Sedentary time reported as mins/hr to adjust for varying wear time between participants. Body composition	test. Bivariate correlations conducted between continuous predictor variables to assess for multicollinearity (multicollinearity for correlations >0.7). Univariate regression analyses used to investigate associations between fatigue and MVPA, sedentary time, age, BMI and waist circumference. Spearman's rank	57.1 mins, range 37.5-59.9 mins. Sedentary time/hr correlation with Fatigue Impact and Severity Self Assessment: β unstandardized 2.1 95% CI for β -0.09, 4.3 p=0.060 (not significant).			time. Dates of data collection not stated. Not reported participatio n rate of eligible participants . No sample size justification .

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				measures = BMI and waist circumference.	correlation analysis used to assess the relationship between fatigue and GMFCS level. Variables that were significantly related to fatigue were included in a backwards stepwise regression analysis. This was used to evaluate relationships between independent variables and fatigue. ANOVA to determine variance attributable to				

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
					fatigue in each model and identify significant predictors of fatigue.				
Oftedal et al., (2016) (223) Australia	Total: 175 Non-amb. participants: 44 Diagnosis: CP Age range: 18-60 m Mean age at recruitment (y) (SD): 2 y 10 m (11 m) GMFCS: I-V	Describe relationship between stature, growth velocity, energy intake, HPA, and sedentary time across GMFCS levels in preschoolers with CP over time.	Longitudinal cohort study	Participants followed up between 18 m - 5 y. 440 assessments undertaken. Height/length ratio measured or estimated via knee height. Height and weight z-scores and growth velocity z-score by age and sex calculated using population-based standards. 3-day ActiGraph GTTM3 / GT3X data used to measure HPA / sedentary time (2	Analysed using multilevel mixed-effects regression models. Variables which were significant at $p<0.05$ using likelihood ratio test were retained in the model. Potential confounders accounted for were oropharyngeal dysphagia, gestational age at birth, birth weight and sex.	84% of participants assessed more than once (allowing calculation of growth velocity z score). 94 participants had data for sedentary time. Sedentary time not significantly associated with height or growth velocity when GMFCS level was accounted for. Sedentary time ranged	1	Fair	Single sensor measurement of sedentary time. <50% of eligible participants took part. Not clear when PA data collection took place in relation to appointments to measure other

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Methods	Statistical analysis	Results (specific to sedentary behaviour)	Critical appraisal tool used (key in table legend)	Quality of article (good / fair)	Reasoning for Quality Rating
				weekdays, 1 weekend day). Wear time diary completed. Position of device / cut point not reported but referenced previous validation papers for this age group with CP so likely to be the same protocol. Food diary data used to measure energy intake. Oropharyngeal dysphagia rated with Dysphagia Disorder Survey (part 2, Pediatric).		between 56-66% across all GMFCS levels.			outcomes. No blinding reported.

Note: ref.: reference, amb.: ambulant, non-amb.: non-ambulant y: years, m: months, hr: hour, hrs: hours, mins: minutes, s: second, CP: Cerebral Palsy, DMD: Duchenne muscular dystrophy, MD: muscular dystrophy, GMFCS: Gross Motor Function Classification Scale Level, HPA: habitual physical activity, METS: Metabolic equivalents, PA: physical activity, cpm: counts per minute, TD: typically developing / typical development, BMI: body mass

index, IQR: Interquartile range, CI: confidence interval. Critical appraisal tool key: 1 = The Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies

Six articles published between 2016 and 2022 were relevant to describing risks associated with sedentary time / behaviour in NAYP (Table 7). All articles were fair quality. Five articles were cross sectional observational studies (45, 47, 221, 222, 224), one was a longitudinal cohort study (223). At least 25% of participants were NAYP in all studies categorised to this sub-question. Participants' diagnoses included CP (45, 221-224) or muscular dystrophy (47). One paper included able-bodied participants (47). Half of the studies included participants over 25 years (47, 221, 224), and another only included 20-22 year olds (45). Participants in this research were therefore older than for other sub-questions, however the highest mean age reported by any single study was 47.1 years (participants with Facioscapulohumeral Muscular Dystrophy) (47). This study included participants with different types of muscular dystrophy. Mean age for each type of muscular dystrophy was reported, but overall mean age was not. Mean age of participants with other types of muscular dystrophy was 24.2 – 43.1 years.

The risks explored were associations between sedentary time and: weight (221, 222), BMI (221, 222), body fat (222), waist to hip ratio (221), lean body mass (47, 222), health related quality of life (45), pain (45) and fatigue (45, 224), muscle size and strength (47), height (223) and growth velocity (223). In a cross-sectional study involving adults with CP, sedentary lifestyle (measured using a validated self-reported measure, the Saltin-Grimby Physical Activity Level Scale) was associated with a poorer physical component of health-related quality of life (HRQoL) in comparison to the population norm for HRQoL in participants in GMFCS levels III-V ($p<0.001$) (45). This study also reported fatigue was highest in those with a sedentary lifestyle. Using a non-parametric test for trends, a significant trend was demonstrated, showing

fatigue increased as activity levels reduced (p=0.035) (45). McPhee et al. (224) also showed a positive correlation between sedentary time and fatigue in adults with CP, but it was not significant (p=0.06). McPhee et al. (224) measured sedentary time using a single triaxial hip worn accelerometer. Differing measures for both sedentary behaviour / time (validated self-report tool measuring behaviour versus single hip worn accelerometer measuring time) and fatigue were employed in these two studies, which may account for this association reaching significance in Jacobson et al's study (45) study, but not in McPhee et al.'s (224). In addition, these sedentary time / behaviour measures may not provide valid assessments of sedentary time, when compared to other methods (i.e. multi-device placement) and therefore limit the strength of this evidence. More research is therefore required to establish the presence of an association between sedentary time and fatigue in NAYP.

In other studies examining aspects of physical health, reported sedentary time (measured using a single triaxial accelerometer worn on the dominant wrist or arm) was significantly negatively associated with lean body mass in participants with DMD, but not those with other dystrophies (47) or CP (222) (measured using a single hip worn triaxial accelerometer). Sedentary time was significantly negatively associated with knee extension isometric maximal voluntary contraction and knee extension isometric maximal voluntary contraction / body mass in Becker's Muscular dystrophy only (47). Again, use of single accelerometers may limit the validity of sedentary time estimates in these studies. Studies also reported no associations between sedentary time (measured using single hip worn triaxial accelerometers) and weight (221, 222), Body Mass Index (221, 222), body fat (222), waist to hip ratio (221), pain (45) (sedentary behaviour measured using a validated self-reported measure), the mental

component of health related quality of life (45) (sedentary time measured using a validated self-reported measure), height (sedentary time measured using a single hip worn triaxial accelerometer) (223) or growth velocity (223).

In the general population, associations between sedentary time and mortality, cardiovascular disease, type 2 diabetes, metabolic health and cancer have been studied (7, 8). These associations have not been explored among NAYP, possibly due to the fact that the emergence of research into health consequences of sedentary time is relatively new (<25 years). However, factors associated with cardiovascular disease, type 2 diabetes and metabolic health in particular, were examined in the included studies (e.g. BMI, body fat and waist to hip ratio), and represent an opportunity to start to accumulate data on the longer-term health consequences of sedentary time for NAYP.

The only outcomes examined in ≥1 study, and including participants with the same diagnosis were weight and BMI. One article included children (222) whereas the other studied adults (221) so the populations were also too dissimilar to consider meta-analysis.

In conclusion, there is very limited evidence of the associations between sedentary time / behaviour and health outcomes in NAYP. Where associations have been found between outcomes such as fatigue and HRQoL and sedentary time, the study designs were cross sectional. It is therefore not possible to establish whether the observed associations are causal or not, i.e. whether high levels of sedentary time caused increased fatigue or reduced HRQoL. Further research would be required to demonstrate causal links and establish the impact reductions in sedentary

behaviours may have on these outcomes. The strength of the evidence that is available is hampered by the quality of the sedentary time / behaviour measure, as no studies in this sub-question used multiple devices.

The focus of this evidence is on body composition / anthropometric measures. Building evidence in this area will be important to determining the potential role of sedentary time for the risk of developing long-term conditions like cardiovascular disease and type 2 diabetes.

2.4.7 Sub-question four. What evidence-based interventions to reduce sedentary behaviour or decrease and break up sedentary time in this population have been evaluated and what is the strength of this evidence?

Table 8 Study characteristics, results and quality assessment for sub-question four – What evidence-based interventions to reduce sedentary behaviour or decrease and break up sedentary time in NAYP have been evaluated?

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Intervent-ion	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical apprais al tool	Quality of article (good/ fair)	Reasoning for Quality Rating
Asselin et al., (2015) (68) USA	Total: 8 Non-amb. participants: 8 Diagnosis: Spinal cord injury (paraplegia) Age range: 24-61 y Mean age (y) (SD):46 (12) American Spinal Cord Injury Association Impairment Scale: A or B	1) Determine energy expenditure and HR whilst using a powered exoskeletal for assisted sitting, standing, and walking 2) Compare oxygen uptake (VO2) using the exoskeleto n to during	One armed observat ional study	Powered exoskelet on for standing and walking	3 training sessions/week in exoskeleton lasting 60-90 mins. 6 min walk tests whilst training. Participants rated perceived exertion at end of training. Metabolic testing undertaken at approx 40th training session. Portable	For outcomes showing a significant effect post hoc analyses using Tukey-Kramer pairwise tests. Paired t-tests to compare walking speed when using / not using	VO2 in sitting and standing not significantly different. VO2 between walking and sitting and walking and standing was significantly different $p<0.001$. % oxygen uptake reserve increased by 24% (± 4%)	1	Fair	Dates of data collection not stated. Not reported participation rate of eligible participants. Small sample size. No blinding reported.

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Intervent-ion	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical apprais al tool	Quality of article (good/ fair)	Reasoning for Quality Rating
		use of other passive gait orthotics by people with paraplegia.			metabolic acquisition system used to measure VO2 and HR, in 1 min epochs. 6 min testing periods in siting/standing/ walking. No rest between conditions. Mean VO2 and HR across 6x1 min epochs, % oxygen uptake reserve and % HRR calculated using modified Karvonen method. Within subject repeated measures	metabolic cart. Stepwise regression to account for level of injury, lower limb motor score, walking speed and level of assistance. Those who did / didn't need assistance to use the exoskeleto n compared using multiple unpaired t-tests with Bonferroni correction.	for legs and 35% ± 7% for arms. There were no significant variables in the stepwise regression for VO2. The increase in HR between sitting and standing was not significant. As for VO2, HR when walking was significantly higher than both sitting and standing $p<0.001$. %HRR was 48% ± 16% when walking.			

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Intervent-ion	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical apprais al tool	Quality of article (good/ fair)	Reasoning for Quality Rating
					analysis of variance to compare sit/stand/walk.					
Verschu ren et al., (2014)(65) Netherla nds	Total: 19 Non-amb. participants: 5 Diagnosis: Spastic CP Age range: 4-20 y Mean age (y, m) (SD): GMFCS I 12.0 (2.3) GMFCS II 10.8 (6.8) GMFCS III 14.3 (5.8) GMFCS IV 12.3 (5.7) GMFCS V 10.5 (7.8) GMFCS: I-V	Measure energy expenditure and muscle activity of children and adolescent s with CP at different GMFCS levels during sitting, lying and standing.	Cohort study	Supporte d and unsupport ed sitting and standing	Height and weight measured. Energy-expenditure and muscle activity measured in lying supine, sitting supported, sitting unsupported, and standing (supported or unsupported). Energy-expenditure measured using indirect calorimetry using Cortex Metamax	Values calculated for each child averaged per posture. Non-parametric Wilcoxon signed rank test due to small sample size in each GMFCS level. Partial correlation analyses used to examine independen	6 children removed from analysis as not comfortable with metabolic testing or unable to maintain independent sitting, 19 remained. Mean energy expenditure >1.5 METs during standing for all GMFCSs (range 1.53 for GMFCS I - 1.88 for GMFCS V	2	Fair	Dates of data collection not stated. Recruitment / selection process not clear. Not reported participation rate of eligible participants. No sample size justification. No blinding reported. No analysis of characteristi cs of those excluded due to

Author (year) (ref.) Country of origin	Participants	Objectives	Design	Intervent-ion	Methods	Statistical analysis	Results (specific to sedentary behaviour / time)	Critical apprais al tool	Quality of article (good/ fair)	Reasoning for Quality Rating
					system and expressed in METs. Muscle activation recorded using surface electromyogra phy (Porti device) bilaterally on 4 large lower limb and spinal muscle groups. Both measurements initiated once energy expenditure was stable for 1 min in each posture. Measurements taken for 5 mins in lying and 2 mins in sitting and standing.	t association s between METs and RMS values in each posture, adjusted for age. 95% CI calculated and $p<0.05$ considered statistically significant.	METs). Energy expenditure in standing increased in line with GMFCS. With age accounted for, partial correlations between relative METs and root mean square of muscle activity total signal were positive, but not significant (absolute value of r = 0.14-0.36, P > .05).			incomplete data to compare with included participants.

Note: Ref.: reference, non-amb.: non-ambulant, y: years, m: months, mins: minutes, CP: Cerebral Palsy, , GMFCS: Gross Motor Function Classification Scale Level, METS: Metabolic equivalents, HRR: heart rate reserve, , CI: confidence interval. Critical appraisal tool key: 1 = The Quality Assessment Tool for Before–After (Pre–Post) Studies With No Control Group 2 = The Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies.

Only two articles were included in sub-question four (Table 8), published between 2014-2015. Both were rated fair quality. Asselin et al.'s (68) study had a single armed observational design including only non-ambulant participants with spinal cord injuries. Verschuren et al.'s (65) was described as a cohort study including participants with spastic CP, in which 26% of participants were non-ambulant. Most participants were adults in Asselin et al.'s (68) study, in which the youngest participant was 24 years old. Verschuren et al.'s (65) included four 20 year olds.

Neither study included an intervention which was specifically designed to reduce sedentary time. However, both studies provide evidence suggesting that the changes of posture / activity performed in their interventions interrupted sedentary time in NAYP, despite this not being their primary aim. They therefore contribute important and valuable information to answering sub-question four and the overarching question of "What is the quality of the evidence relating to sedentary behaviour in NAYP?" and have been included in the review.

Asselin et al.'s (68) participants used a powered exoskeletal for assisted sitting, standing, and walking whereas Verschuren et al.'s (65) were positioned in supported and unsupported sitting and standing. Both protocols involved participants being in these pre-specified postures or walking for a pre-defined time period and measured the metabolic effects of the intervention using gas analysis. Measurement of all elements of the sedentary behaviour definition were therefore accounted for (posture and energy expenditure during waking time). This enabled these studies to demonstrate that their interventions (change of posture / activity), interrupted sedentary time using more robust measurement methods than studies in sub-questions two and three. The reason these articles were rated fair rather than good

despite this rigorous method of estimating sedentary time is due to: small sample size (68), unclear reporting of how participants were recruited and in what timeframe (65, 68), exclusion criteria not being explicitly specified (65), position change only occurring on one (rather than repeated) occasions for each participant (65) and management of confounding factors / removed data not being discussed (65). It was also noted that several values needed to be estimated in the oxygen uptake calculations in Asselin et al.'s (68) study, due to the clinical population participating, which could have influenced the accuracy of energy expenditure measurement.

Despite some weaknesses, these studies provide some valuable findings. In the exoskeleton, a significant difference in energy expenditure (measured using % oxygen uptake reserve (mL/kg/min) and % heart rate reserve) was not observed between sitting and standing behaviours. However, there was a significant difference between sitting and walking and standing and walking for both variables. Whilst walking, participants reached approximately 25 – 33% of their estimated maximum oxygen uptake reserve (11.2 ml/kg/min).(68), indicating that walking in the exoskeleton interrupted sedentary time. Energy expenditure was not converted into METs, so it was not possible to explore whether standing in the exoskeleton exceeded 1.5 METs. However, the authors reported that the non-significant increase in energy expenditure when moving from sitting (3.5 ml/kg/min) to standing (4.3 ml/kg/min) was in a similar range to the increase seen in able-bodied people when they transition from sitting to standing.

Verschuren et al.(65) were able to demonstrate that average energy expenditure in standing exceeded 1.5 METs for participants at all GMFCS levels, including those in supported standing in a standing frame. Energy expenditure in supported and

unsupported sitting was below 1.5 METs for all GMFCS levels. There was a positive correlation between energy expenditure in standing and GMFCS level reported in the results of this study, but this findings was not interpreted or discussed further in the paper.

A study categorised to sub question two (involving direct observation of children with disabilities during physical education (PE) classes), highlighted some missed opportunities to reduce sedentary time (213). Examples included children who can self-propel being pushed, children not being moved out of their wheelchair during PE and assistant staff throwing a ball on their behalf rather than encouraging them to throw themselves (213). This finding suggests that developing interventions which aim to change the behaviour of adults who support NAYP would be beneficial, encouraging them to facilitate NAYP to move more independently.

As the studies in this sub-question explore different interventions, it is clear that no meta-analysis can be undertaken to combine these studies.

The small number of studies included in this sub-question highlight the large evidence gap in relation to interventions to reduce sedentary time in NAYP. Neither of the studies that are included were designed to reduce sedentary time in response to intervention. It remains the case that at present, there are no evidence based clinical interventions that have been specifically designed to reduce sedentary time in NAYP.

2.5 Discussion

This is the first review which has identified research relating to sedentary time in NAYP and assessed its quality and strength to inform a best evidence synthesis. Fifty-three articles were critically appraised. Five were rated as being good quality, 33 were fair quality and 15 were excluded due to poor quality. Key findings of the review, answering four sub-questions relating to sedentary time / behaviour measurement, patterns, risks and interventions in NAYP were:

1) validity of device-based measures of sedentary time that use multiple devices placed in different sites and analyse raw (not count-based) accelerometer data has been established under laboratory conditions, but not in free-living environments,

2) NAYP spend 74% - 96% of the day sedentary. It is likely that there is a relationship between sedentary behaviour and physical function and age, with those who are older with greater functional difficulties being more sedentary. Multiple social, environment and cultural influences on sedentary behaviour of NAYP have been identified, however further in-depth qualitative research is required to deepen understanding,

3) evidence of associations between sedentary time / behaviour and health outcomes in NAYP are very limited and hampered by study designs being cross sectional (so causality cannot be implied) and the quality of the sedentary time / behaviour measurement, as no studies relating to health outcomes used multiple devices. Existing research focuses on body composition / anthropometric measures. There was no research relating to risks of non-communicable diseases.

4) there are no evidence based clinical interventions that have been specifically designed to reduce sedentary time in NAYP.

2.5.1 Article screening

Eighteen articles were excluded at full text screening because they did not apply the accepted definition of sedentary time (3). These articles tended to either pre-dated the definition, or were published as the definition was becoming established. A lack of application of the accepted definition was less frequent in recently published studies (e.g. from 2017 onwards), however an excluded study published as recently as 2022 had used the term sedentary to describe a lack of MVPA (225). Use of the term “inactive” instead of “sedentary” to describe a lack of engagement in MVPA became more consistent in later publications. There was a tendency for studies including participants with spinal cord injury patients to use the term sedentary rather than inactive (225-228).

2.5.2 Sub-question one. Do validated measures of sedentary time or behaviour of NAYP exist?

It was unclear why observed static standing was coded as sedentary behaviour in two articles (204, 206). This is not in keeping with the definition of sedentary time. Sitting and standing cannot be distinguished by a single proximally placed accelerometer. However, use of a device that contains an inclinometer, such as an ActivPAL to measure sedentary time in NAYP would allow sitting and standing time to be separated, resolving this issue. Verschuren et al. (65) have provided evidence that supported standing expends energy > 1.5 METS in participants in GMFCS levels IV-V. Therefore, use of a standing frame or any other form of supported standing should be classed as LPA, and may contribute to a reduction in sedentary time in future

interventional studies. Use of a standing frame is a common and often daily intervention for NAYP, so ensuring it is classed as LPA has potential to lower sedentary time estimates considerably. Energetic upper limb activities such as self-propelling or hand cycling may also be misclassified due to placement of devices on the trunk, thigh or hip. Swimming and hydrotherapy are also common activities undertaken by NAYP. Devices were frequently removed for water based activities in the existing literature (see Table 5, Table 6, Table 7 and Table 8). Selecting waterproof devices to undertake research in this population could also improve the accuracy of PA estimates. Taking these points which are specific to NAYP into account, it is likely that sedentary time of NAYP has been overestimated, and LPA / MVPA has been underestimated, in existing literature where data is collected in free-living environments.

ActivPAL devices are generally considered the gold standard for measuring sedentary time in free-living environments (229, 230), however their validity for measuring sedentary time in NAYP has not yet been investigated. This may account for why ActivPAL devices were only used in two studies included in this review (39, 221). Assessing the validity of ActivPAL devices to measure sedentary time of NAYP would be valuable, as they can capture both posture and acceleration. However, it is unlikely they would detect upper limb activity such as self-propelling or hand cycling.

The best evidence synthesis highlighted that using multiple devices in differing locations improves the validity of sedentary time measurement in NAYP (173, 208). There is insufficient evidence to determine the best devices to use or where they should be placed. This research is in its infancy at present, but it is likely that evolving machine learning technology has a role to play in combining data from devices to

provide the most valid estimates of sedentary time (157, 173, 231). Developing personalised models for each individual using these techniques has proved beneficial for ambulant young people with CP in a simulated free-living environment (231). Fully personalised models outperformed both whole group and GMFCS level specific group models in GMFCS levels I and II, but not III. Further research is needed in this area. For NAYP, both multi-device and machine learning models are yet to be tested in free-living environments. It is important that validity of sedentary time measurement is assessed across all age groups, as movement patterns change as children grow and mature (see sub-question 2).

2.5.3 Sub-question two. Have patterns of sedentary time or behaviour of NAYP been described?

The consensus across studies in sub-question two provides evidence that NAYP spend more time sedentary than their able-bodied peers and ambulant young people with disabilities. NAYP spent ≥ 74% of the day sedentary. Factors such as physical function, age, day of the week and socioeconomic status may influence the amount of time spent sedentary. There was consensus that sex does not influence sedentary time in NAYP in research undertaken to date. However, as valid measures of sedentary time in free-living environments are not yet established, this research can only provide estimates of sedentary time and its relationship to these factors. When validated measures have been established, further research is needed to investigate how sedentary time of NAYP is influenced by these factors.

It is likely that sedentary time increases with age in NAYP and that those with greater physical and functional mobility impairments are more sedentary. A study that only included young children was not able to demonstrate this relationship with age,

probably due to the narrow age range (159). Bloemen et al.'s (210) finding that age only influenced sedentary time on weekdays may be reflecting changes in school life as children grow older. An increasing emphasis on academic achievement and greater resources being needed to help young people to move as they grow both have potential to reduce movement opportunities at school. During weekends family members may have more time to assist with moving and the home environment may be more amenable to creating opportunities for movement.

It is interesting that differences in sedentary time between ambulant and NAYP with disabilities were not significant in one study including children under 10 years (222). The authors suggested that involuntary movement in those with dyskinetic CP may have resulted in increased time in LPA or that factors relating to care may be reducing sedentary time in those with more severe CP. Accelerometers cannot distinguish between a movement the young person makes, and a movement which is carried out passively by a carer. Whilst children can still be lifted in and out of equipment without needing a hoist or multiple carers, NAYP may have more opportunities to move. It is possible that the difference between ambulant and NAYP becomes greater once they reach adolescence and this is no longer possible.

2.5.4 Sub-question three. Have risks associated with sedentary time or behaviour been explored or quantified for NAYP?

There were very limited studies included in sub-question three, investigating the health consequences of sedentary time for NAYP. Considering more immediate (short term) health consequences, results suggest there may be a positive correlation between sedentary time and fatigue (45, 224) and a negative correlation between sedentary time and physical components of quality of life (45) in NAYP. However,

heterogeneity in measurement methods, diagnosis and age range of participants in included studies make synthesising the evidence from the limited research challenging. Further research considering among more homogenous samples, and with more harmonised methods are needed to better understand the health consequences of sedentary time for NAYP.

Research in the general population suggests sedentary time holds longer-term consequences for the development of non-communicable diseases, such as cardiovascular disease, type 2 diabetes and cancer (7, 8). It is difficult to investigate relationships between sedentary time and such conditions in NAYP, owing to the fact they are more prevalent in later life. It is known that adults with CP (18-30 years) have a higher prevalence of osteopenia, osteoporosis, hypertension, myocardial infarction, hyperlipidaemia, asthma, and multimorbidity in comparison to able-bodied controls (49). They are at higher risk of musculoskeletal and cardiometabolic morbidity and multimorbidity. Additionally, those in GMFCS levels IV-V are at higher risk of osteopenia / osteoporosis, osteoarthritis, hypertension, cardiovascular conditions, pulmonary embolism, and multimorbidity, musculoskeletal / cardiometabolic / pulmonary morbidity and multimorbidity in comparison to those in GMFCS levels I-III (49). Pingel et al. have demonstrated that children with CP have higher levels of systemic inflammation in comparison to able-bodied adults and adults with CP (232). Yehuda et al. have demonstrated higher cardiovascular disease risk in children with a range of disabilities in comparison to those without disabilities (233) and there is evidence that ambulant children with CP are not as physically fit as their able-bodied peers (234). These risks and observations may or may not be related to high levels of sedentary behaviour, their relationship to it has not been

investigated. However, based on what is known about the general population, it seems logical that high levels of sedentary behaviour may be contributing to these findings. Ryan et al. have demonstrated an association between sedentary behaviour and increased blood pressure in ambulant children with CP (51).

More research investigating markers and risk factors for these non-communicable diseases in NAYP and their relationship to sedentary time should be undertaken. Alternatively, prospective cohort studies in NAYP and able-bodied controls, observing associations between sedentary time and the development of poor health outcomes, would provide valuable information about the risks of sedentary time.

2.5.5 Sub-question 4. What evidence-based interventions to reduce sedentary behaviour or decrease and break up sedentary time in this population have been evaluated and what is the strength of this evidence?

The results of sub-question four highlight the most striking evidence gap in this body of literature. There are no evidence-based interventions that are specifically designed to reduce sedentary time in NAYP. The evidence in this review shows NAYP are likely to be more sedentary than any other population in their age group, potentially putting them at high risk of associated poor health outcomes. Whilst the available data does not confirm a causal role of sedentary time in the development of adverse outcomes for NAYP, the available evidence from able-bodied young people suggests it would still be prudent to develop interventions in this domain. These interventions can then be evaluated not only to establish if they are effective for reducing sedentary time, but to determine any beneficial changes in health outcomes that may result alongside positive intervention effects.

Verschuren et al.'s (65) work demonstrates that moving NAYP with CP from a sitting to standing position interrupts sedentary time, even when standing is static and supported by a standing frame. This is in keeping with the definition of sedentary time that is applied in the general population, and may offer an avenue for intervention. Indeed, finding ways to enable NAYP to attain supported standing more frequently and for a greater proportion of their day could be an achievable way to reduce their sedentary time. Introducing more equipment such as sit to stand wheelchairs or indoor seating that can assist young people to stand without transferring to an additional piece of equipment could be simple interventions to consider.

Qualitative evidence from sub-question two highlighted how parents and carers felt unprepared for NAYP being increasingly drawn to sedentary activities as they went through puberty (40) and that health professionals rarely give advice about sedentary behaviour at present (217). This provides an opportunity for developing behaviour change interventions in which healthcare professionals are trained to discuss sedentary behaviour with families of NAYP and provide advice.

Missed opportunities to reduce sedentary time which were highlighted in direct observation of PE lessons (213) provide useful ideas for potential interventions and implications for clinical practice. It is important for NAYP who have the ability to self-propel to be provided with a wheelchair that allows them to do so, even if this is only over short distances which may not be functional. Encouraging them to self-propel whenever possible without inducing fatigue and pain would help to reduce their sedentary time. Transferring young people out of their seating during PE and at other times during the days gives them an opportunity to move actively around the floor or to use equipment such as walking frames or tricycles to move. If transferring out of

seating is not possible, doing upper limb activity in a seated position, such as hand cycling, batting a ballon, throwing a ball or beanbag or using a racquet or bat to play a ball game is another alternative.

Whilst this review has highlighted some considerable gaps in the literature regarding our understanding of the role of sedentary time for NAYP, healthcare professionals across disciplines need to be aware of potential risks, and share national guidelines (which include recommendations for people living with disabilities), with families and NAYP. Providing advice about the importance of reducing sedentary time and practical ways of achieving that needs to be incorporated into routine practice, whilst research in this area continues to evolve.

2.5.6 Strengths and weaknesses

A systematic search using a robust and comprehensive search strategy has been undertaken to identify evidence relating to sedentary behaviours of NAYP. The addition of critical appraisal to assess the quality of the research and the exclusion of poor quality articles builds on previously published literature relating to this topic.

The review incorporates a wide age range, allowing consideration of how sedentary behaviour changes in transition from childhood to adulthood.

Limitations of this review include that only peer-reviewed literature has been included. Grey literature was excluded, but this decision was made largely to ensure the best quality evidence was reviewed. Only studies written in English language or translated into English have been included. Due to resource constraints, it was not possible for both reviewers to independently undertake data extraction. Data extraction was completed by the first author and verified by the second. There was a

mismatch between the inclusion criteria and the wording of sub-question one. The inclusion criteria stated all articles exploring measurement of sedentary time should be included, whereas the sub-question specifically focused on validity of measurement methods. This resulted in three studies being included that discussed measurement of sedentary time but did not seek to answer sub-question one (203, 205, 207). Those studies were still included in the evidence synthesis of sub-question one, as that remained the most appropriate sub-question.

2.6 Conclusions

Thirty-eight articles rated as good or fair quality were included in this review. Articles were summarised in a best evidence synthesis to describe quality of evidence relating to sedentary behaviour in NAYP across four sub-questions. It was not possible to undertake meta-analysis of studies for any of the sub-questions.

Combining data from multiple devices was the most robust method of measuring sedentary time in NAYP. However, feasibility and validity of using multi-device systems in free-living environments has not yet been evaluated. This review demonstrates weaknesses in the measurement methods used in the majority of studies relating to patterns of sedentary time in NAYP and the associated risks. This reduced the strength of this evidence; however, these device-based estimates of sedentary time are more robust than self-reported measures.

It is estimated that NAYP spend 74% - 96% of the day sedentary. It’s likely that this is significantly longer than able-bodied young people and ambulant young people with disabilities. Evidence suggests there are relationships between sedentary time, physical function and age.

Further exploration of patterns of sedentary time in NAYP and associated risks is needed, including investigation of associations with non-communicable diseases and mortality. Evidence based clinical interventions that specifically aim to reduce sedentary time in NAYP are needed.

3 Chapter 3: Step one of the Six Steps in Quality Intervention Development (6SQuID). Understanding the problem – data collection via crowdsourcing.

3.1 Pre-face to Chapter 3

Chapter 2 described a systematic search and review of literature relating to sedentary behaviour in non-ambulant young people (NAYP). The review was undertaken to meet the first aim of step one of the Six Steps in Quality Intervention Development (6SQuID) (86), defining the problem. It identified weaknesses in the majority of the quantitative evidence; however the weaknesses were not fatal flaws. Good quality evidence included qualitative studies and scoping reviews.

The best evidence synthesis highlighted that device-based measures of sedentary time of NAYP need to be validated in free-living environments. This will make it possible to evaluate interventions to reduce sedentary time. Sedentary time of NAYP has been estimated and there is consensus across this literature that there are high levels of sedentary behaviour, however issues surrounding measurement methods need to be considered when interpreting this evidence. Further research is needed to understand the impact high levels of sedentary behaviour has on NAYP's health and wellbeing during adolescence, young adulthood and in later life. There were no evidence-based interventions which were specifically designed to reduce sedentary behaviour in NAYP. In terms of the 6SQuID, this latter finding assists with defining the problem, by highlighting a need for new interventions to be developed. The intervention development described in this thesis will address this problem.

The evidence suggested that sedentary behaviour of children with disabilities increases with age and severity of gross motor function impairment. Good quality qualitative evidence supported this finding. Therefore, adolescents and young adults who use a wheelchair for mobility are likely to be highly sedentary and at risk of associated poor health outcomes. The review in chapter 2 defined the problem by informing decision making in relation to the population the intervention development should target. The intervention has therefore been designed for adolescents and young adults who are unable to walk, or only walk short distances in walkers that provide trunk support (not those who can walk with a hand held walker).

This chapter focuses on the second aim of step one of the 6SQuID, gaining an in depth understanding of the problem and its causes from the perspective of a range of stakeholders, who have participated in co-designing the intervention.

3.2 Title: Using crowdsourcing to explore sedentary behaviour and movement patterns of non-ambulant young people.

3.3 Introduction

The scientific definition of sedentary behaviour(3) has three key elements: 1) the individual undertaking the behaviour is awake 2) they are in a seated, lying or semi-reclined posture 3) they are using ≤1.5 metabolic equivalent units (METs) of energy, i.e. energy expenditure is low. In adulthood, there is strong evidence that high levels of total daily sitting time or television viewing time (>six-eight hours) increases the risk of all cause and cardiovascular disease mortality and the incidence of type two diabetes (8). High levels of recreational screen time and sedentary time are associated with poor health outcomes such as reduced fitness (18, 19), overweight / obesity (18, 19, 23, 235), poor cardiometabolic health (18), spending less time

sleeping (20), lower quality of life (21), low self-esteem (18), behavioural difficulties (18, 23) and poor mental health (22-24) in children and young people. There is insufficient evidence to demonstrate a dose–response relationship between reduced sedentary time and positive health outcomes for children and young people (23). However, current evidence is sufficient to result in both the World Health Organisation's (WHO) and the United Kingdom's (UK)'s physical activity guidance advising that children and young people should limit their sedentary time (23, 26).

Children and young people with physical disabilities have higher levels of sedentary time than their able-bodied peers (38, 47, 193, 212) and are therefore at greater risk of experiencing the associated negative health outcomes (236). In this study, children and young people who only walk short distances indoors, using a walker with wheels that supports their trunk, pelvis or head, or are unable to walk due to long-term physical disabilities are referred to as non-ambulant young people (NAYP). NAYP can have disabilities such as cerebral palsy (CP), muscular dystrophy, spina bifida, rare conditions or spinal / head injury. NAYP are more sedentary than ambulant young people with disabilities (39). In both NAYP and able-bodied young people, it is likely that sedentary behaviour increases with age (27, 28, 39, 40). There is minimal evidence relating to associations between sedentary behaviour and health outcomes for children and young people with disabilities (41), however NAYP with CP (who have high sedentary time) are more likely to have osteopenia / osteoporosis, osteoarthritis, hypertension, other cardiovascular conditions, pulmonary embolism, morbidity relating to musculoskeletal, cardiometabolic or pulmonary conditions and multimorbidity in comparison to ambulant young people with CP (49). Studies suggest there are significant associations between fatigue and sedentary lifestyle in

young adults with CP and their sedentary lifestyles are associated with poorer physical components of health-related quality of life in comparison to able-bodied young adults (45). Sedentary behaviour is negatively associated with lean body mass in NAYP with Duchenne Muscular Dystrophy (DMD) (47) and positively correlated with poorer cardiac function in a study where 29/46 participants of participants with DMD were non-ambulant (48).

A scoping review relating to sedentary behaviour in children with disabilities identified three interventional studies that aimed to increase physical activity, but also measured sedentary time as an outcome (38). Two studies involving children with CP evaluated feasibility of physical activity prescription for children in Gross Motor Function Classification System (GMFCS) levels I-V (61) and effectiveness of an internet based physical activity intervention for ambulant children in GMFCS levels I-III via a randomised control trial (RCT) (59). GMFCS levels describe the functional mobility of children and adolescents with CP (2). There are five levels, with level I being mild mobility difficulties and level V severe difficulties. Those in levels I-III are ambulant and those in levels IV-V are non-ambulant. In the first study, the intervention included motivational interviewing and production of a physical activity prescription (61). It was reported that changes in sedentary time pre and post intervention were variable, but the sedentary time data was not presented in the results (61). In the second study, there was no change in sedentary time (59). An RCT for children with Down's Syndrome investigated the effects of a bicycle riding program on physical activity and health related outcomes (60). This intervention did reduce sedentary time at seven weeks post intervention and at 12 month follow up.

There are five interventional studies including non-ambulant children and young people which measured sedentary time (64, 65, 67-69), but were not included in the Ganz et al. review (38). With the exception of a RaceRunning intervention (64), these studies explored whether an intervention produced a physiological response that interrupted sedentary time, rather than evaluating the effectiveness of the intervention for reducing sedentary behaviour over time. The 12 week RaceRunning intervention for young people with CP in GMFCS levels III-IV resulted in no significant change in sedentary time.

In summary, none of the interventions described had a primary aim of reducing sedentary behaviours for NAYP, so there are currently no evidence-based interventions to achieve this. There is evidence that school-based interventions to increase physical activity can reduce sedentary time in healthy children (237) and that parent-based interventions can reduce screen time in healthy adolescents (238), however NAYP face different barriers to increasing their physical activity (239) which need to be addressed.

Barriers and facilitators of reducing sedentary behaviour of NAYP have not been explored in isolation. Existing research focuses on barriers and facilitators to physical activity in isolation or to both physical activity and sedentary time. Poor health is a barrier to physical activity for young people with DMD (56). Making friends and having fun is a facilitator (56). Parents in a study exploring physical activity participation of children with CP felt their child's motivation for being physically active was influenced by family culture and attitudes (57). They described how people who are important in children’s lives can facilitate or hinder physical activity participation. Children needed a sense of belonging in the family and friends were also important,

however finding friends could be challenging. Young people needed space to be more independent, but to achieve this, parents needed to competent people from outside the family to be available to help their child. There was an understanding that physical activity had physical benefits and acknowledgement that it was a challenging for young people. There needed to be options to opt out when needed and more opportunities needed to be available. Young people with CP identified the following barriers to physical activity: negative attitudes, negative experiences of physical activity, physical and structural environmental factors, GMFCS level, policy barriers and lack of support from professionals, parents and friends (53, 54). Supportive healthcare professionals encouraging young people to participate in physical activities they enjoy increases young people's participation (55). Social factors such as self-confidence, persistence, athletic competence, parental participation in physical activity and close friendship experiences all influence physical activity in this group and could be addressed within interventions (58).

The first step in intervention development as defined by frameworks such as the Six Steps in Quality Intervention Development (86) is gaining an in depth understanding of the problem and its causes by clarifying the problem with stakeholders, in addition to referring to the existing evidence. The causal pathways that shape and perpetuate the problem need to be understood from the differing perspectives of each group of stakeholders (86). In this study the perspectives of NAYP aged 12-25, family members of NAYP, professionals who work with NAYP and experts in disability, intervention development and sedentary time were sought.

Engaging young people with disabilities and their family members in research and creating an environment where they can contribute confidently and comfortably is

challenging (240). Potential participants have varying physical, communication and learning abilities, experience barriers to travelling, are spread over a wide geographical area and have limited time (240). To overcome these challenges, crowdsourcing offers an innovative method of data collection to facilitate intervention development.

Volunteers, who are referred to as “the crowd”, are invited through open advertisement to help achieve a specific goal, by undertaking a series of online tasks (113). The volunteers work collaboratively with other people in the crowd. Who is being invited to participate is pre-defined, for example it could be staff from a particular organisation, people who have a particular health condition or people with a specific skill, such as software design. In the crowdsourcing conversations, members of the crowd respond anonymously to a list of specific questions posed by the researchers. They can choose which questions they respond to. It is not compulsory to respond to every question. The crowd can read the responses of others and comment on them, they can also like or dislike responses and comments from other members of the crowd. These features create potential for an interactive dialogue between the volunteers in the crowd.

Utilising this method to engage young people in research has been advocated (241-243) and the “AHPs into action” document (244) demonstrates clinician engagement. Participants who are unable to type can contribute using voice recognition software, or with support from friends, family members or carers who can type on their behalf. Contributing via a proxy does introduce risk of bias, as the young person may not be able to be as honest if they have an existing relationship with the person typing for them. However, if using a proxy to type facilitates more equitable access to

participation in research for a young person with disabilities, it is worthwhile accepting this limitation.

The objectives of this study were therefore to employ crowdsourcing as a means to engage NAYP and other stakeholders in research, with the aims of:

1) Exploring what NAYP, family members of NAYP, professionals who work with NAYP and experts in sedentary behaviour, paediatric disability, behaviour change, and/or digital health interventions think about the volume and frequency of movement and sedentary behaviour in this group of young people, and their perceived importance of these behaviours,

2) Identifying barriers and facilitators for reducing sedentary time and increasing movement from their perspectives.

3.4 Methods

3.4.1 Participants

Five groups of key stakeholders were recruited to take part in this study. These were: 1) NAYP, 2) family members of NAYP, 3) professionals who work with NAYP (for example education and healthcare professionals or carers), 4) experts in sedentary behaviour, disability, behaviour change and/or digital health interventions 5) other interested members of the public. The inclusion criteria for NAYP were, children and young people aged 12-25 years, who are non-ambulant due to a lifelong disability. Participants in groups two-five needed to be aged 16 or above. Groups one – three and five needed to live in the UK. Group four participants (experts) could be recruited worldwide. Inclusion criteria for all stakeholder groups were; ability to communicate in English Language online, and sufficient understanding of the English language to

communicate their assent or consent and to answer questions asked. Adults aged 26 and over with disabilities who wished to participate were encouraged to do so via the "other interested members of the public" group.

3.4.2 Study design

To allow in depth exploration of differing stakeholders perspectives, qualitative data was collected via crowdsourcing (anonymous web-based conversations).

3.4.3 Sample size

As data collection via crowdsourcing is a novel methodology, it was not possible to predict engagement based on existing literature. Therefore, no minimum or maximum sample size was set for any of the groups who participated in crowdsourcing. In addition, having to disregard data collected via crowdsourcing because a minimum sample size threshold had not been met was deemed inappropriate. All online contributions were considered relevant and valuable. The aim of using crowdsourcing methodology was to get as many voices as possible heard, however, with limited control over recruitment and a wide diversity of participants there was not an intention to reach saturation.

3.4.4 Recruitment

A variety of posters, social media posts (Appendix 1), videos and a public engagement video (supporting digital material, file 1) were produced to outline key details of the study. Videos were shared via social media and websites. These recruitment materials were tailored to target specific stakeholder groups. Dissemination of recruitment materials was targeted to UK audiences for all but the experts group. All recruitment materials directed potential participants to visit the

study website via a link, QR code and/or the website address being written on the advertisement. On the website, potential participants could click on a banner to indicate that they wished to join the study. If they clicked this banner, they began the e-consent process. Participant information sheets, tailored to the needs of each of the five key stakeholder groups could be downloaded from the website (Appendix 2).

Recruitment took place during the COVID-19 pandemic, so there were limited opportunities for face-to-face engagement. Relevant organisations and individuals were approached via email to request their assistance with promoting recruitment to the study in a variety of ways, such as displaying posters, posting information or videos on their websites, or informing relevant families directly when communicating with them. Health, education, charitable and sporting organisations, professional bodies/research networks and companies who provide rehabilitation equipment were contacted. Appendix 3 provides a full list of organisations that were contacted and the roles of individuals who were contacted. The study was promoted to potential participants in virtual meetings for a range of organisations.

Clinical teams in a community NHS Foundation Trust were encouraged to discuss the study with families they worked with during appointments.

3.4.5 Consent

Participants were asked to provide their consent digitally via the study website. Informed consent was obtained before any research activities commenced, and followed best practice guidelines for online consent (245). When a potential participant visiting the study website clicked the banner to indicate that they wished

to participate, they were asked to specify their age and stakeholder group, so they followed the appropriate consent procedure (Figure 7).

For participants aged 12-15 years, a consent meeting with the participant and their parent/guardian was arranged with the chief investigator (CI) via video conferencing prior to consent being provided. This was for safeguarding purposes, allowing identity of the participant as a NAYP to be verified and an opportunity to assess whether the young person was being pressurised by an adult to provide their assent**.**

With the exception of 12-15 year olds, the recruitment and consent processes were remote and crowdsource participants remained anonymous, so it was not possible for the research team to verify their identity. Therefore, although it is unlikely, it would have been possible for participants to enrol and participate who did not meet the specified inclusion/exclusion criteria. The “other interested members of the public” stakeholder group was added to the inclusion criteria to mitigate this risk, as it allowed anyone living in the UK and over 16 to contribute without falsely stating that they were in one of the alternative stakeholder groups.

Figure 7 summarises the process for recruitment, consent and participation in the study for different age groups. Further details of the consent procedure are outlined in the study protocol (Appendix 4).

Ethical approval was granted by the London - Camberwell St. Giles Research Ethics Committee (Ref: 20/LO/0011).

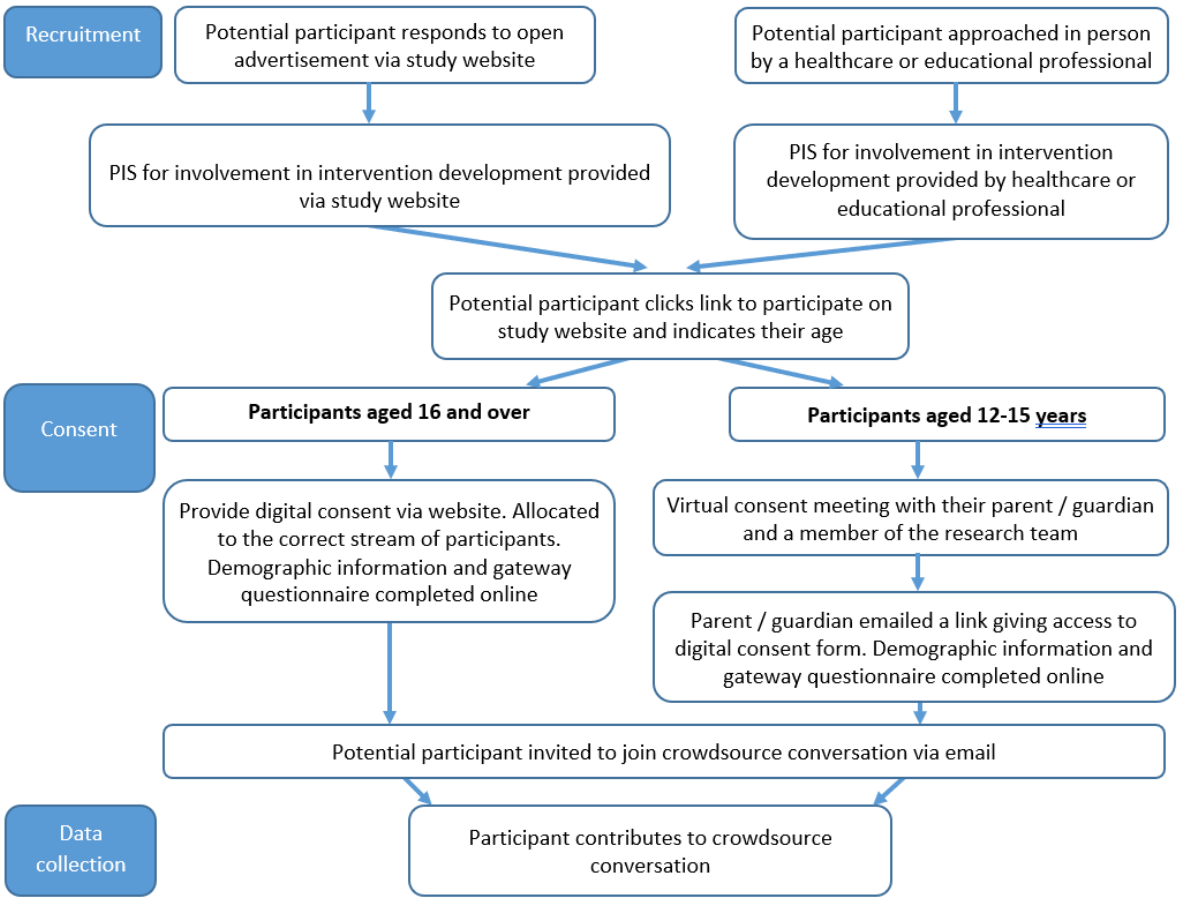


Figure 7 Study design and consent processes – Step one of co-design – understanding the problem.

PIS = Participant information sheet

3.4.6 Data collection

3.4.6.1 Participant characteristics:

Demographic information was collected online, including; name, age, email address, stakeholder group, high level location (first three characters of postcode or town/country if outside the UK), gender, ethnicity, employment status and diagnosis if the participant had a disability. Following this, participants completed a gateway questionnaire which included questions specific to their stakeholder group (Appendix 5), and were provided with further information on what to do next.

The crowdsourcing platform was hosted by London based collaborators Clever Together, who have considerable experience of healthcare related projects.

3.4.6.2 Crowdsourcing conversations:

Ground rules for participating were outlined and agreed by participants (Appendix 4, pages 39-40). Consenting participants were invited by email to log in and participate in the crowdsourcing conversation after completing the gateway questionnaire. Crowdsource conversations were hosted for each of the following groups:

1) family members

2) health and education professionals, experts and other interested parties

3) NAYP aged 12-15

4) NAYP 16-25.

Separate crowdsource conversations were held for each group listed above, and groups were not able to interact with each other. The young people's group was divided by age into 12-15 year olds and 16-25 year olds to safeguard contributors who were under 16.

3.4.6.3 Crowdsourcing format and questions:

Crowdsourcing conversations were hosted in English language only. Wording of questions posed in the crowdsource conversations varied slightly depending on stakeholder group, and are outlined in Table 9. When responding to questions, participants were asked not to post content which made them identifiable. The crowdsourcing conversations were closely monitored. Participants could report inappropriate content to the moderator (the chief investigator / first author). Any

entries flagged by a participant as being inappropriate, having potential to identify a participant or including inappropriate words would be removed immediately and automatically for review by the research team. A link signposting participants to voluntary support organisations if they needed additional support was included on the study website.

The use of the term “sedentary” was intentionally minimised in crowdsourcing questions, and in broader communication with participants. This was because it has a specific definition in the context of this research (3) which is difficult to explain. Also, it had potential to make participants feel judged or labelled as lazy (246), reducing their psychological safety during data collection. Instead, communication focused on young people’s movement, for example, exploring what helps them to move more. Using this terminology was intended to reduce focus on moderate to vigorous activity and emphasise light physical activity, avoiding the terms exercise and physical activity. Adults with disabilities have previously given negative feedback about the term “sit less” being used in public health messaging intended to reduce sedentary time (43). Often people who use a wheelchair are physically active in sitting, for example self-propelling a wheelchair or cycling using an arm crank. Focussing on moving more rather than sitting less where possible avoided this difficulty.

Table 9 Crowdsource conversation questions for NAYP.

Question number	Title	Prompt questions
1	Why move?	Do you think young people with disabilities want to move more during their day or not? Share with us why you think that. What are the benefits or drawbacks of moving more? How important is it? What makes you want to move and why?
2	What about sitting and lying down?	Do you think young people with disabilities want to change the amount of time they spend sitting and lying down during their day? Let us know why you think that. What are the benefits or drawbacks of sitting and lying down less? What are the benefits or drawbacks of spending more time crawling, standing, or using a walker? Could young people with disabilities do any different activities whilst / instead of sitting or lying down that would help them to move more? Do you want to sit and lie down less, or more? Let us know why.
3	What helps you to move?	What do you think helps young people with disabilities to move more during their day? What do you think helps them to sit and lye less than they currently do? Share with us why you think these things help.
4	What stops you moving?	What stops young people with disabilities moving (as much as they are able to) during the day? What stops them from moving as often as they could? Are there things that stop young people with disabilities sitting and lying still less? What are they?
5	COVID-19 Pandemic	Has the COVID-19 pandemic changed how much you move? If it has, tell us about your experiences. Has the pandemic changed the amount of time you spend sitting or lying down? If it has, tell us about your experiences.

Later in data collection, the questions for the crowdsourcing workshop were simplified to just two questions due to poor engagement, which were:

1. What helps or stops young people with disabilities from moving more?

2. Is it important for young people with disabilities to move more – why do you think this?

To contribute to the conversation, participants selected a question they wished to comment on, then submitted a new idea to answer that question. They wrote a title for their idea then described it in more detail below the title. Alternatively, they could comment on ideas that others had already posted.

To facilitate discussion and boost participant's confidence to contribute, seed ideas were added by the researchers prior to the online conversation opening. They are not analysed as part of the data, but any comments participants made about the seed idea were analysed. This was standard practice in the processes used by the crowdsource platform hosts. To boost engagement, further seed ideas were added when the questions in the conversations were simplified.

Observation of the crowdsourcing conversations whilst they were open allowed the level of contribution from the various stakeholder groups to be monitored. As NAYP and family members were not participating, the conversations remained open for as long as possible whilst additional recruitment activities were undertaken. Email reminders were sent to participants prompting them to contribute. The consent processes, gateway questionnaires and crowdsource questions were reviewed by pre-registration speech and language therapy students on placement with the research and innovation team. Language was simplified, extra explanations were provided and crowdsource questions were simplified as described above. Additional seed ideas were posted in the conversations to stimulate conversation and boost

confidence to participate. Social media posts informed participants that emails may be filtered into junk folders.

These changes were unsuccessful, so an alternative data collection method which was being used for the purposes of triangulation was used to ensure a number of NAYP and family members were represented in step one of the co-design. Data collected via this alternative method is reported in Chapter 4. The crowdsource conversations were closed to allow step two to commence. Step one participants were invited to contribute to the subsequent steps of the intervention development process.

3.4.7 Public and patient involvement

Young people with disabilities, their parents and members of the public were involved in producing/featured in a public engagement video that was produced to raise awareness of the study and to support recruitment (Supporting digital material, file 1). The West Midlands Clinical Research Network Young Persons Steering Group and public and patient involvement (PPI) representatives who are NAYP reviewed the recruitment materials and participant information sheets (Appendix 1 and Appendix 2). The consent process was reviewed by pre-registration speech and language therapy students. The gateway questionnaire and crowdsource questions were reviewed and piloted by adults with disabilities, parents of special school pupils and young people with disabilities. The seed ideas were also checked by a PPI representative prior to the online conversation opening. Changes were made to all documents based on their feedback. The Young Persons Steering Group were approached to assist with distribution of posters, but their numbers were limited at this time and the restrictions in place due to the COVID-19 pandemic meant many

were attending universities virtually rather than in person. A PPI representative was involved in a local radio interview to promote the study. PPI reps were encouraged to promote the study via their own networks. A PPI representative was a coder of raw data during the data analysis (see section 3.8.4.1).

3.4.8 Analysis

An inductive thematic analysis of the ideas participants submitted and comments they made in the online conversation was undertaken using the reflexive thematic analysis method described by Braun and Clarke (247), adopting an ontological position of realism. This means that reality exists independently of those who observe it, but the researcher can only view and interpret it via the lens of individuals (including themselves) with differing vantage points, experiences and understanding (248). Analysis was undertaken in three steps; 1) five coders independently coded the raw data using the reflexive thematic analysis method described by Braun and Clarke (247) 2)coders met to produce a list of consensus codes which incorporated their differing vantage points and to group the codes to identify themes 3) the coders used the list of final codes and themes to identify barriers and facilitators, categorised into themes. The coders did this together in a meeting.

3.4.8.1 Step one (coding raw data):

Braun and Clarke describe a code as the smallest unit of analysis which briefly describes a singular idea in the raw data. The codes are the building blocks of the rest of the analysis. A table was produced breaking down the raw data from the crowdsource conversation into short sections. The raw data in the first column in the table was not edited or summarised. Each short section was on a new row. The CI, a

PPI representative and three pre-registration speech and language therapy students who were on placement with the Research and Innovation team at a community NHS Foundation Trust independently coded the rows of raw data using the table. The students were provided with reading materials about the Braun and Clarke thematic analysis approach, instructions and the opportunity to discuss the task with the CI prior to coding the data. In keeping with the ontological position adopted, it was important that coders with differing experiences and understanding were involved in the analysis, as they each interpret the meaning of the raw data through their own lens. Each coder's independently produced codes were added to the table in separate columns to allow them to be compared easily in step two of the analysis (Table 10).

The group undertaking coding analysis did not intend to reach a statistical level of inter-rater reliability, as this approach is considered to be ineffective and inappropriate for qualitative research (249). The group acted as critical friends, challenging each other's interpretations to construct a defendable and plausible interpretation, whilst acknowledging that other plausible interpretations that are not being utilised in this research at this time also exist (249).

3.4.8.2 Step two (producing consensus codes and themes):

Coders attended virtual consensus meetings in which a final consensus code/s were agreed for each row of the table and were written in the final column of the table. When this was completed, the coders discussed whether the codes could be grouped into themes. Some of the consensus codes themselves became themes that other codes could be categorised under. These codes were highlighted in bold. Table

10 shows a section of the completed table as an example. Some new themes were needed to group together similar codes when the codes themselves were not appropriate theme names. These themes were decided by the group of coders.

Table 10 Extract from the coding table.

Raw Data (Title participants gave their contribution is underlined, their contribution is on the row/s below)	**Coder 1**	**Coder 2**	**Coder 3**	**Coder 4**	**Coder 5**	**Final codes / themes** (Themes in bold)
Question 1 – Why move?						
<u>Difficulties with moving more</u>	Comorbidities		Barrier to moving more			**Comorbidities**
Young people with Autism often also don't like to exercise as there can be sensory aspects (feeling hot / sweaty / pulse racing)		Sensory aspects of exercise are difficult to tolerate	Dislike of sensory sensation of exercise	Unwanted aspects of exercising	Beliefs and attitudes	Sensory aspects of exercise are difficult to tolerate Autism
expectation of team participation (such as for team sports) which they find unpleasant or challenging		Social / participatory requirements of team sports.	Dislike of team participation		• Beliefs and attitudes plus • Environmental (team participation) • Negative impact	Autism Expectation of participation / social interaction in team sports challenging.
<u>Move more BUT move better</u>	Posture		Quality of movement			
It is so important that we enable young people with disabilities to not only move more but move better		Importance of 'quality' of movement			Service impact Knowledge and understanding	Enabling good quality of movement

3.4.8.3 Step three (identifying barriers and facilitators):

A second table with two columns (barriers and facilitators) was produced in which the consensus codes were grouped into themes and divided into barriers and facilitators of moving more. All coders were involved in this and agreed the final barrier / facilitator table. When a code could be a barrier or a facilitator, it was entered into both columns and worded to explain the context in which it was considered to be a barrier or facilitator. For example “Barrier: lack of safe space. Facilitator: safe space.”

3.5 Results

The crowdsourcing workshop opened February 2021. Eighty-nine participants chose to participate via crowdsourcing following completion of the gateway questionnaire. Forty-six went on to log in and contribute, however only 10 wrote an idea or comment. The remaining 36 participants contributed by liking or disliking a comment or idea but did not write any comments or ideas themselves. They were therefore excluded from the analysis.

Crowdsource questions were simplified to promote increased engagement in July 2021. To ensure participants existing responses were still visible to new and existing participants, participant’s previous responses were redistributed into the most appropriate new question. Two new participants (one family member and one professional) contributed to the crowdsource conversations following the question change. They contributed four new ideas. Overall, contributions to the crowdsource conversation were minimal, with only 25 ideas and 12 comments contributed in total. The crowdsource conversations closed in October 2021.

3.5.1 Participant characteristics

Upon conclusion of data collection via crowdsourcing, a total of ten participants contributed to the conversations. Participants included; one family member, seven professionals, and two experts. One of the experts was an academic with an interest in childhood disability and the second trained professionals about postural care and assessment of body shape. No NAYP contributed to the conversations.

Participant characteristics are shown in Table 11. In summary, all participants were white females. There was one international participant from Australia within the experts group. Areas UK participants lived in are listed below. Participants were from the North, South and Midlands areas of the UK, including rural and city environments.

- Birmingham
- Crewe
- Glasgow
- Halesowen
- Stroud
- Surrey
- Tamworth

3.5.2 Gateway questionnaire data

Table 12, Table 13, Table 14 and Table 15 present the gateway questionnaire responses of participants who contributed via crowdsourcing for each stakeholder group.

The family member who participated was the mother of a 12 year old boy who had CP (Table 12). All but one of the professionals were physiotherapists and worked with NAYP daily or weekly (Table 14). Interestingly, 57% of professionals monitored sitting

or lying time via postural management programs, subjective information, or objective measurement of the percentage of time young people spent sitting or lying (Table 14).

Table 11 Step one Participant characteristics for crowdsourcing contributors in step one.

Stakeholder group / characteristic	**Number of participants (%)**	**Age in years: mean, median, range**	**Gender: Number (%)**	**Ethnicity: Number (%)**	**Employment status / Role: Number (%)**
Family members of non-ambulant children and young people	1 (10%)	50, 50, 50	Female: 1 (100%)	White – British: 1 (100%)	Working part time: 1 (100%)
Health and Education professionals	7 (70%)	37, 36, 28-49	Female: 7 (100%)	White – British: 6 (86%) White – Other: 1 (14%)	Working full time: 5 (71%) Working part time: 2 (29%)
Experts – Academics / industry experts interested in disability, sedentary time, digital health.	2 (20%)	40, 39.5, 34-45	Female: 2 (100%)	White – British: 1 (50%) White – Irish: 1 (50%)	Working full time: 1 (50%) Working part time: 1 (50%)
Total	10 (100%)	39, 38.5, 28-50	Female: 10 (100%)	White – British: 8 (80%) White – Irish: 1 (10%) White – Other: 1 (10%)	Working full time: 6 (60%) Working part time: 4 (40%)

Table 12 Gateway questionnaire responses: Family members - crowdsourcing contributors.

Family member's diagnosis	Relationship to family member with disabilities	Do you live with your family member with disabilities?	Age of family member with disabilities	Does your family member have learning difficulties?	Can your family member tell you what they want?	Do you help your family member to spend time moving?	How do you help your family member to move? What do you do or say?	Activities your family member does that involve movement	Activities your family member does when sitting and lying
CP	Parent	Yes	12	No	Yes	Yes	We help them into equipment to get them moving around and they understand why they need to do it for their bone strength, build up muscles, etc	Ride a trike. Walk in a heavily adapted walker. Can ride a horse with assistance.	Sit in a supported chair. Can only use one hand so has to be supervised. Can fall when seated on the floor so must be supervised. Encouraged to play board games.

Note: CP: cerebral palsy.

Table 13 Functional abilities of non-ambulant young person whose family members participated - crowdsourcing contributors.

Functional Ability	**Family members ability to do task (Yes , No, Unsure)**
Roll over	Yes
Independent lye to sit	No
Floor sit, no support	Yes
Sit on edge of bed, no support	No
Crawl	No
Kneel, no support	No
Kneel with support / something to hold	Yes
Use a tablet	Yes
Bat balloon	Yes
Throw a ball	Yes
Shake a tambourine	Yes
Hold a basketball in both hands	No
Use a standing frame	Yes
Use a body support walker	Yes
Steer a power chair	Yes
Self-propel a wheel-chair	No

Table 14 Gateway questionnaire responses: Professionals – crowdsourcing contributors.

Participant	Job role	Frequency of working with NAYP	Number of years working with young people with physical disabilities	Do you measure / monitor the amount of time NAYP spend sitting or lying still?	How do you measure / monitor amount of time NAYP spend sitting or lying still?
Professional 1	Physiotherapist	Weekly	2-5 years	Yes	24 hour postural management plan using Acheeva, sleep system or walking/standing frames.
Professional 2	Paediatrician	Weekly	6 - 10 years	No	
Professional 3	Paediatric physiotherapist	Daily	11 – 20 years	No	
Professional 4	Paediatric physiotherapist	Daily	20 years or more	Yes	Time as percentage of day
Professional 5	Paediatric physiotherapist	Daily	2-5 years	No	
Professional 6	Paediatric physiotherapist	Daily	2-5 years	Yes	Subjective information
Professional 7	Independent paediatric physiotherapist	Daily	20 years or more	Yes	Questions from carers, school, equipment, part of their 24 hour posture plan
Totals	Physiotherapist: 6 Paediatrician: 1	Daily: 5 Weekly: 2	2-5 years: 3 6 - 10 years: 1 11 – 20 years: 1 20 years or more: 2	Yes: 4 No: 3	Monitor as part of 24 hour postural care: 2 Subjective information: 1 Time as percentage of day: 1

Note: NAYP = Non-ambulant young people

Table 15 Gateway questionnaire responses: Experts – crowdsourcing contributors.

Name	Job role	How does your work relate to this study?	Number of years working in this field	Do you measure / monitor the amount of time NAYP spend sitting or lying still?	How do you measure / monitor amount of time NAYP spend sitting or lying still?
Expert 1	Academic researcher (Physiotherapist)	Physiotherapist who conduct's research into physical activity and meaningful participation for young people with CP.	11 – 20 years	Yes	I have done as a part of previous research projects. I have used ActiGraphs and questionnaires
Expert 2	Developing CPD accredited training for healthcare practitioners in the use of therapeutic positioning and measurement of body symmetry	Stability is the foundation of movement. If a child's 24 hour positioning needs are not properly assessed, met and monitored their movement will be negatively impacted.	20 years or more	Yes	At every assessment it is a key question - what is the child's preferred sleeping position and for how long is the child in that position

Note: NAYP = Non-ambulant young people

3.5.3 Crowdsourcing conversations

3.5.3.1 Objective 1: Do participants see movement as important for this group of young people and what do they think about how much or how frequently they move?

Crowdsourcing questions relating to this objective were initially under the heading "Why move" and asked whether or not NAYP wanted to move more during their day, what the benefits / drawbacks of moving more were, how important it was and what makes them want to move more and why. This was later changed to "Is it important for young people with disabilities to move more – why do you think this?"

Idea titles that were posted in the online conversation by participants in relation to these questions included:

- independence
- health benefits – physical and mental
- medically it's so much better for the child
- move more BUT move better
- fun with friends
- opportunity to move
- a symmetrical, comfortable body shape

Those who contributed thought young people needed more opportunities to move and that moving more is beneficial. Quotes illustrating this include:

"A lot of our children have been told that they cannot move or have always been moved by their parents because its quicker than allowing the child to do this independently. We should be promoting functional movement as much as possible

throughout the day. There are of course several barriers to participation in sport for children with disability and more work is needed to facilitate this. I think NHS services should be looking to host/facilitate sessions to improve quality of life and reduce the risk of long-term secondary complications to sedentary lifestyles." Professional three.

"Moving and playing physical games with friends is something that typically developing young people enjoy and get a great deal from – it's no different for those with disabilities!....I think its often the environmental barriers that are stopping them from moving, not a lack of desire." Expert one.

"Movement improves so many parts of the body. It increases bone density and promotes growth. It opens up the internal space and lets the organs work properly instead of being squashed. It helps with the bowels. It also shows other children that the child can move about and is not just restricted and gives opportunity to create new games and ideas for inclusion." Family member.

"It is so important that we enable young people with disabilities to not only move more but move better." Professional four.

3.5.3.2 Objective 2: Barriers and Facilitators

The barriers and facilitators for reducing sedentary time for NAYP identified from the coded crowdsourcing data are reported in Table 16. The themes they are divided into (bold text denotes a theme) were identified in the consensus meeting as described in the methods section above.

Table 16 Barriers and facilitators identified in crowdsourcing data.

Barriers	**Facilitators**
Comorbidities	
Autism	
Sensory aspects of exercise are difficult to tolerate	
Limited cardiovascular fitness	
Poor sleep and tiredness	
Learning disability	
Differentiation of resources and rewards for all intellectual levels needed.	Differentiation of resources and rewards for all intellectual levels needed.
Environment	**Environment**
Lack of safe space	Safe space
Lack of clean space	Clean space
Lack of appropriately sized space	Appropriately sized space
Need to be in wheelchair outside the house.	
Space at home limited	
Reduced opportunity to move due to inappropriate space	Providing opportunities to access outdoor space
Lack of equipment and facilities limits participation in sport	
Ensuring sports participation is safe	Ensuring sports participation is safe
Access to equipment at home	
Lack of help increases sitting time	
Lack of availability of specialised help	Availability of specialised help
Education	Education
Socioeconomic Status	**Socioeconomic Status**
Social deprivation limits space	
Lack of Access to equipment at home.	Access to equipment at home.
Equipment	**Equipment**
Lack of access to equipment at home	Access to suitable equipment at home
Lack of equipment and facilities limits participation in sport	
Sharing equipment.	Access to own suitable equipment
	Schools offer equipment at home in holidays
COVID-19 reduced access to equipment	
Ensuring sports participation is safe	Ensuring sports participation is safe
Physical aspect of their healthcare is not prioritised	**Physical aspect of their healthcare is prioritised**
Physical needs not prioritised in EHCP	Specialised help increases frequency of movement and position change
Covid -19	**Covid-19**
Limited access to healthcare and education services	

Barriers	Facilitators
More sitting	
Increased strain on school staff	
Virtual health appointments	Virtual health appointments
Prolonged reduced access to face to face health services	
Reduced health services affecting ability to move	
Reduced access to equipment	
Reduced access to medication	
Increased strain on health services	
Covid -19 – reduced capacity of parents if caring for siblings	
Education	**Education**
Capacity and capability of professionals to ensure EHCP appropriate and up to date	Capacity and capability of professionals to ensure EHCP appropriate and up to date
EHCP plan appropriate and current	EHCP plan appropriate and current
Lack of expertise and resources needed to create appropriate intervention	Expertise and resources to create appropriate intervention available
Physical needs not prioritised in EHCP	
Experiences of movement	**Experiences of movement**
Sensory aspects of exercise are difficult to tolerate	Reassurance and education can desensitise response to breathlessness
Breathlessness misunderstood due to limited experience	
Expectation of participation / social interaction in team sports challenging.	
Interventions for the general population not always beneficial for this group.	
Availability and capability of professionals	
Lack of availability of specialised help	Availability of specialised help
Enabling good quality of movement	Enabling good quality of movement
Lack of expertise and resources needed to create appropriate intervention	Expertise and resources to create appropriate intervention available
Ensuring sports participation is safe	Ensuring sports participation is safe

Table 16 includes data collected in the crowdsource conversations between February and April 2021. This table was shared with virtual workshop and 1:1 interview participants at the end of their step one virtual co-design workshops /1:1 interviews (see Chapter 4). The data collected via crowdsourcing after April 2021 was incorporated into the analysis of the virtual workshops and 1:1 interviews, as described in Chapter

3.6 Discussion

The crowdsourcing conversations initiated exploration of what family members, professionals who work with NAYP and experts think about the volume and frequency of movement and sedentary behaviour in NAYP and their perceived importance of these behaviours. Participants felt NAYP needed more opportunities to move and believed moving more would be beneficial to them. Barriers and facilitators for reducing sedentary time and increasing movement from the perspective of those who participated were identified and included co-morbidities, environmental and socioeconomic factors, experiences of movement, whether physical aspects of healthcare were prioritised or not, equipment, the impact of the covid-19 pandemic and capacity and capability to facilitate movement in educational facilities. The aims of the research have only partially been met due to the lack of engagement of NAYP, the minimal contribution from family members and the small number of participants overall.

Having an opportunity to explore how the Covid-19 pandemic influenced sedentary behaviours of NAYP was a novel and interesting aspect of this work. The negative impact it had on access to healthcare, education and access to equipment that usually facilitates regular movement and position changes for NAYP was highlighted.

The question related to the impact of COVID-19 was added to the crowdsource questions as part of a protocol amendment. Data collection took place between February and October 2021. In January 2021, the UK entered its third national lockdown in response to the COVID-19 pandemic. The pandemic was having a significant influence on participant's lives with significant restrictions on socialising and household mixing for the majority of the data collection period. Schools reopened

in March 2021 and the vaccine rollout was underway. Considering this context, it was important to consider the impact the pandemic was having on movement for NAYP in this research.

Some of the barriers and facilitators identified in this study are similar to barriers and facilitators that have been identified in previous studies exploring barriers and facilitators to physical activity for this population, for example environmental factors, negative experiences and policy barriers (53, 54). Policy barriers / facilitators in relation to educational provision via education and healthcare plans were particularly highlighted in this study. Availability of people with the right skills to provide support and access to equipment that is safe were also common themes (57). Some barriers / facilitators were specific to this study, such as the impact of comorbidities and socioeconomic status. The facilitators of making friends, having fun and striving for independence that have been previously reported (56, 57) were not strong themes in this study. This could be because the majority of participants were professionals and experts and not NAYP or their family members.

The number of professionals reporting in the gateway questionnaire that they measured the amount of time NAYP spend sitting or lying still was encouraging. However, the methods of measurement they described using suggested that they relied largely on self-report rather than device-based (more objective) methods and did not include an estimation of energy expenditure. As a result, sedentary time as defined by the Sedentary Behaviour Research Network (3) (energy expenditure of ≤1.5 METs) was not being measured. One professional reported that they measure the time spent sitting / lying still as a percentage of the day. It is not clear whether this was a self-reported estimation, or an estimate assessed by a device (for example an

accelerometer). It would be interesting to explore whether professional's view device-based measurement of sedentary time for this population as a useful clinical outcome measure and why they think it is useful / not useful. For clinicians to measure sedentary time in clinical practice for this population, further research to establish reliable, validated methods of doing so are needed, as highlighted in Chapter 2 and proposed in Appendix 6 (protocol for the Stationary study). The feasibility of devise-based measurement of sedentary time in clinical practice would also need to be explored, including young people's and parent's / guardian's acceptance of wearing devices and the time and skills clinician's would require to access and interpret the data.

Whilst using crowdsourcing for academic research, a tension existed between designing specific questions to facilitate a response that includes the information being sought and taking the opposite approach of asking simple, broad questions, then facilitating the resulting conversation anonymously to ensure answers to the specific questions are still elicited. Changing from the former to the later approach during data collection resulted in some additional data being collected, but ultimately did not result in engagement of NAYP. It is possible that some NAYP would have engaged if a small number of simple questions had been asked the first time they joined the conversation.

Possible barriers to engagement with crowdsourcing could include:

1) Participants not understanding that there was a further data collection activity after consenting and completing the gateway questionnaire.

2) The consent processes and gateway questionnaire being too in depth, resulting in participants not understanding them or not wishing to/having time to contribute to the crowdsource conversations.
3) Email invites to the crowdsource conversations being filtered into junk email folders, so they were not received.
4) Participants finding the crowdsource questions too complex or being uncertain of what to write/not feeling confident to contribute.
5) Potential participants choosing to avoid committing to an additional online activity when education and work was being conducted virtually during the Covid-19 pandemic.
6) Participants preferring a more interactive communication method than the crowdsourcing workshop to undertake a creative process such as co-design.
7) For 12–15-year-olds, the additional step of having a video consent meeting prior to initiating the consent processes. This could have been a barrier because it introduced complexity or because the young person wished to take part, but the parent/guardian didn't have capacity or time to arrange the meeting/didn't wish to consent to their child's participation.
8) Willingness and capacity to volunteer time and energy to assist with research when services and support for young people with disabilities were limited due to redeployment of NHS staff and social distancing restrictions during the Covid-19 pandemic (250). Young people with disabilities and their families felt isolated and abandoned at this time (250).

A possible explanation for why more professionals and experts than young people and family members engaged via crowdsourcing is that they may have had more

confidence and experience expressing their ideas and thoughts by writing text and via digital methods than family members and young people.

3.6.1 Reflexivity

I was mindful throughout the analysis of my own preconceived ideas of why moving more is important and my views of what the barriers / facilitators of moving more are. Having worked as a paediatric physiotherapist in community NHS services for 15 years prior to becoming a PhD candidate, I am passionate about creating opportunities for NAYP to move. I have observed and attempted to influence the barriers / facilitators we were identifying from this data for a wide range NAYP in multiple environments. Working with a team to undertake the analysis was therefore essential to minimise the influence of my pre-conceived ideas and ensure the analysis was trustworthy. I was aware of the potential power imbalances between myself and the students and PPI rep in the analysis team. During analysis meetings I strived to adopt suggestions from other members of the team above my own wherever possible to create a psychologically safe environment for challenging and discussing each other's ideas.

3.6.2 Strengths and limitations

Recruiting via an open call of variable extent is included in the definition of crowdsourcing (113). This is a weakness of this methodology, as it creates a high risk of self-selection bias, potentially resulting in a sample which is not representative of the general population.

As acknowledged in the methods section, it was possible for participants to enrol and participate who did not meet the specified inclusion / exclusion criteria. This risk was

mitigated by adding an additional stakeholder group, allowing anyone living in the UK and over 16 to contribute legitimately. Undertaking further research to collect data relating to this topic, but employing more traditional data collection methods would act as a method of triangulation to validate this data collected via crowdsourcing.

The researchers had minimal interaction with the participants, reducing the risk of researcher bias influencing participant's contributions. To reduce potential bias, seed ideas were written based on real life examples or existing data sources and were shared with PPI reps for feedback prior to being added to the conversations.

Crowdsourcing did not provide an in depth understanding of the problem from the perspective of a range of stakeholders due to the lack of engagement of NAYP and the minimal contribution from family members. Further data collection is required to achieve this aim, using a method that NAYP will engage in. It was not possible to contact participants to ask them their reasons for not logging into the crowdsourcing workshops (or logging in but not writing ideas or comments) because ethical approval to contact them for this purpose was not obtained.

Analysis of the data by several independent coders, with a wide range of experiences and perspectives and their subsequent meetings to compare their coding increased trustworthiness of this work.

3.6.3 Implications for future research

Crowdsourcing could be a useful tool to widen engagement of underserved communities in research, but it needs to be used alongside traditional data collection methods such as interviews, focus groups or workshops. Optimisation of the delivery of crowdsourcing is required. It would be helpful to understand more about the

factors that contributed to the lack of engagement with crowdsourcing to inform future protocols.

3.7 Conclusion

The crowdsourcing conversations were a useful tool to initiate exploration of what family members, professionals who work with NAYP and experts think about the volume and frequency of movement and sedentary behaviour in NAYP and their perceived importance of these behaviours. It allowed identification of barriers / facilitators of moving more for NAYP by some stakeholder groups.

Participant engagement with crowdsourcing as a vehicle for intervention development was disappointing. Use of an alternative data collection method which engages NAYP and family members is required to gain an in depth understanding of the problem and its causes that includes the perspectives of all stakeholder groups. Further data collection via an alternative method is required to achieve this aim.

4 Chapter 4: Step one of the Six Steps in Quality Intervention Development (6SQuID). Understanding the problem – data collection via virtual co-design workshops and 1:1 interviews.

4.1 Pre-face to Chapter 4

Chapter 3 described progress made towards the second aim of step one of the Six Steps in Quality Intervention Development (6SQuID) (gaining an in depth understanding of the problem and its causes from the perspective of a range of stakeholders) via a crowdsourcing methodology. Due to the low engagement with data collection via crowdsourcing and an indication that it had potential to create inequality between participant groups; a decision was made to remove data collection via crowdsourcing from the remaining steps of the co-design. Alternative methods of virtual co-design workshops and 1:1 interviews were therefore used to complete step one and the results are reported in this chapter.

To enable completion of step one and the subsequent steps of the co-design via virtual workshops and 1:1 interviews, a protocol amendment was submitted and approved to enable as many participants as possible to contribute to the co-design. The amendment allowed virtual 1:1 interviews to be offered to all participants, so those who did not feel confident about speaking in a group or those who were unable to attend a workshop due to other commitments could still take part. Interviews were also conducted in instances where only one person attended a virtual co-design workshop.

The virtual co-design workshops / virtual 1:1 interviews provided an additional source of rich data to triangulate the crowdsourcing data, because it is collected via an

alternative method. Using this alternative data collection method facilitated sufficient data collection to allow barriers / facilitators for reducing sedentary time and increasing movement to be identified from the perspective of a range of stakeholders.

4.2 Title: Using virtual workshops to explore sedentary behaviour and movement patterns of non-ambulant young people.

4.3 Introduction

There is a large body of evidence demonstrating that children and young people with physical disabilities spend more time sedentary than their able-bodied peers (33, 38, 47, 158, 159, 193, 209, 212). Non-ambulant children and young people are more sedentary than young people with physical disabilities who are able to walk (33, 39, 158, 159, 210, 215). In this study non-ambulant young people (NAYP) refers to those who are 12-25 years old and are unable to walk, or only walk short distances using a walker that supports their body (i.e. not a handheld walker). NAYP often walk short distances indoors only, and this walking may form part of an exercise or therapy program. Sedentary behaviour increases with age for all children and young people, including those with physical disabilities (27, 39, 40). This evidence highlights that adolescents and young adults who are non-ambulant are highly sedentary and are therefore more likely to experience negative health outcomes associated with sedentary time (236).

There is a specific definition of sedentary behaviour which has been adopted by the scientific community. The definition includes three conditions. To be sedentary, individuals must be: a) awake, b) in a sitting, lying or reclining posture, c) using ≤1.5 metabolic equivalents (METs) of energy, which is a low threshold (3). Sedentary

behaviour is therefore different to being inactive, which is a lack of moderate to vigorous physical activity (17).

World Health Organisation (WHO) and United Kingdom (UK) physical activity guidance advises children and young people to limit their sedentary time (23, 26). Recreational screen time is a popular sedentary activity for children and young people (131). There is a positive association between recreational screen time and poor health outcomes such as reduced fitness (18, 19), poor cardiometabolic health (18), less sleep (20, 251), higher adiposity (18, 19, 23, 235), behavioural difficulties (18) and poor mental health (22-24) in children and young people. Poor mental health outcomes included increased odds of depressive symptoms in adolescents spending ≥3 hours per day being sedentary (22) and associations between sedentary behaviour and anxiety symptoms (24). The association between sedentary behaviour and anxiety was present in children in adolescents, but was not as strong as the association observed in adults (24). The overall impact of these negative health outcomes is a reduction in quality of life for adolescents with high levels of recreational screen time (21, 252). In adulthood, high levels of total sitting time / television (TV) viewing time increases the incidence of type two diabetes and the risk of all cause and cardiovascular disease mortality (8).

There is evidence of additional poor health outcomes related to high levels of sedentary time which are specific to children and young people with physical disabilities. Physical components of health-related quality of life are significantly less favourable for young adults with cerebral palsy (CP) who have sedentary lifestyles, in comparison to the population norm (45). Fatigue and reduced sleep quality are also associated with sedentary lifestyles amongst children and young adults with CP, but

the association is weaker in non-ambulant children than those who are ambulant for young adults (45, 46). Sedentary behaviour and lean body mass were negatively associated in non-ambulant children and young people with Duchenne Muscular Dystrophy (DMD) (47).

Four studies including non-ambulant children and young people have explored whether specific interventions interrupt sedentary time, however this was not the primary aim of these interventions. The first study, which involved children with CP in Gross Motor Function Classification System (GMFCS) levels I-V, aimed to quantify energy expenditure in lying, sitting and standing (65). GMFCS levels classify level of functional mobility for children and young people with CP (2). Level I includes those with mild mobility limitations and level V those with severely limited mobility. Individuals in levels IV-V are non-ambulant. For those who were unable to stand independently, standing frames were used (65). The study found that standing was not a sedentary activity, even when the young person was supported in a standing frame, as energy expenditure was > 1.5 METS (65). The second study (which also involved children with CP, but only those in GMFCS levels IV and V), partially supported Verschuren et al.'s findings. It showed a significant increase in heart rate in supported standing and repeated performance of the highest Gross Motor Function Measure (GMFM) assessment task an individual was able to perform for GMFCS level IV, but not V (67). The third study, which involved NAYP with paraplegia, demonstrated that assisted walking in a powered exoskeleton also interrupted sedentary time (68). Finally, measurement of energy expenditure during therapeutic horseback riding for children with moderate to severe motor impairments

showed that riding achieved both light and moderate to vigorous physical activity, even though participants were sitting or lying on down the horse (69).

A study involving NAYP with CP measured blood glucose and blood lactate levels during dynamic standing (66). Dynamic standing was achieved using a motorized device which facilitated assisted passive movements in a weight bearing position (66). Elevated blood lactate levels were observed at rest and after dynamic standing. Participants in GMFCS level V had significantly higher blood lactate than those in GMFCS level IV. Those with higher resting blood lactate showed a significantly larger reduction in blood lactate after dynamic standing than those with lower resting levels (66). Presuming sedentary time was interrupted by the dynamic standing, based on the evidence presented above (65), this suggests that interrupting sedentary time reduces blood lactate when there are high resting levels.

There are a small number of studies evaluating interventions to increase physical activity for children with physical disabilities that have also hoped to reduce sedentary time. The majority of these interventions were designed for children with CP. One such study evaluated feasibility of physical activity prescription for children in GMFCS levels I-V (61), and therefore included NAYP. The effectiveness of face to face motivational interviewing and production of a physical activity prescription was tested (61). Changes in sedentary time pre and post intervention were not analysed, but it was reported that changes were variable (61). Two randomised control trials (RCTs) involving ambulant children with CP (GMFCS levels I-III) aimed to determine the effectiveness of an internet based physical activity intervention (59) and to investigate the efficacy of an eight-week goal-directed, individualized, participation-focused therapy intervention (63). Unfortunately, neither intervention successfully

reduced sedentary time. A 12-week RaceRunning intervention for young people with CP in GMFCS levels III-IV also did not significantly reduce sedentary time (64). An RCT for children with Down's Syndrome investigated the effects of a bicycle riding intervention which reduced sedentary time at seven weeks post intervention and 12 month follow up (60). There are no evidence-based interventions that were specifically designed to reduce sedentary behaviours for NAYP (38).

In able-bodied children, school-based interventions to increase physical activity can reduce sedentary time (237). Also, parent-based interventions can reduce screen time in healthy adolescents (238). It is unlikely that interventions such as these would address the population specific barriers to physical activity faced by NAYP (239). For young people with CP, these barriers include: negative attitudes and experiences of physical activity, environmental factors (physical / structural), professionals, parents and friends not being supportive, GMFCS level and policy barriers (53, 54). The importance of healthcare professional's roles to increasing physical activity by supporting and encouraging young people to pursue leisure activities they enjoy has been highlighted (55).

Interventions to maximise participation in physical activity for children and young people with CP can address modifiable factors at differing levels, such as personal, social and family factors including: self-confidence, persistence, athletic ability, friendship experiences and parental engagement in physical activity (58). Family culture and attitudes affect children's motivation for being physically active (57). Parents need reassurance that there are people who are skilled and experienced available to support their child (57). Parents of children with CP identified the following factors which influence their child's participation in physical activity:

"belonging and taking space in the family", "important persons facilitating and hindering", "friends important but hard to get", "good for the body but challenging", "availability and opting out possibilities" and "protecting and pushing towards independence" (57). Making friends when participating in physical activity was also an important facilitator for young people with DMD, as was having fun. Insufficient health was a key barrier (56). These studies focused on barriers and facilitators of physical activity only or barriers and facilitators of both physical activity and sedentary behaviour. Barriers and facilitators specific to sedentary behaviour only have not been explored for children and young people with physical disabilities.

The first step of the Six Steps in Quality Intervention Development (6SQuID) intervention development framework involves reviewing the existing evidence relating to a problem and listening to stakeholder perspectives; to achieve an in depth understanding of the problem from their differing perspectives and to understand the causal pathways that create and sustain the problem (86). Stakeholder groups involved in this study were NAYP aged 12-25, family members of NAYP, professionals who work with NAYP (for example education and healthcare professionals or carers) and experts in sedentary behaviour, paediatric disability, behaviour change, and/or digital health interventions. This work initiated a broader intervention development following the 6SQuID framework. The intervention being co-designed will support NAYP to reduce their sedentary behaviours.

The co-design workshops and interviews in this study needed to be held virtually due to restrictions on socialising and household mixing that were in place during the data collection period. Co-design is a creative process (95). Generating a creative environment in a virtual workshop can be challenging. Advice was sought from a co-

design hub (253) that experienced barriers when moving their projects online during the pandemic, as creativity was stifled in an online environment. Their previous work had centred around building tangible objects as part of creative process (95). Inspired by their previous work (254), and advice, the approach taken in this study was to focus discussions on tangible objects, despite the workshops being virtual. This was achieved by participants drawing or thinking of an object or symbol that represented what they wanted to portray or using images to promote discussion.

Due to the number and complexity of barriers and facilitators identified by the stakeholders, a relevant, evidence-based categorisation system was required to enable meaningful sharing of the results with participants. The Systems of Sedentary behaviours (SOS) Framework (118) maps determinants of sedentary behaviour across all age groups. It accounts for social and ethnic diversity and is presented as a systems-based map (Figure 8) (118). There are six determinants of sedentary behaviour identified in the SOS Framework: (1) physical health and wellbeing, (2) social and cultural context, (3) built and natural environment, (4) psychology and behaviour, (5) politics and economics and (6) institutional and home settings. The map in Figure 8 lists the factors that each of these six determinants encompasses (118).

Bianco et al. previously used the SOS framework to categorise 79 factors that influenced the physical fitness of a sample of adolescent survey respondents into three broader determinants (119). It has been used in this study in a similar way, to consider which of the SOS framework's determinants are most relevant to sedentary behaviour for NAYP based on stakeholders perspectives. The SOS framework overcomes limitations of the ecological model of sedentary behaviour, which does not

adequately capture the complexity of determinants or the interplay between them. Including multidisciplinary perspectives and removing assumptions that influences on sedentary behaviour are hierarchical strengthens the framework (118). The SOS framework is ideal for categorising barriers and facilitators of sedentary time identified in this study because it is specific to sedentary behaviour (rather than physical activity in general), and a rigorous international and transdisciplinary consensus process was used to develop it.

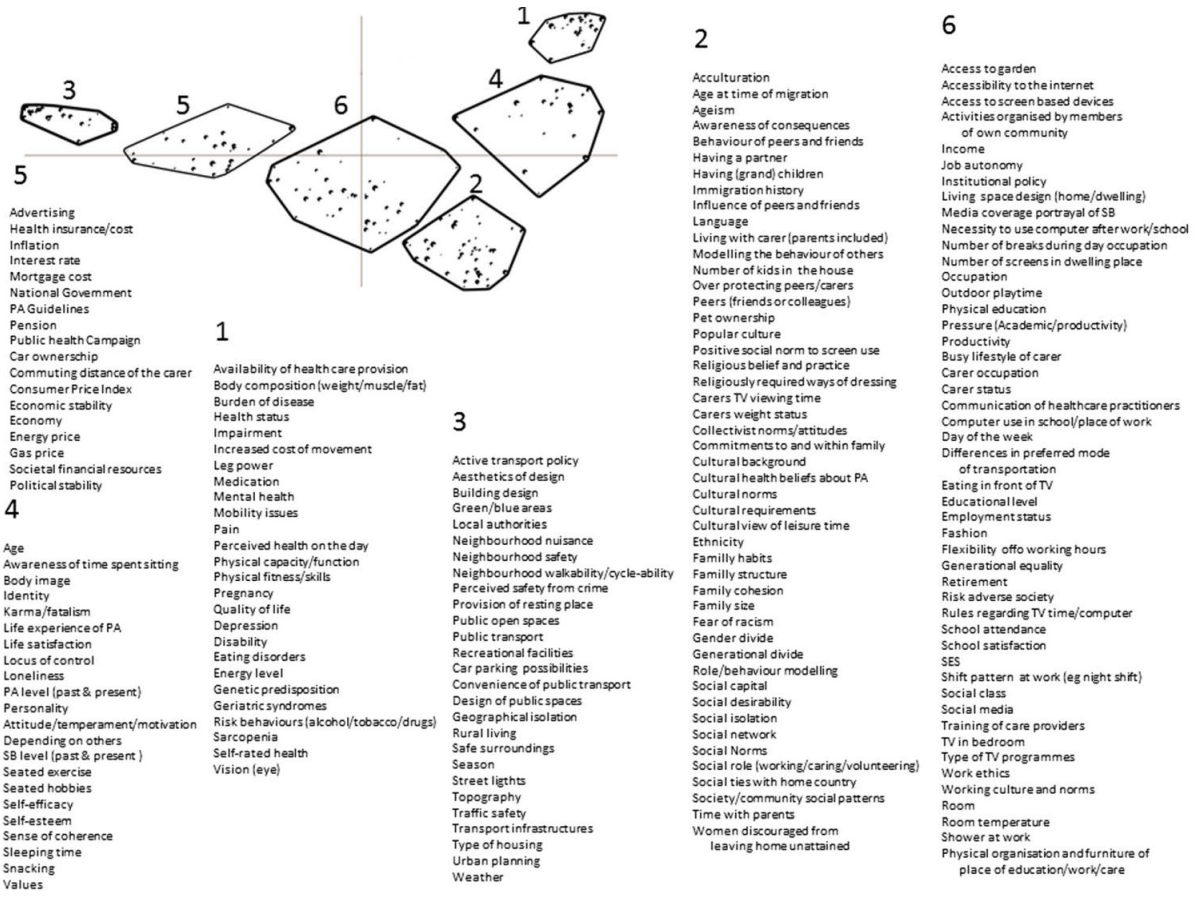


Figure 8 Concept map from the Systems of Sedentary Behaviours Framework with position (dots) and list of factors within the six clusters. Reproduced from Chastin et al., (2016) (112) in its original form under the terms of the Creative Commons Attribution 4.0 International License (http://creativecommons.org/licenses/by/4.0/)

The objectives of this study were to engage NAYP and other stakeholders in the first stage of intervention development, with the aim of:

1) Exploring the stakeholder groups' views about volume and frequency of movement and sedentary behaviour in NAYP, and the perceived importance of these behaviours,

2) Identifying barriers and facilitators of reducing sedentary behaviours and moving more from their perspectives.

3) Categorising the barriers and facilitators identified according to the determinants of sedentary behaviour identified in the SOS Framework

4.4 Methods

Ethical approval for this study was granted by the London - Camberwell St. Giles Research Ethics Committee (Ref: 20/LO/0011). Data collection took place between April and June 2021. Due to the significant social distancing restrictions in place in the UK at this time, the planned face to face co-design workshops were adapted to a virtual format. This change also enabled engagement from international participants and participants from any area of the UK.

4.4.1 Participants and recruitment

Recruitment processes, consent procedures, and inclusion and exclusion criteria followed the processes outlined in Chapter 3. Payments of £10 were offered to virtual co-design workshop / 1:1 interview participants to thank them for their contributions.

4.4.2 Sample size

The minimum sample size was four, as it was important that the four major stakeholder groups were represented [1) NAYP, 2) family members of NAYP, 3)

professionals who work with NAYP, 4) experts]. This small minimum number reflects that participants were being engaged as experts in this topic area, either professionally or via lived experience. There was no predefined maximum sample size. The number of workshops/interviews held and therefore overall sample size was limited by recruitment and availability of participants. Due to the anticipated challenges with recruitment, it was not realistic to aim to reach data saturation. All participants who responded to invitations to participate took part in a workshop or interview. Informed by the literature relating to focus group sizes, a minimum of two and maximum of 10 participants were invited to each workshop (248).

4.4.3 Data collection

Participant characteristics:

The following demographic information was collected online:

- Name
- age
- email address,
- stakeholder group,
- high level location (first three characters of postcode or town/country if outside the UK)
- gender,
- ethnicity,
- employment status
- diagnosis (if the participant had a disability).

4.4.4 Gateway questionnaire

Participants completed an online gateway questionnaire, which was specific to their stakeholder group. Questions for each stakeholder group are detailed in Appendix 5. The questionnaire was written specifically for this intervention co-design and is not validated. However, the questions for NAYP and family members were reviewed by parents attending a wheelchair clinic as part of public and patient involvement (PPI) work.

Two multiple choice questions in the gateway questionnaire for NAYP were designed to address objective 1 of this study (exploring the stakeholder groups' views about volume and frequency of movement and sedentary behaviour in NAYP). These questions were:

1) "How much of your day is spent sitting or lying still (from getting up to going to bed)?" Responses they could give for question one were:

- a little
- less than half the day
- more than half the day
- most of the day
- almost all of the day.

2) "What is the longest time you stay in one sitting or lying position for without moving whilst you are awake?". Responses for question two were:

- less than 15 minutes
- between 15 minutes and one hour
- one-two hours, three-four hours

- five-six hours
- more than seven hours.

4.4.5 Workshop groups

Workshops were arranged via e-mail. Separate virtual co-design workshops or 1:1 interviews were held for; 1) NAYP aged 12-15 years and 2) mixed groups of NAYP aged 16-25, with family members, professionals, experts and other interested members of the public wherever possible. This is because existing literature relating to conducting focus groups with children recommends participants are from within a narrow age range (255, 256).

4.4.6 Workshop structure

The workshops and interviews were held on Microsoft Teams.

Participants and facilitators used Jamboard throughout the workshops and interviews. Jamboard is a digital interactive whiteboard provided by google. It allowed the participants to work collaboratively on the whiteboard in real time. Brief information about Jamboard and the link to join it was emailed to participants prior to the workshops/interviews. To ensure participant's first responses to the questions posed were captured, they were asked not to use the link until they joined the workshop/interview. Participants were provided with a second Jamboard link to allow them to familiarise themselves with how to use it prior to the workshop/interview. A topic guide was produced on Jamboard to structure the workshops and interviews (Figure 9). Participants were encouraged to draw and use the post it notes function to record their thoughts. Participants were asked to put their initials bedside their

Jamboard contributions, so their identity was known during analysis, but all contributions on the Jamboard remained anonymous.

All workshops and interviews were led by a professional with experience of working with NAYP and their families and facilitating co-design workshops. For the requirements of the PhD it was important that the author led the workshops in order to gain experience of facilitating co-design workshops and to have the opportunity to reflect on their facilitation techniques. This introduced potential for the first author to influence the direction of conversations in the workshops/interviews as a result of their pre-existing experience and knowledge of the topic. Strategies employed to minimise this risk included avoiding contributing to the Jamboard wherever possible, by encouraging participants or those supporting them to do this. During workshops multiple participants spoke, providing time for other participants to think and draw/write. During interviews participants had less time to write/draw and found it easier for the facilitator to make notes whilst they were thinking and speaking. The author took care to validate what they wrote with the participant, ensuring it reflected their point accurately. Other strategies included the author making participants aware of the risk of the author unintentionally influencing the workshop and asking participants to challenge the author if they felt this was happening. The author encouraged participants to voice their thoughts if they had a different perspective to the direction discussions were going in. This created a psychologically safe environment where permission was given to speak openly and honestly, including respectfully challenging the facilitator or other participants. Lastly, the author endeavoured to use examples from previous research or other workshops /

interviews to probe and encourage more in-depth conversation, rather than using their own experiences or opinions.

A second facilitator was available in the workshops. Second facilitators were either other PhD candidates or a member of the research and innovation team at a community NHS Trust. Neither had experience of interacting with young people with disabilities or their parents. They could leave the workshop and support participants privately over the telephone / in a second online meeting if required and offer signposting to other services if needed. If a participant struggled with using the Jamboard, the second facilitator could write or draw something on their behalf. The second facilitator prompted participants to add their initials to contributions if they forgot. They took notes about their observations and what was said and summarised the contents of the workshop at the end when this was appropriate.

Sufficient workshops and interviews were arranged to allow all participants who chose to contribute via a virtual co-design workshop or 1:1 interview to do so wherever possible.

The use of the term “sedentary” was minimised in communication with participants. This was because it is difficult to explain its specific definition in a research context (3) and there was potential for participants to feel judged or labelled as lazy (246), reducing their psychological safety. Instead, communication focused on young people’s movement, for example, exploring what helps them to move more. Using this terminology was intended to reduce focus on moderate to vigorous activity and emphasise light physical activity, avoiding the terms exercise and physical activity. As people who use a wheelchair are frequently physically active in sitting; for example

self-propelling a wheelchair or cycling using an arm crank, they have given negative feedback about the term “sit less” being used in public health messaging intended to reduce sedentary time (43). Focusing on moving more rather than sitting less where possible avoided this issue. Participants were asked to think about what helped or hindered them form moving a little more, regularly throughout their day and to avoid focusing on opportunities for exercise activities.

Table 17 describes the structure of the groups and rationale for the structure.

Table 17 Structure of virtual co-design workshops / interviews and rationale.

Activity	**Rationale**
Ground rules reminder.	Participants accepted ground rules when providing digital consent, which may have been several weeks prior to attending the workshop/interview.
Introductions. Participants asked to avoid identifying where they lived / worked / attended school.	Participants aware of each other’s stakeholder group/experiences/motivation for participating.
Ice breaker activity. Participants asked to write or draw an object that represents something that makes them smile.	Allowed participants to share some information about themselves. This can help participants (particularly young people) to feel relaxed and to have contributed something to the group (257). Helped to introduce participants to using the Jamboard and the concept of focusing discussions on tangible objects.
Workshop/interview questions. 5 Jamboard screens (Figure 9).	Data collection.
Sharing a summary of data collected via crowdsourcing in a previous study. Participants asked whether the barriers / facilitators shared reflected their discussions. Asked to highlight barriers / facilitators that they did not agree with. Asked to identify barriers / facilitators that hadn’t been discussed in their conversations and share their thoughts about them.	Triangulation of crowdsource data. Helped to draw workshop/interview to a close.

Figure 9 shows an example of a completed Jamboard from a step one virtual co-design workshop.

Workshops and interviews were recorded and the videos and transcripts were downloaded at the end of the workshop. Transcripts were edited to create a verbatim version and anonymised.

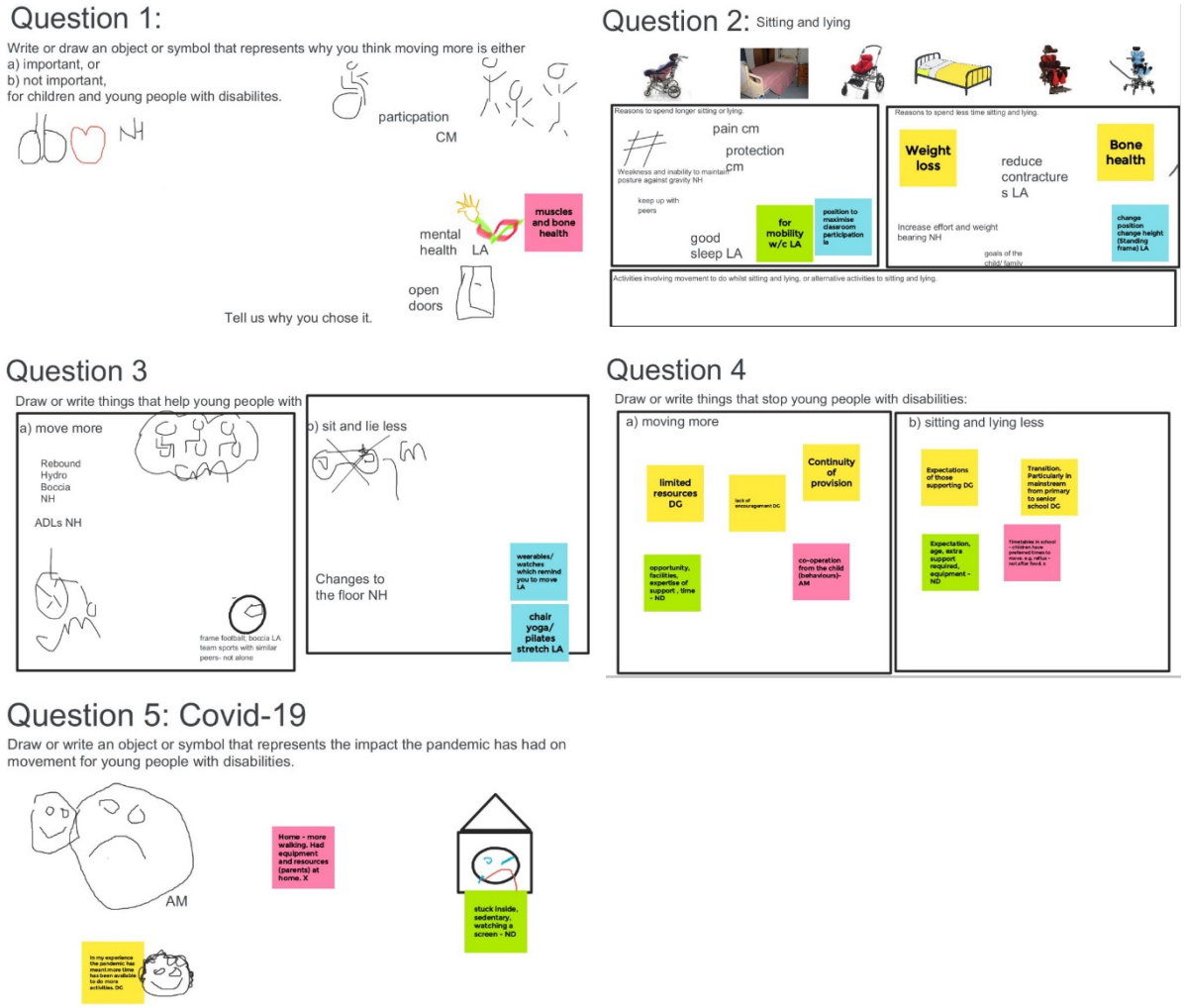


Figure 9 An example of a completed Jamboard from a step one virtual co-design workshop.

4.4.7 Analysis

An inductive thematic analysis of the workshop / interview transcripts was undertaken using the reflexive thematic analysis method described by Braun and Clarke (247), adopting an ontological position of realism. This means that reality exists independently of those who observe it, but the researcher can only view and interpret

it via the lens of individuals (including themselves) with differing vantage points, experiences and understanding (248). Analysis was undertaken in six steps; 1) two coders independently coding transcripts for the first three virtual co-design workshops using the reflexive thematic analysis method described by Braun and Clarke (247) 2) coders met to produce a list of consensus codes 3) a barriers and facilitators table was produced by the chief investigator (CI) by identifying barriers and facilitators from the consensus codes and grouping the barriers and facilitators into broader categories 4) reviewing and refining the barriers and facilitators table with coders 5) indexing of raw data according to refined barrier / facilitator table 6) categorising the final barriers / facilitators according to six determinants of sedentary behaviour identified in the SOS Framework (118).

4.4.7.1 Step one (coding the first three workshop transcripts):

Two independent coders coded each transcript then held a consensus meeting. The CI coded all three transcripts, as did one other coder. Other coders included a PPI representative and two Advanced Clinical Practitioner nurses. A code is the smallest unit of analysis which briefly describes a singular idea in the raw data (247). The codes are the building blocks of the rest of the analysis. Reading materials about the Braun and Clarke thematic analysis approach were provided for the coders, as were instructions and the opportunity to discuss coding the transcripts with the CI prior to commencing. Involving coders with differing backgrounds in the analysis was in keeping with the ontological position of realism, as they interpret the meaning of the data using their individual experiences.

The coders did not intend to reach a statistical level of inter-rater reliability, because this approach is not considered to be effective or appropriate for qualitative research (249). The coders acted as critical friends, acknowledging that multiple plausible interpretations exist, and challenging each other's interpretations to construct a defendable and plausible interpretation (249).

4.4.7.2 Step two (producing consensus codes and themes for the first three workshop transcripts):

Both coders met virtually to decide on consensus codes for each singular idea in the transcript which incorporated their differing vantage points.

4.4.7.3 Step three (producing a barriers / facilitators table):

The CI used the consensus codes to form a barriers and facilitators table[1]. Many of the consensus codes became a barrier or facilitator. Some codes were given a new barrier / facilitator title where the code itself was not an adequate description, or several codes were amalgamated to form a barrier / facilitator. Some broad categories of barriers / facilitators were proposed that the barriers / facilitators were grouped within.

4.4.7.4 Step four (reviewing and refining the barriers / facilitators table):

The table was shared with the independent coders prior to a virtual meeting in which the number of broad categories and barriers / facilitators were condensed into a manageable list; by reducing duplication and amalgamating similar barriers /

[1] This list was produced without reference to the barriers / facilitators table produced from the crowdsourcing data (Table 16) in order to preserve any differences in the data produced by the two different methods of data collection.

facilitators. The final table was reproduced as nodes (categories of barriers / facilitators) and sub nodes (barrier / facilitators) in NIVIVO, a qualitative data management software package (258).

4.4.7.5 Step five (indexing of raw data according to refined barrier / facilitator table)

The raw data was then indexed in NVIVO by labelling it using the refined barriers and facilitators (248). This ensured that each point made in the raw data "belonged" in one of the barriers or facilitators in the refined table and nothing had been omitted in the process of refining it. During indexing, a description of what each barrier / facilitator included was produced, so the meaning of each barrier / facilitator was clearly defined.

The remaining two workshops and four interview transcripts were not coded. They were analysed by labelling the data using the refined barrier / facilitator table. When a new idea was identified, the barrier / facilitator descriptions were expanded to incorporate it. Some barriers / facilitators needed to be renamed to incorporate this additional content in the code title. A small number of entirely new barriers / facilitators were added.

The Jamboards were reviewed and the barrier / facilitator descriptions were expanded to include this data also[2]. Each addition to the barrier / facilitator descriptions to incorporate Jamboard data was recorded in a reflexive diary.

[2] Barriers / facilitators and raw data from the crowdsource conversations were reviewed and barrier / facilitator descriptions were expanded to include this data. A document tracking where each crowdsource barrier / facilitator was represented in the table produced from the virtual workshops and interviews was produced. Each addition to the barrier / facilitator descriptions to incorporate crowdsource data was recorded in a reflexive diary.

When all of the workshop, interview and Jamboard data had been indexed, the barrier / facilitator table (including the descriptions) was sent to the three independent coders of the first three virtual workshops for comment. It was amended again based on their feedback to lead to a final version. Member reflection (249) was attempted with a young person and one of their parents who participated.

4.4.7.6 Step six (categorising the final barriers / facilitators according to six determinants of sedentary behaviour identified in the SOS Framework)

To understand the barriers and facilitators for reducing sedentary time identified by stakeholders in this study in the context of existing evidence, the barriers / facilitators were categorised according to six determinants of sedentary behaviour identified in the SOS Framework (118). Specifically; (1) physical health and wellbeing, (2) social and cultural context, (3) built and natural environment, (4) psychology and behaviour, (5) politics and economics and (6) institutional and home settings (118).

A concept map lists the factors included in each determinant (Figure 8) (118). This map was used to categorise the barriers and facilitators identified by stakeholders in this study according to the SOS Framework determinants of sedentary time.

Once categorised, the barriers / facilitators were fed back to the co-design participants via an online meeting, to provide further opportunity for feedback. To achieve this, a series of six slides, one for each of the six SOS Framework determinants of sedentary behaviour, was produced. These slides display speech bubbles reflecting the relevant barriers and facilitators from our data for each SOS

Framework determinant. Sharing these slides provided a second successful opportunity for member reflection[3] (249).

4.5 Results

Five virtual co-design workshops and four virtual interviews involving 22 people in total were held between April and June 2021. Each co-design workshop had three or four participants. Four young people chose to have virtual interviews, only one contributed as part of a group. No professionals, experts or family members chose to be interviewed. Most workshops contained a mixture of family members, professionals and experts. There was only one workshop in which there was no one with lived experience present.

4.5.1 Participant characteristics

Twenty-two participants contributed (5 young people, five family members, 11 professionals, one expert). Participant characteristics are shown in Table 18. More professionals participated than any other stakeholder group. The majority of participants were female and white-British, however there was considerable diversity in relation to gender and ethnicity amongst the participants (Table 18). The expert was a researcher whose area of interest was sedentary behaviour in people who have had a stroke. The researcher also had experience in co-designing behaviour change interventions. One young person who was interviewed used an eye gaze communication aid to communicate with the support of a carer.

[3] Sharing of the slides for member reflection was undertaken at the beginning of the step two workshops (chapter 5).

Table 18 Step one Participant characteristics for step one virtual co-design workshops and interviews

Stakeholder group / characteristic	**Number of participants (%)**	**Age in years: mean, median, range**	**Gender: Number (%)**	**Ethnicity: Number (%)**	**Employment status / Role: Number (%)**
Young person aged 12-25 who is non-ambulant.	5 (23%)	18.2, 17, 15-22	Female: 4 (80%) Male: 1 (20%)	White – British: 5 (100%)	School/college/sixth form student: 3 (60%) University student: 1 (20%) At home most days (not working): 1 (20%)
Family members of non-ambulant children and young people	5 (23%)	48, 53, 36-54	Female: 4 (80%) Male: 1 (20%)	White – British: 3 (60%) White – Irish: 1 (20%) Chinese: 1 (20%)	At home most days (not working): 3 (60%) Working full time 1 (20%) Working part time: 1 (20%)
Health and education professionals	11 (50%)	41, 42, 27-60	Female: 9 (82%) Male: 2 (18%)	White – British: 9 (82%) Black or Black British – African: 1 (9%) Mixed – Any other background: 1 (9%)	Working full time: 8 (73%) Working part time: 3 (27%)
Experts – Academics / industry experts interested in disability, sedentary time, digital health.	1 (4%)	45, 45, 45	Female: 1 (100%)	White – British: 1 (100%)	Working full time: 1 (100%)
Total	22 (100%)	38, 39, 15-60	Female: 18 (82%) Male: 4 (18%)	White – British: 18 (82%) White – Irish: 1 (4.5%) Chinese: 1 (4.5%) Black or Black British – African: 1 (4.5%) Mixed – Any other background: 1 (4.5%)	Working full time: 10 (45.5%) Working part time: 4 (18%) At home most days (not working): 4 (18%) School/college/sixth form student: 3 (14%) University student: 1 (4.5%)

The areas of UK participants lived in are listed below. Rural and urban environments were represented.

- Birmingham
- Cambridge
- Chesterfield
- Edinburgh
- Fleetwood
- Lancaster
- Leeds
- London
- Newcastle-Under-Lyme
- Oxfordshire
- Portsmouth
- Peterborough
- Reading
- Redditch
- Rotherham
- Sheffield
- Sutton Coldfield
- Warrington
- Wells
- Worcester

4.5.2 Gateway questionnaire data.

Table 19, Table 20, Table 21, Table 22, Table 23 and Table 24 summarise the gateway questionnaire data for each stakeholder group. The young people who participated had a range of diagnoses, with CP being the most common (Table 19). They all lived at home with their parents or parents and siblings and spent almost all or most of the day sitting or lying. A range of differing activities involving movement

and activities done in lying and sitting were reported, showing there was considerable variation between participants. Their functional abilities also varied (Table 20). Young person five was able to do most of the activities listed in the survey, whereas there was only a small number that young person four was able to do. Young person two and young person 3's responses indicated that they had good upper limb function.

Most family members who participated had a family member with CP. The only alternative diagnosis reported was FOXG1 syndrome. All the family members were parents of the NAYP and lived with them. Their children were aged seven – 17 years and all but one of them had a learning disability. However, only one of their children was unable to communicate their needs. All the parents helped their child to move and mentioned their child using equipment such as standing frames or walkers when asked about activities that involve movement (Table 21). The functional abilities of their children were variable (Table 22).

Table 19 Gateway questionnaire responses: young people who are non-ambulant, virtual co-design workshops and 1:1 interviews.

Participant	Diagnosis	Number of people in household (including participant)	Other members of household	Proportion of a typical day spent lying / sitting	Uninterrupted sitting / lying	Activities involving movement	Activity duration (movement)	Activities done in sitting and lying	Activity duration (sitting and lying)
Young person 1	CP / Fibromyalgia / Osteoarthritis	3	A parent A sibling	Almost all of the day	More than 7 hours. Lying in hospital bed 8-10 hours. Sitting in manual wheelchair 1-3 hours	Changing position in bed using bed control	Movement time not specified	Playing Video Games	8-12 hours
						Propelling in manual wheelchair	30 mins	Cuddle with cat	3-9 hours
						Getting changed	30 mins – 1 hours	Read Comics / Manga Books	1-2 hours
						Showering	1 hour	On computer (typing, looking things up, YouTube, Facebook)	1-4 hours

Participant	Diagnosis	Number of people in household (including participant)	Other members of household	Proportion of a typical day spent lying / sitting	Uninterrupted sitting / lying	Activities involving movement	Activity duration (movement)	Activities done in sitting and lying	Activity duration (sitting and lying)
						Eating	2 hours	Watch Cartoons / Anime	2-8 hours
						Using the toilet	30 mins – 1 hour		
Young person 2	Spastic Quadriplegic cerebral palsy	4	Two parents brother	Most of the day	1-2 hours	Using a standing frame	1 hour x 3 times a week	Craft activities	2-4 hours a day
						Toileting - standing transfers	6-8 times a day	School work	2-4 hours a day
						Using hands to do crafts	Every afternoon	Watching Netflix	2 hours a week
						Using hands to cycle moto-med hand cycle	Once a month	Video calling friends	2 hours a night
						Physiotherapy programme	Once a week	Listening to a book	1 hour a night
						Wheelchair dancing	1 hour per week		
						School PE zoom	15 minutes per week		
						Assisted to wash	Everyday		
						Assisted to shower	Twice a week		

Participant	Diagnosis	Number of people in household (including participant)	Other members of household	Proportion of a typical day spent lying / sitting	Uninterrupted sitting / lying	Activities involving movement	Activity duration (movement)	Activities done in sitting and lying	Activity duration (sitting and lying)
Young person 3	Undiagnosed	3	Two parents	Almost all of the day	More than 7 hours	Self propelling wheelchair	2 hours a day	University work on laptop	5 hours a day
						Getting dressed and undressed	30 mins a day		
Young person 4	Cerebral palsy	3	Two parents Sister	Almost all of the day	5-6 hours	Innowalk	3 hours a week	Talking to family and friends	
						Physio	1 hour a week	Watching TV	
						Standing frame	1 hour a week	School lessons	
						Swimming	4 hours a week in the summer		
Young person 5	Acquired brain injury	2	A parent	Most of the day	1-2 hours	Yoga	45 mins	On tablet (games/Net flix)	30 mins-2 hours
						Swimming	30-45 mins	School classes	45 mins-1.5 hours
						Physiotherapy at school (multi gym / race runner / hydrotherapy / standing frame / soft play /	45 mins	Meals	30 mins-1 hour twice a day

Participant	Diagnosis	Number of people in household (including participant)	Other members of household	Proportion of a typical day spent lying / sitting	Uninterrupted sitting / lying	Activities involving movement	Activity duration (movement)	Activities done in sitting and lying	Activity duration (sitting and lying)
						trampoline / fit ball / motomed)			
						Sport at school (boccia / table cricket / polybat)	45 mins – 1.5 hours		
						NINO segway wheelchair	As required		
						shuffle on one leg around short distances	As required		

Table 20 Functional abilities of young people who are non-ambulant in virtual co-design workshops and 1:1 interviews.

	Ability to do task (Yes, No, Unsure)				
Participant	**Young Person 1**	**Young person 2**	**Young person 3**	**Young person 4**	**Young person 5**
Roll over	Unsure	No	No	Yes	Yes
Independent lye to sit	Unsure	No	Yes	No	Yes
Floor sit, no support	No	No	Yes	No	Yes
Sit on edge of bed, no support	Unsure	No	Yes	No	Yes
Crawl	No	No	No	No	Yes
Kneel, no support	Unsure	No	No	No	Yes
Kneel with support / something to hold	Yes	No	Yes	No	Yes
Use a tablet	Yes	Yes	Yes	No	Yes
Bat balloon	Unsure	Yes	Yes	No	Yes
Throw ball	Yes	Yes	Yes	No	Yes
Shake tambo-urine	Yes	Yes	Yes	No	Yes
Hold basketball in both hands	Yes	Yes	Yes	No	No
Use a standing frame	Unsure	Yes	No	No	Yes
Use a body support walker	No	No	No	Yes	No
Steer a power chair	Yes	Yes	Yes	Unsure	Yes
Self-propel a wheelchair	No	Yes	Yes	No	No

Table 21 Gateway questionnaire responses: Family members, virtual co-design workshops and 1:1 interviews

Participant	Family member's diagnosis	Relationship to family member with disabilities	Do you live with your family member with disabilities?	Age of family member with disabilities	Does your family member have learning difficulties?	Can your family member tell you what they want?	Do you help your family member to spend time moving?	How do you help your family member to move? What do you do or say?	Activities your family member does that involve movement	Activities your family member does when sitting and lying
Parent 1	FOXG1 syndrome	Parent	Yes	11	Yes	No	Yes	Physically move his legs/arms to move them/to help him roll or get onto his stomach.	He has some purposeful hand movements. He can roll onto his side and sometimes onto his front. He uses a standing frame at school	Plays musical instruments. Uses his hands to explore sensory items. Watches sensory lights and listens to music.
Parent 2	Spastic quadriplegic CP	Parent	Yes	17	Yes	Yes	Yes	Encouraging her to stretch as she is being washed	Self-propelling a wheelchair. Using a standing frame.	Arts and crafts. Watching TV.

Participant	Family member's diagnosis	Relationship to family member with disabilities	Do you live with your family member with disabilities?	Age of family member with disabilities	Does your family member have learning difficulties?	Can your family member tell you what they want?	Do you help your family member to spend time moving?	How do you help your family member to move? What do you do or say?	Activities your family member does that involve movement	Activities your family member does when sitting and lying
								and stretched. Putting her in standing frame. Encouraging her to self-propel her wheelchair	Doing physiotherapy exercises. Dressing, washing. Arts and crafts	
Parent 3	CP	Parent	Yes	17	Yes	Yes	Yes	We use hoist to move. Use sign or symbol	Using Standing frame. Innowalk. Power wheelchair.	Playing
Parent 4	CP	Parent	Yes	15	Yes	Yes	Yes	Help with all activities	Exercise in an innowalk. Attend physiotherapy	Involuntary movement.

Participant	Family member's diagnosis	Relationship to family member with disabilities	Do you live with your family member with disabilities?	Age of family member with disabilities	Does your family member have learning difficulties?	Can your family member tell you what they want?	Do you help your family member to spend time moving?	How do you help your family member to move? What do you do or say?	Activities your family member does that involve movement	Activities your family member does when sitting and lying
									sessions. Swim. Non voluntary movement.	
Parent 5	CP	Parent	Yes	7	No	Yes	Yes	"Can you help mummy?"	Standing frame. Transfer from bed to commode. Rolling around the floor. Kneeling to high kneeling Walking in walker a short distance.	IPad and computer

Table 22 Functional abilities of non-ambulant young people whose family members participated, virtual co-design workshops and 1:1 interviews

	Family members ability to do task (Yes, No, Unsure)				
Participant	**Parent 1**	**Parent 2**	**Parent 3**	**Parent 4**	**Parent 5**
Roll over	Yes	No	No	Yes	Yes
Independent lye to sit	No	No	No	No	No
Floor sit, no support	No	No	No	No	Yes
Sit on edge of bed, no support	No	No	No	No	Yes
Crawl	No	No	No	No	No
Kneel, no support	No	No	No	No	Yes
Kneel with support / something to hold	No	No	No	No	Yes
Use a tablet	Yes	Yes	No	No	Yes
Bat balloon	Yes	Yes	No	No	Yes
Throw ball	No	Yes	No	No	Yes
Shake tambourine	No	Yes	No	No	Yes
Hold a basketball in both hands	No	Yes	No	No	No
Use a standing frame	Yes	Yes	Yes	No	Yes
Use a body support walker	Unsure	No	Unsure	Yes	Yes
Steer a power chair	No	Yes	Unsure	Unsure	Yes
Self-propel a wheelchair	No	Yes	No	No	No

Table 23 Gateway questionnaire responses: Professionals, virtual co-design workshops and 1:1 interviews

Participant	Job role	Frequency of working with NAYP	Number of years working with young people with physical disabilities	Do you measure / monitor the amount of time NAYP spend sitting or lying still?	How do you measure / monitor amount of time NAYP spend sitting or lying still?
Professional 1	Paediatric physiotherapist	Daily	6 - 10 years	Yes	Promoting 24-hour positioning and changes in position using time in each postural set
Professional 2	Physiotherapist	Daily	2-5 years	No	
Professional 3	Head of Physical Education (Teacher)	Daily	11 – 20 years	No	
Professional 4	Advanced physiotherapist	Daily	11 – 20 years	No	
Professional 5	Clinical specialist physiotherapist neurosciences	Missing data	11 – 20 years	Yes	Verbal summary of activity. Not formally measured
Professional 6	Support worker for people with disabilities	Daily	2-5 years	Not relevant	
Professional 7	Paediatric physiotherapist	Daily	6 - 10 years	Yes	Liaison with parents and children and young people
Professional 8	Paediatric physiotherapist	Daily	20 years or more	No	
Professional 9	Paediatric occupational therapist	Daily	11 – 20 years	Yes	We monitor how long as part of our 24-hour postural plans
Professional 10	Physiotherapist - advanced practitioner	Daily	20 years or more	No	
Name	Job role	Frequency of working with NAYP	Number of years working with young	Do you measure / monitor the amount	How do you measure / monitor amount of time

Participant	Job role	Frequency of working with NAYP	Number of years working with young people with physical disabilities	Do you measure / monitor the amount of time NAYP spend sitting or lying still?	How do you measure / monitor amount of time NAYP spend sitting or lying still?
			people with physical disabilities	of time NAYP spend sitting or lying still?	NAYP spend sitting or lying still?
Professional 11	Advanced physiotherapist, paediatric pain management	Weekly	11 – 20 years	No	
Totals	Physiotherapist: Occupational therapist: Teacher: Support worker: 1 Total: 11	Daily: 14 Weekly: 3 Missing data: 1	2-5 years: 5 6 - 10 years: 3 11 – 20 years: 6 20 years or more: 4	Yes: 8 No: 9 Not relevant: 1	Monitor as part of 24 hour postural care: 4 Verbal feedback: 4 Time as percentage of day: 1

Table 24 Gateway questionnaire responses: Experts, virtual co-design workshops and 1:1 interviews

Participant	Job role	How does your work relate to this study?	Number of years working in this field	Do you measure / monitor the amount of time NAYP spend sitting or lying still?	How do you measure / monitor amount of time NAYP spend sitting or lying still?
Expert	Researcher	Sedentary behaviour research in the context of stroke; general health behaviour research; use codesign to develop interventions for health behaviour change and improving long-term health.	6 - 10 years	No	

4.5.3 Workshop and interview objectives

4.5.3.1 Objective 1: Do participants see movement as important for this group of young people and what do they think about how much or how frequently they move?

Table 19 shows that three young people were sitting or lying still for almost all of the day and two for most of the day. Two young people reported that they had more than seven hours of uninterrupted sitting / lying time per day, one reported five-six hours and two reported one-two hours. Family members, professionals and experts were not asked to estimate NAYP's volume / frequency of movement in the gateway quesitonniare as it would be difficult for them to have a detailed picture of what happens throughout the young person's day, for example when they are at school or work.

Activity one on the Jamboard in the virtual workshops and interviews was to "write or draw an object or symbol that represents why you think moving more is either a) important or b) not important for children and young people with disabilities."

All participants thought it was important. Things they drew / wrote about why included:

"To make people happy" Parent three

"Important – independence / happy" Professional one

"It gives them a chance to take control of their bodies" Parent two

Drawing: Heart and lungs. Professional one

"Participation" Professional four

“Mental Health” Professional five

“Sensory regulation” Professional six

“Fun” Professional eight

“Avoid further surgery” Parent five

“If (name) was on her bed and couldn’t move she would go crazy” Young Person two (written on Young Person two’s behalf by carer).

“Being outdoors” Young person four

“Meet friends” Young person four

4.5.3.2 Objective 2: Barriers and Facilitators

Fifty-two barriers and 35 facilitators for reducing sedentary behaviour were identified from the inductive thematic analysis of data collected in the virtual workshops and interveiws (Table 25). Bold text indicates a category of barriers / facilitators, or a barrier / facilitator that had no additional barriers / facilitators nested within it. Indented barriers / facilitators indicate the level of nesting within a broader barrier / facilitator. The descriptions of the data included in each barrier / facilitator is in Appendix 7.

Table 25 Barriers and facilitators of sedentary behaviour in non-ambulant young people identified in virtual workshops and interviews.

Barriers	**Facilitators**
Attitudes of others	**Attitudes of others**
Family attitudes and routines in relation to movement	Family attitudes and routines in relation to movement
Family, staff, carers not feeling moving is important	Understanding benefits of moving and risks associated with prolonged sitting

Barriers	Facilitators
Professionals' beliefs, attitudes, behaviour	Professionals' beliefs, attitudes, behaviours
Social perceptions of disability	
Cultural attitudes to movement	
Availability of resources	**Availability of resources**
Access to organised activities	Access to activities and resources that suit the individual's needs
Access to therapy	Therapies
Affordability and funding	Funding
Inappropriate facilities or housing	Facilities for wheelchair users
Becoming socially isolated	
Being independent	**Being independent**
Moving less to achieve greater independence or participation	**Being outdoors**
Boring and / or repetitive activities	**Competition and individual challenge**
Covid	**Covid**
Advise for maintaining physical activity not appropriate for non ambulant young people	Being at home during lockdown
Demands on parents	Virtual health appointments
Deterioration in physical health and wellbeing	
Disability events and activities closed or cancelled	
Increased screen time and virtual services	
Inequality increased	
Not attending school or school resources limited	
Prolonged reduced social interaction	
Reduced access to equipment	
Reduced access to healthcare services	
Reduced movement	
Shielding or limited opportunities to go out	
Education and Healthcare Plans	
Individual's characteristics, feelings and experiences	**Individual's characteristics, feelings and experiences**
Age	Age
Cognitive capability	Physical abilities
Dislike of being different	Good medical management of condition
Experiences of prolonged sitting and lying	Involuntary movements
Negative emotions when unable to move	Resilience
Feeling trapped	Young person wants to move
Not feeling able to express an opinion	
Reduced health and wellbeing	Improvements to health and wellbeing
Limited Physical Capability	Improving motor skills through movement
Young person doesn't want to move or chooses to sit or lye	Improving mental health

Barriers	Facilitators
Not succeeding	
Knowing how to facilitate more movement	**Making movement enjoyable**
Multiple demands on families	Participating in fun, exciting, motivating activities
	Music
	Pets
	Screen time that promotes activity
Not having support from others to move	**Having support from others to move**
Peer support	Peer support
Not knowing about appropriate local facilities	
Planning for movement	**Planning for movement**
Accessing appropriate equipment	Accessing appropriate equipment
People needed	People needed
Remembering	Movement integrated into daily routines
Safety	Safety
Space	Space
Time	Time
Transport	Transport
Reasons to be in sitting or lying	
Screen time	
Transition Points	**Transition points**

To show the process of identifying these barriers and facilitators from the data, Table 26 shows an example for the barriers / facilitators in the “Attitudes of others” category. The first column is the barrier / facilitator itself, the second is the description of the barrier / facilitator and the third is quotes from the data from which it was derived.

Table 26 An example of how barriers / facilitators of sedentary behaviour in non-ambulant young people were identified from the raw data for the "Attitudes of others" category.

Barrier / Facilitator	**Description**	**Supporting Quotes**
Barrier: Cultural attitudes to movement	Some social groups particularly those for non-Caucasian background may struggle to participate in physical activities because they do not have a role model. This is particularly true for girls and young women. Young people don't have role models who are physically active in their families. Professionals should recommend activities that fit individual's cultures and lifestyles. Teenage girls may wish to avoid activities that involve physical contact with others.	*"I think some of the children, young people, from some of the Asian backgrounds, it just, particularly for girls, but some of both, is like being active and joining groups is, like activity groups, is just not something that they seem to do as part of their family and they maybe don't have the role models in their family who are being as active. I mean, I don t know, maybe that's a generalization, but certainly children with spina bifida from the, sort of Asian communities, I find are less active generally."* Professional 5 *"In some cultures actually being overweight, we struggle with that, in that families think that's a good thing. Um, we've got some Slovakian families where, actually it's a status to have their, you know, to be overweight, and it's just something that is mind boggling to us because, you know, it really impacts on the child's disability, but its ingrained in them that this is, its OK um, and that's really difficult"* Professional 4 *"Teenage girls don't necessarily want to do a team, something they just want to do, you know, they might really enjoy watching, but they also might prefer to do something more like pilates you know, where they're not having to be…..* *..touched by the people or I don't know, it depends."* Professional 5
Barrier: Family attitudes and routines in relation to movement	Prioritising academic learning. Parents don't encourage / support physical activity. Safety concerns if participating in sport. Believing children can't / shouldn't do PE. Feeling physio is the only appropriate physical activity. Being protective. Families finding it easier if child doesn't move. Family don't expect disabled children to become independently mobile.	*"One pupil that springs to mind, someone who was a brilliant athlete when he was with me, an he had the opportunity to take part in the disability athletics events and things like that. And then he went to mainstream because that was what his parents thought was the right thing for him academically, should we say? And when I spoke to him and caught up with him, he didn't do any PE again and he didn't take part in any of the events that he used to do when he was with us, and which is a real shame because he was, he was an athlete."* Professional 3 *"…he's got to year three and had never done PE, never picked up like a ball and kicked it in his life and stuff like that. And I asked the parent why this was, and she was like 'well he gets physio, that's physical education, he gets physio.' Well yeah yeah no that is agreed, he's moving. But it's not the same, and they were like, she was like 'Oh well, I got told that if I'm if I got him involved in sport he'd injure himself even more'."* Young person 3

Barrier / Facilitator	Description	Supporting Quotes
	Families feel it's a battle fighting for services and equipment. Many factors of home situations influence engagement with movement. Lack of physically active role models in family.	*"We have some parents that probably aren't so encouraging or supportive of their children and, and make, you know, helping them with opportunities and doing things…"* Professional 3 *"…that's a very sad thing to say about it all, but obviously, having two young children myself, as soon as they started to move, they became a lot harder to deal with…but actually, uh, as they got, and and I am someone that encourages them to move a lot and I don't want them sat still or anything like that, but actually, if you've got a big family or you've got a number of children and you've got one that is a bit older, but that, you know, has movement difficulties or has eating difficulties and needs extra support, actually sometimes it's easier to have them in one place, than it is actually encouraging them to move around, and move."* Professional 3 *"There's that nurturing aspect as well, and protecting your child and all those other psychological things that go with supporting children, and yeah, so I'm sure there are children who can do more"* Professional 1 *"One of the physios we worked with once said that she was handed a 3, 4 year old child, and the person handed it to her said, "here's the baby" and it was almost like that person's expectation of the child was that it wasn't going to grow up to be moving. She expected it to be a baby, so she hadn't…helped it to be moved, to move and and grow from that point and she was quite surprised at that."* Parent 2 *"…they maybe don't have the role models in their family who are being as active."* Professional 5
Barrier: Family, staff, carers not feeling moving is important	Lack of education / awareness about benefits and risks of not moving. Miscommunication / missed opportunities to share information from professionals. Physical aspects of healthcare not prioritised, focus on medical / equipment needs. School staff not engaging with training about movement opportunities. Parents don't get feedback from school about what movement child has done. Helping children to move	*"The physio tried to get somebody from something like CP Sport to come in and talk to the PE teachers and the PE teachers didn't turn up to the meeting."* Parent 2 *"Where they were now living in supported living, it was quite sad to see that you know they were even struggling to get into the gym for 10 minutes because there just wasn t any funding or time from the physiotherapist to be able to help them with any movement. So yeah, that was that. So I think those continuity of health packages need to involve a lot more physical activity than just focusing on, you know, the the medical sort of side."* Professional 2 *"Family tend to orientate to, kind of like, worry about things like the equipment, and you know, all the other things that are peripheral, but actually, sometimes the child themselves gets forgotten, in terms of their, sort of activity and health and what that can provide."* Professional 1 *"They don't seem to want to get, you know, do the timetable like you say and tell me what he's done. yeah so…* *(Facilitator: Do you think it would affect what was done if… staff are aware that you had that tool? Or*

Barrier / Facilitator	Description	Supporting Quotes
	needs to be compulsory for school staff, not done if it's optional. Lack of recognition that learning is influenced by physical comfort. “Move more not move less” ethos needed in schools. EHCP movement section or physical activity section does not contain enough information.	*not?)* *Yeah, because then they would be sort of pressured into doing it in a way.* *And it would be on the forefront of their mind and it would be like “oh, we've got to show that we've done this today,” at the moment, that doesn't happen.* *It's more of a choice thing. It's their choice, not my choice. It's their choice what they do in school.”* Parent 5 *“If it's optional, which it sounds like it is now, then they'll opt not to do it, because it's the easy option. It has to become non optional, and then they have to do something about it. So you-you do have to keep battling with the wretched bloody EHCP thing”* Parent 4 *“It's all about a whole change of mindset and a recognition that physical health and well-being and comfort leads to increased learning.”* Professional 8 *“if you could just get a physio to go in and point these things out and get that into the ethos of the school, that it is a move more school, rather than a move less school, then that makes a difference. And it's not. It's not an uncommon….”* Professional 8 *Cont…“…It's all coming down, I think, to individual teachers. I think it's coming down to individual teachers, yeah?”* Parent 5 *Cont…“But it's not uncommon, it's widespread. (Facilitator: No, it's not. It's not uncommon. It's really familiar to me as well. What you're saying, yeah, yeah)* *It's widespread. And. And you're right that the EHCP’s, we're told not to put needs 12 hours of physio or something that, because perhaps one day I might have to go in and I might be there for three hours sorting out a standing frame, and then you would lose three hours out of your 12 hours sort of thing. So we were told to put in ‘would benefit from say, you know, sessions every half term’ or something like that”* Professional 8
Barrier: Professionals beliefs, attitudes, behaviour	Beliefs and perceptions of healthcare professionals. e.g. prognosis of individuals physical abilities, needing to diagnose / categorise individuals into boxes or groups for accessing services and support. Difficult if you don't fit a box. Impractical advice /	*“We have some children that we know we're not going to get them up and out. There's some evidence that if they haven't stood by the time they're six, it's just not going to happen.”* Professional 4 *“I hate the medical model of having to fit people into a box. That's just no, it's wrong. But on the other hand, I've always wanted to just tick a box so I can get a support network behind me. Because growing up without that support, especially when you hit teenage years, was so hard when all of my friends who had said like had CP and they have muscular dystrophy, and obviously their support networks out there for them. I didn't even fit, the charity ‘SWAN’ and I don't even fit in there because it's this, SWAN is for genetic conditions without a name, and mine's not genetic.”* Young person 3

Barrier / Facilitator	Description	Supporting Quotes
	solutions from professionals. Sugar coating information for parents / young people to protect them. Professionals hope parents will google to understand risks. A professional participant previously discouraged floor time without postural support but is revaluating due to this study as this limits children's opportunities to move.	*"I feel that that transition between paediatric to adult, it isn't there. Um, and the language, so when I was like, oh, I transitioned early for urology, but for like neurology when I was 16/17/18, they were still sugarcoating stuff like I was 5. And then all of a sudden, when you're 18, so I was 18 on the 2nd of July and on the 5th of July, I had major surgery as an adult. And all of a sudden you're dropped into the adult world of adult language. Of them, not sugar coating. So it's kinda like, I feel that paediatrics actually is, they don't fully prepare you in that transition period."* Young person 3 *"parents they do get sugarcoated that actually their child, their child is disabled. Their child can't do sport. They can't do any movement of any kind apart from physio. And I feel doctors don't really tell them, but actually if you get them into sport now or any form of that type of physical education, they might not be the next, Jonnie Peacock or Hannah Cockroft…… They've got this disabled child, they don't want to put them in harm's way, they want to bubble wrap them. But on the other side of the coin if you get your child, your child is like any other child and he's just in a chair or it just has an extra difficulty. Doesn't mean it can't do what friends are doing."* Young person 3 *"They (healthcare professionals) leave it for parents to go google. Parents aren't going to go Google, have not got time to go and put it in google. Like activity alliance or disability alliance, like, they've not got time for that. They've got lives to lead and if they've got a disabled child it's 10 times harder"* Young person 3
Barrier: Social perceptions of disability	Perception of disability and whether parents or healthcare professionals subscribe to the medical or social model of disability. Negative connotations and labels which are associated with disabled people and physical activity. Lack of understanding of disability e.g. wheelchair users don't move / can't leave chair / organized club or group needed. Stigma. Can't do sport / PE. Low expectations from supporting	*"even like when I'm in hospital they put my chair, they store the chair on like the other side of the room and it's like, well now I'm bedbound. Now I'm at the mercy of you lot because you put my chair over there. Otherwise I would be fully independent."* Young person 3 *"Parent: I think it would help for society to change its limitations on…'Cause I think society is a massive block to people moving more.* *Young person: Yeah.* *Parent: I mean, that's just my personal view, but if you agree I can put it in.* *Young person: Yeah.* *Parent: What should we call that? Society's barriers? maybe?* *Young person: Yeah.* *(Facilitator: Yeah. That's good. So (name), what kind of things do you think society could have a different attitude to that would help you, what things would help?)*

Barrier / Facilitator	Description	Supporting Quotes
	adults. Society's barriers to movement for disabled people. Lack of friendliness / disgust from able-bodied people towards disabled people. Young people adopt the perspectives of those around them. Academic work more important than moving. Friends and family of parents who care for a disabled child don't understand what it's like to be a parent to a disabled child. Parents can feel isolated. Less media exposure for disability resources / restrictions on what is shown. Being "wheeled out" for ofsted inspections.	*Young person: Well, I would say that....Sometimes they—a lot of the time they don't put much, like, I wanna say clubs on."* Young person 5 and their parent who was present to support her but not a study participant *"It feels demoralizing, that there can be opportunities around, but then you will find that opportunity is bar coded to this post code. So you will qualify for something, and everyone will go, 'this exists in this area', and then you look into it and it does exist in this area, but only for this small segment of people in this area or with this condition, or this way round of doing it. And you've looked into it and then you end up in arguments with the people who, well not arguments but disagreements, with the people who maybe recommended it, or did, who were trying to help because they know this is open and people can do this and then you're trying to explain but it doesn t apply to me for these reasons and people just don t see that. Because they haven't experienced the situation you're sat in or are in. They don't see the complete difference between this and that, and why that applies or why that doesn t."* Young person 1 *"we all know what we're told, don't we, and unless you're given a chance to see things in a different way, no matter who you are, you'll only ever have that, that point of view. Unless somebody gives you a different one."* Parent 2 *"often they might even get pushed more to academic stuff, which you know, is, is really difficult if they really want to do PE for example, as a GCSE … it's often like schools think, 'oh you couldn't possibly do that', you know, 'you've got a disability'"* Professional 4 *"my son's 25 and he doesn't want to be seen on a trike."* Parent 2 *"it's almost like, oh, we haven't got time for all that. We haven't got time. It's always been this way that the pupils with disabilities don't take part in sport"* Parent 2 *"I think there is sort of this notion that movement isn't as important as getting your studies done"* Expert 1 *"Anyone that does wheelchair sports will know you need a sports chair, because otherwise your normal chair is going to get absolutely destroyed. Of course, there's a limited number of them, and people sort of struggle saying no, if …. there's, the girl in a wheelchair… and that girl in the wheelchair has a physically able-bodied brother, but he doesn't have any disabilities or issues. They will struggle saying no to the brother because the girl can do it. So the girl will get a physical chair and so will he. So then you've got physically disabled person in a chair, will end up having to be in their own chair, instead of a sports chair, and of course, then they end up on the floor because it's not a sports chair*

Barrier / Facilitator	Description	Supporting Quotes
		and it wasn't meant to do that, and in worst case scenario, they've broke their day chair." Young person 1 *"Parent: Sometimes just people don't include you 'cause there's that..they look at you and you can see they're thinking something not very positive* *Young person: Yeah I got that all the time.* *Parent: So, a lack of …* *Young person: Friendliness.* *Parent: Yeah….You know, when (name) was in mainstream she said, I don't I don't want to remind you of this because it's a bit painful, but (name) said she, you know, 'I can see a glimmer of disgust coming across people's face'. You know, there is a sort of..* *Young person: Like 'eurgh'.* *Parent: Yeah, so I'm raising it as a sort of real thing that maybe more mainstream people have to overcome is, you know, maybe it's looking at someone's body and seeing something different. Or you know, maybe somebody's, you know, 'cause we've been to (name of charity for disability) before where maybe there's someone dribbling and you know, we would just think, 'oh well that's just someone dribbling'. But someone who's not used to that would just be 'eurgh'. So you know, I'm, I'm just being honest that there's there's a cer—there's quite a lot of barriers."* Young person 5 and their parent who was present to support her but not a study participant *"None of our friends have really, disabled children. They don't understand and, and frankly, why should they understand, quite what it's like to have a disabled child and quite what a different experience it is, to having a normal child… so it is quite a lonely life being the parent of a disabled child…. we talked a lot in this about, you know, the needs of the children and things, but the needs of the parents shouldn't be forgotten either. 'cause without the parents the children have had it basically, is the truth."* Parent 4 *"Where's the disabled Joe Wicks? I mean yeah, he broke his hand, half, he did break his arm or whatever he did half way. But I don't think that counts…. (Facilitator: but would they, would they breakthrough? Would our cultures put them in the right place to do that?) No.. I don't think it would work. As I say, one girl did it for wheel power. So wheel power put one on but it was once a week and she didn't break it. It didn't get through to where she needed to be and…..she did it all the way through lockdown. I think she, she's continued to do it ….wheel power have found that they physically cannot get it out there. Like apart from on their social media, they're stuck."* Young person 3

Barrier / Facilitator	Description	Supporting Quotes
		"(Facilitator: is that a barrier? The people controlling what goes out in mainstream media?)…whether or not they've had the, they've been told right you can show Joe. You can show Joe Wicks because, you know, he's big, but you can't do this, this and this. And yeah, I think yeah, I think they, the answer is probably, probably yes. They're probably being told what they can and can't show." Young person 3
Facilitator: Family attitudes and routines in relation to movement	Quality time, gives hope, doing activities together. Fighting for services and equipment. Parents are advocates for promoting movement. Resilience. Parents are positive and encouraging about movement. Parents want child to walk. Parents asking for movement tasks to be done at school and requesting feedback.	*"We have joy as well. Watching they can do something themselves." Parent 3* *"Well, lots of therapists not happy, we are feeding him in standing, but, but the kids is very robust, they coping really well."* Parent 3 *"I'm really sort of enjoying listening to the parents talk as well, because I think it's nice to hear, and I don't want this to be taken wrong, but it's nice to have some parents, listen to them, that, that obviously actively encourage and are positive about moving and supporting their children."* Professional 3 *"you've seen that the, the student, the child is better engaged at home because they have that sort of family support, they want to impress their parents, by showing them what they can do and what they've been doing, you know, in their sessions at school."* Professional 2 *"So you're doing a lot yourself. And your finding out and no one really tells you anything. You have to go out there and source everything, and then fight for those things that your child needs, because if it wasn't for me fighting, we'd be in a different position. (Son's name) would be in a completely different, and he wouldn t be able to move as much as he moves now because he wouldn't have had the support."* Parent 5 *"….going in, or messaging every day, 'can (name) go on his standing frame, can he have his gaitors on?' 'cause you feel like you're being a nuisance. You become that nuisance parent"* Parent 5 *"I think, this is just occurred to me is about mental health and your resilience, and often, that people have experiences which that are quite disappointing or unpleasant or hurtful. I'm not saying that's necessarily on purpose, but it happens, and that then impacts their, you know, you have to be really quite resilient in order to then push your own agenda and make a case or as parents to advocate for your child, in some of these situations where it isn t that easy to get access."* Professional 11
Facilitator: Professionals beliefs, attitudes, behaviours	Child feeling respected and understood by teachers. Willing helpers. Can do attitude. Motivated adults / carers.	*"Willing helpers" – Jamboard post,* Parent 4 *"Attitude – need a can-do attitude, rather than looking at the barriers" – Jamboard post, Professional 8* *"Young person: we used to spend a lot of time—'cause they have these like soft play rooms, and like we just have these...like... what's that thing?* *Parent: Soft play balls. Yeah.*

Barrier / Facilitator	Description	Supporting Quotes
		Young person: Yeah, and we just throw them at each other, and it was fun because even the adults would join in and we'd all have a laugh and... *Parent: some of it was social, wasn't it as well?* *Young person: Yeah. And honestly the adult—all the adults were amazing. They understand, they treat me with respect, which I haven't really had before….And I'm impressed because some of them have, like, been there for like 10 years, so they clearly really like their job."* Young person 5 and their parent who was present to support her but not a study participant *"Year 5, we were still in middle school. It didn't change (participant was previously able-bodied) and they were all accepting. They're like 'you can do PE, like you can do anything you want to do.' Uh, and then when we turned into a secondary school in,… when I was in year 6, so I was 11. That's when it changed."* Young person 3
Facilitator: Understanding benefits of moving and risks associated with prolonged sitting	Moving important as affects all areas of life. Educating staff about importance of movement and promoting movement. Young person understanding early is better, this nurtures good behaviours. Discuss risks sensitively with child, use peers experiences. Awareness of evidence. People with disabilities leading training and education around physical activity for disabled people. Being aware children need opportunities to move. Being aware children may be uncomfortable if not moved.	*"I think it (moving) should be, very important, it should be very important to them, because it's about their life. It's, it's sort of, it will affect them their whole life, but I don't know that it's necessarily seen as the most important thing"* Professional 5 *"I work in, erm, a primary school for children with disabilities and we're always trying to promote movement and education to the staff"* Professional 7 *"so a lot of its around, sort of education, in helping them to understand why it's important first and getting that baseline before then, going in and saying well 'these are the activities to practice'"* Professional 7 *"it was to do with the erm, sort of the health, the negative health benefits, so the risks I suppose, associated with spending too much time sitting and I think that would need to be really carefully tailored for the child audience, obviously. But yeah, I think people need to know, you know, and if you're learning that from an early age that feel, feeds into your adult life, so I think it nurtures really good behaviours from an early age, but it's how it's done I suppose, and that's why I was sort of reluctant to put it up."* Expert 1 *"I think it ties into the peer support. You know, because of someone over similar age said to you, you know, 'I used to be like that and then I started doing this and now I feel...' or, 'this is how it improves things for me.' I think it can, that can be a really good way of getting that sort of negative message across in a positive way."* Expert 1

Barrier / Facilitator	Description	Supporting Quotes
		“I'll make sure that movement happens, and then I’ll think he’s been on his knees too long, he needs to stretch them out, and it's about being aware that the child cannot sit there all day, and it's not fair. They need to be able to have that opportunity to move.” Parent 5

Note: EHCP = Education and healthcare plan

Triangulation with crowdsourcing data

When barriers / facilitators identified from the crowdsource workshop (Chapter 3, Table 16) were shared at the end of the virtual workshops and interviews, all participants felt that overall, they reflected the discussions they had in their virtual workshops / interviews. No participants challenged any of the crowdsource barriers or facilitators.

As a greater volume of data was collected via the virtual workshops/interviews, the barriers / facilitators identified from this analysis were retained. The descriptions of the barriers / facilitators were expanded to incorporate the crowdsource data.

4.5.3.3 Objective 3: Categorising barriers and facilitators according to the SOS Framework determinants of sedentary behaviour.

Table 27 shows which SOS Framework determinant of sedentary behaviour (118) each barrier / facilitator was categorised within. Barriers / facilitators that were specific to Covid-19 were not categorised, as they related to a particular set of circumstances which will not reflect the context in which the intervention is used in the future.

The SOS Framework determinant each barrier / facilitator was relevant to was decided with reference to the barrier / facilitator descriptions which summarise the raw data (Appendix 7). Some barriers / facilitators were relevant to multiple SOS Framework determinants. For example, safety was discussed in terms of avoiding injury for NAYP or those caring for them (health and wellbeing SOS Framework determinant), other people being concerned for the NAYPs safety and therefore not doing a movement activity or limiting it and safe participation in sport (social and

cultural context SOS Framework determinant), fear about injury (psychology and behaviour SOS Framework determinant) and the safety of physical spaces (built and natural environment SOS Framework determinant). Interestingly, the latter included a feeling of vulnerability associated with using a power chair in the community, as the battery can go flat or the power can fail leaving the person stranded.

Table 27 Barriers / facilitators for reducing sedentary behaviour categorised according to the six determinants of sedentary behaviour identified in the Systems of Sedentary Behaviour Framework (112).

SOS Framework determinant of sedentary time	**Physical health and wellbeing**	**Social and cultural context**	**Built and natural environment**	**Psychology and behaviour**	**Politics and economics**	**Institutional and home settings**
Barriers	Access to therapy	Cultural attitudes to movement	Inappropriate facilities or housing	Dislike of being different	Affordability and funding	Family, staff, carers not feeling moving is important
	Moving less to achieve greater independence or participation	Social perceptions of disability		Negative emotions when unable to move	Education and Healthcare Plans	Feeling trapped
	Boring and / or repetitive activities	Access to organised activities		Young person doesn't want to move or chooses to sit or lye		Not feeling able to express an opinion
	Cognitive capability	Becoming socially isolated		Not succeeding		Knowing how to facilitate more movement
	Experiences of prolonged sitting and lying	Not knowing about appropriate local facilities		Remembering		Multiple demands on families
	Reduced health and wellbeing	Screen time				Not having support from others to move
	Limited Physical Capability					
	Young person doesn't want to move or chooses to sit or lye					
	Reasons to be in sitting or lying					

SOS Framework determinant of sedentary time	Physical health and wellbeing	Social and cultural context	Built and natural environment	Psychology and behaviour	Politics and economics	Institutional and home settings
Facilitators	Understanding benefits of moving and risks associated with prolonged sitting	Access to activities and resources that suit the individual's needs	Facilities for wheelchair users	Being independent	Funding	Having support from others to move
	Therapies	Music	Being outdoors	Competition and individual challenge		Movement integrated into daily routines
	Physical abilities	Pets		Young person wants to move		
	Good medical management of condition	Screen time that promotes activity		Participating in fun, exciting, motivating activities		
	Involuntary movements					
	Improvements to health and wellbeing					
	Improving mental health					
Barrier or facilitator	Safety	Safety	Safety	Safety		Family attitudes and routines in relation to movement
		Age	Transport	Age	Transport	Professional’s beliefs, attitudes, behaviours
		Peer support				Accessing appropriate equipment
		Transition points				People needed
			Space			Space
						Time

4.5.4 Summarising the barriers and facilitators in preparation for step two (identifying barriers / facilitators which are malleable and have greatest scope for change).

In preparation for step two (which identifies causal and contextual factors which are malleable and have greatest scope for change), the barriers and facilitators needed to be presented in a way that would allow participants to easily conceptualise and prioritise them. For participants to achieve a true understanding of the barriers / facilitators and their meaning, they required insight into the barrier / facilitator descriptions in addition to a simple list of barriers / facilitators without context. The SOS framework (118) provides a useful structure to achieve this.

Two PowerPoint presentations were produced to share with participants prior to step two workshops. One presented barriers / facilitators which had potential for change, taking into consideration that a digital intervention would be the vehicle for change (Appendix 8). The second presented barriers / facilitators that the research team did not consider to be malleable via a digital intervention (Appendix 9).

The two presentations included one slide for each of the six SOS Framework determinants of sedentary time (118). The data was presented using text which represented the barriers / facilitators in speech bubbles to aid understanding (Figure 10). The text was not quotes from the raw data because the raw data was not sufficiently concise to be presented in this way. The text aimed to summarise the descriptions of the barriers / facilitators which were produced from the raw data. Speech bubbles were colour coded to represent barriers (red), facilitators (green) and factors that could be considered either a barrier or facilitator, depending on the person and their circumstances (amber). It was not possible to present all the detail

included in the barrier / facilitator descriptions on the slides as this would have been too much information for young people participating to read and understand. However, the presentations were dynamic, so participants could roll their cursor over a speech bubble to see more detail. The presentations (including this dynamic function) can be reviewed in the supporting digital material, files two and three. Figure 10 shows an example of one of the slides for barriers and facilitators which had potential for change. The two presentations were reviewed by the supervision team, a PPI representative and a collaborator and amended in relation to their feedback prior to being shared with participants.

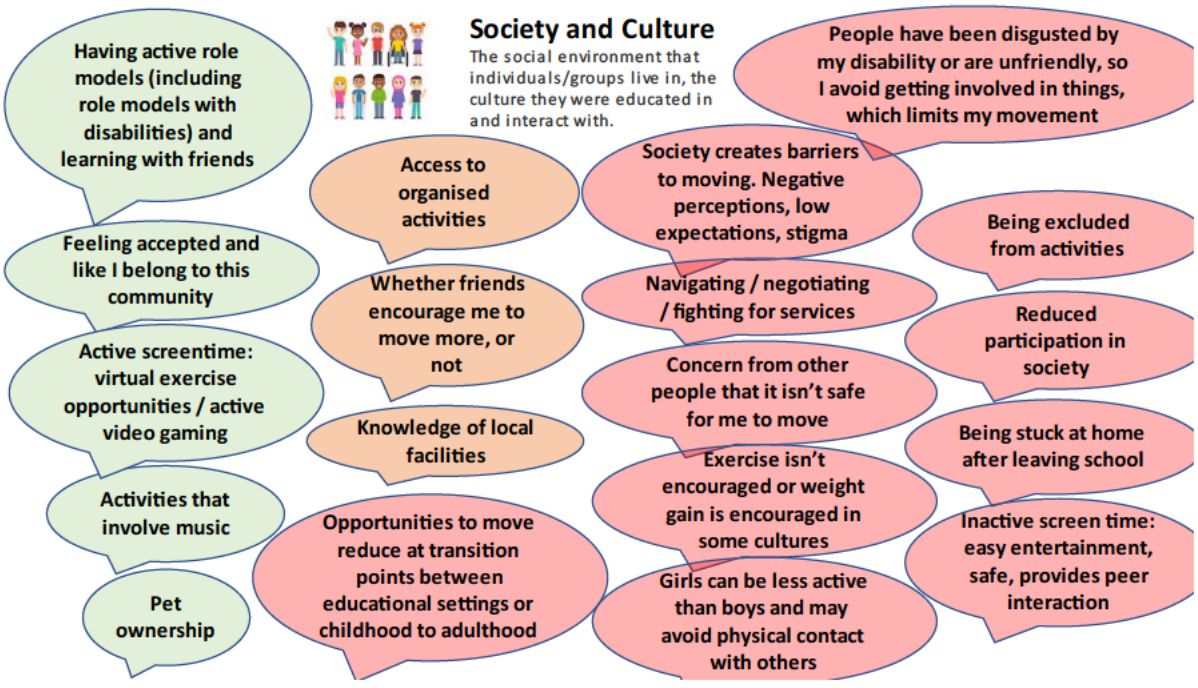


Figure 10 A slide from the presentation describing barriers / facilitators that had potential to change for Systems of Sedentary Behaviour Framework "social and cultural context" determinant of sedentary time.

4.6 Discussion

In this study NAYP and other stakeholders were engaged in the first stage of an intervention development, which involved an in-depth exploration of NAYP's sedentary behaviours from their differing perspectives. The results show that participants think it is important for NAYP to move more and feel there are many benefits of doing so. They felt NAYP need more opportunities to move and identified more barriers to moving than facilitators. The 52 barriers and 35 facilitators identified in an inductive thematic analysis of stakeholder data were categorised into six SOS Framework determinants of sedentary behaviour, which are defined in an existing evidence-based framework (118). The categorised barriers / facilitators were summarised in a way that provides understandable and meaningful feedback for participants in the next stage of the intervention development. Considering that NAYP are the population being studied, it is unsurprising that more barriers / facilitators were categorised under the physical health and wellbeing SOS Framework determinant than any other. Looking beyond this, the strong influence of the attitudes and actions of adults surrounding the NAYP, the interactions between the NAYP and these adults, and the culture they created within an environment such as home or school was striking throughout our data. Barriers / facilitators relating to this were categorised in the "Social and cultural context" and "Institutional and home settings" SOS Framework determinants, which were both prominent. NAYP are reliant on the assistance of the adults who support them to be able to move. Any intervention which aims to reduce NAYP's sedentary time through behaviour change therefore needs to involve these adults in addition to the NAYP.

Although there have been references to the attitudes and support of others being a barrier / facilitator to physical activity for children and young people with disabilities in previous literature (54, 57, 239), it has not been such a prominent theme as it was in this study. This may be because this work focused entirely on NAYP, whereas these previous studies have included only ambulant (239), or a mixture of ambulant and non-ambulant children and young people (54, 57).

There were important barriers / facilitators that related to the NAYP's own psychology and behaviour, such as dislike of being different, experiences of a lack of success when doing activities that involve movement, the importance of independence, fun and personal motivation to move. However, because NAYP are reliant on adult supporters to assist them to move, if the adults did not or could not create opportunities for them to do so, how the young person would have felt about it no longer influenced their sedentary time. NAYP and their family members frequently reported not having the help NAYP needed to move as a barrier.

There were fewer barriers / facilitators relating to the "Politics and economics" and "Built and Natural Environments" SOS Framework determinants, however those that were identified had a significant influence on movement, for example lack of funding for carers, equipment or therapy and the accessibility of buildings and facilities for wheelchair users.

In the field of physical activity research, sedentary behaviour, physical inactivity and physical activity are clearly defined constructs which have independent associated health risks and benefits (3, 8). Sedentary behaviours were defined earlier. Being physically inactive is performing insufficient moderate to vigorous physical activity in

comparison to recommendations given in physical activity guidelines (17). People who perform the recommended amount of moderate to vigorous physical activity are considered to be physically active (17). It is therefore possible to be highly sedentary and physically active on the same day if the required amount of moderate to vigorous activity is undertaken for a short period of time, but the majority of the day is spent being sedentary. It is also possible to be inactive but not sedentary, if for example someone stands up for most of the day, but do not perform any moderate to vigorous physical activity. It is accepted that those who are both highly sedentary and physically inactive are at the highest risk of negative health outcomes (17).

The existing body literature of relating to barriers / facilitators to physical activity for this population (which was summarised in the introduction), focuses largely on maximising physical activity and not on reducing sedentary time. This study focused specifically on barriers / facilitators of sedentary behaviours of NAYP. As described in the methods section, use of the word “sedentary” was intentionally limited due to its specific definition being difficult to understand and associated negative connotations. However, participants were encouraged to think about what facilitated or prevented light, low intensity movement that is done as part of regular daily routines and how to avoid sitting or lying still for long periods of time. They were asked to avoid focusing on sport or exercise, that are associated with moderate to vigorous physical activity. Despite this, the barriers / facilitators of reducing sedentary behaviours identified in this work are similar to the barriers / facilitators to physical activity that have previously been reported for young people with physical disabilities.

Previously reported barriers such as negative experiences and attitudes, physical and structural environmental factors, level of functional impairment, policy barriers

and lack of personal support from professionals, parents and friends (53, 54) were all represented in our data. Previously reported facilitators such as support from healthcare professionals to encourage participation in active leisure pursuits (55) making friends and having fun (56, 57) belonging, the influence of important people in the young person's life availability of opportunities, independence and perceived safety of activities (57) were also present.

Two possible explanations for this are that 1) participants conceptualise increasing physical activity and reducing sedentary time as the same construct, and therefore the same barriers / facilitators are discussed, or 2) that barriers / facilitators of reducing sedentary behaviours actually do not differ from barriers / facilitators of increasing physical activity for this population. Further research would be needed to understand which explanation is more likely, in which in depth explanations of the differences between sedentary time, physical inactivity and physical activity were highlighted to participants prior to exploring whether previously reported barriers / facilitators of physical activity are different for reducing sedentary time.

Strengths and Limitations

The triangulation of data previously collected via crowdsourcing with the data collected via these virtual co-design workshops / interviews contributed to verification of the previously collected data, using a more conventional methodology. A strength of sharing this previously collected data was that it facilitated participants to discuss things that were raised in the crowdsource conversations, but not in their workshop / interview. The barriers / facilitators identified in the crowdsource conversations therefore acted as a cue for participants to discuss a broader range of topics,

resulting in richer data collection. An example of this was education and healthcare plans being discussed in depth at the end of a virtual workshop. This topic would not have been raised in the workshop if the barriers / facilitators from the crowdsource conversations had not been shared.

A lead facilitator with less pre-existing knowledge and clinical experience relating to this topic would have added additional credibility to the data collection process. Neither of the second facilitators had experience of interacting with young people with disabilities or their parents, so they introduced minimal risk to credibility of data collection.

Involvement of multiple coders in the thematic analysis added rigor, enabling establishment of a barriers / facilitators table for which there was consensus amongst the coders. The coders then reviewed and fed back on the final barriers / facilitators once all data had been labelled to ensure they agreed with additional content that was added later in the analysis. Seeking and responding to member reflections on the presentations produced also contributed to the robustness of the analysis (249) (Chapter 5).

Across data collection via crowdsourcing and virtual co-design workshops interviews, the participants included a large number of female physiotherapists. Approximately 76% of physiotherapists in the UK are female (259), however 89% of the professionals who contributed were female and 78% were physiotherapists. As the author is a physiotherapist, the networks she is part of and advertised within may have influenced this. Attempts were made to reach other professional groups by encouraging colleagues in multidisciplinary teams to advertise via their networks and

by advertising in a special educational needs magazine for education professionals. Occupational therapists, teachers, paediatricians and support workers were represented but in small numbers.

There was a risk that young people and family members chose to participate because they are motivated about being physically active / their family member being physically active and are therefore more knowledgeable about opportunities to move and more active than other young people who are non-ambulant. Despite that possibility, participants reported many barriers to moving more that they have observed or experienced. The variable functional abilities of the NAYP participating was a strength, as it allowed a wider range of experiences to be captured.

To support young people with communication and confidence during virtual workshops / interviews, they could have a parent or carer present. There were carers / parents present in three virtual interviews with young people. Their presence had potential to influence what young people said or direction of the conversation. The author was aware of this and aimed to ensure the young person's voice was heard via their facilitation techniques.

Limiting data collection to online methods risked exclusion of participants who experience barriers to accessing technology. Unfortunately, this was necessary due to the social distancing measures in place during data collection. Potential participants may have been excluded due to digital inequalities, such as lack of access to Wi-Fi or devices. Sensory impairments such as visual or hearing difficulties or fine motor impairments could also have limited use of technology. Accessibility features within devices have the potential to overcome sensory and fine motor

difficulties, but knowledge of their availability and an understanding of how to use them are required. Having carers / parents present helped to overcome some of these difficulties, allowing NAYP to participate. However, potential participants who do not routinely access technology were less likely to be aware of the study, as recruitment was largely virtual.

Sample size was limited by the number of participants that could be recruited to the study.

4.6.1 Reflexivity

The first author and lead facilitator appreciates that they had existing preconceptions relating to the topic resulting from their clinical experiences and knowledge of the existing literature relating to sedentary behaviours and barriers / facilitators of physical activity for NAYP. They considered their potential to influence conversations held during workshops and interviews prior to data collection and employed strategies described in the methods to minimise their influence.

The CI kept a reflective diary throughout this analysis.

4.7 Conclusion

Co-design participants valued movement opportunities and believed moving more is important and beneficial for the health and wellbeing of NAYP. NAYP experience more barriers than facilitators in relation to reducing their sedentary behaviour. Co-design participants described these barriers / facilitators, allowing the researcher to achieve an in depth understanding of the problem. NAYP needed the assistance of adult supporters to help them to move. Their opportunities to move were therefore dependent on the beliefs, attitudes, skills and behaviours of their adult supporters in

addition to their own beliefs and behaviours. The barriers / facilitators of moving for this population may be similar regardless of the intensity of physical activity that is being pursued, but further research would be required to confirm this.

5 Chapter 5: Step two of the Six Steps in Quality Intervention Development (6SQuID). Identifying modifiable causal or contextual factors.

5.1 Title: Which barriers and facilitators of reducing sedentary behaviour of non-ambulant young people have the greatest scope for change? Co-designing the MoveMore app.

5.2 Introduction

Sedentary behaviour is defined as “any waking behaviour characterized by an energy expenditure ≤1.5 metabolic equivalent units (METs) while in a sitting or reclining posture” (3). It therefore differs from a lack of moderate to vigorous physical activity, which is described as inactivity (17). There are health risks associated with high levels of sedentary behaviour, including increased likelihood of developing cardiovascular disease or type 2 diabetes, some cancers and a higher likelihood of death form any cause (7, 8). It is estimated that 69,276 deaths could be avoided over a 12 month period in the United Kingdom (UK) by eliminating prolonged sitting (13). UK and worldwide physical activity recommendations therefore advise limiting sedentary time (6, 26).

Non-ambulant young people (NAYP) have long term conditions, such as cerebral palsy (CP), spina bifida, muscular dystrophy or traumatic brain / spinal cord injuries. NAYP may be unable to walk, or able to walk short distances indoors, using equipment such as a body support walker. If they are able to walk short distances, their walking is therapeutic and usually forms part of an exercise program, rather than being a functional method of mobility. NAYP are more sedentary than able-

bodied young people (33, 158, 159, 209, 212) and young people with disabilities who are ambulant (33, 158, 159, 210, 215). There is some evidence that young people with disabilities become increasingly sedentary with age (33, 40, 214), however not all studies have demonstrated this relationship (159, 210). Despite evidence indicating that NAYP have high levels of sedentary behaviour, there are no evidence based interventions that have been designed specifically to reduce it (38).

This study describes the second step of a co-design process, to develop an evidence-based, digital intervention (smartphone app), which supports NAYP (aged 13-25), to reduce their sedentary behaviour – the MoveMore app. The MoveMore app co-design aims to produce the first evidence based invention which aims to support NAYP to reduce their sedentary behaviour.

The co-design process for the MoveMore app, follows the Six Steps in Quality Intervention Development (6SQuID) intervention development framework (86). 6SQuID is a six-step participatory approach (94, 95), with an emphasis on stakeholder engagement. Step one (defining and understanding the problem and it's causes), has been described elsewhere (Chapters 3 and 4). Briefly, Step one involved gaining an in-depth understanding of sedentary behaviour of NAYP from stakeholders to identify barriers and facilitators of reducing it. Stakeholders included NAYP aged 12-25, NAYP's family members, health, social care and education professionals working with NAYP and an expert in sedentary behaviour and behaviour change in clinical populations. This work identified 35 facilitators and 52 barriers of reducing sedentary behaviour, which were categorised according to the six determinants of sedentary behaviour identified in the Systems of Sedentary behaviours (SOS) Framework (118). Step one highlighted that adults who support

NAYP influence the number of movement opportunities available to them. It was concluded that any intervention intended to reduce sedentary time therefore needed to involve family members, carers and health and education professionals in addition to the young person themselves.

The SOS Framework (118) is systems-based and maps determinants of sedentary behaviour across age groups; taking into account ethnic and social diversity and multidisciplinary perspectives. It is not hierarchical, in recognition of the complex interplay between influences on sedentary time. The six determinants of sedentary time in the framework are: physical health and wellbeing, social and cultural context, built and natural environment, psychology and behaviour, politics and economics and institutional and home settings (118). Categorisation of the barriers and facilitators identified in step one into the six determinants of sedentary behaviour in the SOS Framework allowed participants in this study to prioritise which broad determinants of sedentary behaviour were most amenable to change for NAYP. They could then focus on specific barriers and facilitators within the most relevant determinants only. It was recently used in a similar way to structure risk factors for TV viewing in older adults with intellectual disabilities (260) and was previously used to categorise factors influencing physical fitness in adolescents into broader determinants (119).

The aim of step two of the 6SQuID, is to identify which causal and contextual factors are modifiable (86). The objectives of step two of the 6SQuID (86) in the co-design of the MoveMore app were to:

1) identify which determinants of sedentary behaviour from the SOS Framework were most amenable to change to reduce sedentary behaviour of NAYP,

2) from within the SOS determinants identified as being amenable to change, select which barriers and facilitators of reducing sedentary behaviours were the most modifiable
3) identify key goals of the proposed digital behaviour change intervention using the list of modifiable barriers and facilitators.

5.3 Methods

Ethical approval for this study was granted by the London - Camberwell St. Giles Research Ethics Committee (Ref: 20/LO/0011). Data collection took place between October and November 2021. Co-design workshops and 1:1 interviews were conducted virtually due socialising and household mixing restrictions that were in place due to the Covid-19 pandemic during data collection. This allowed participants from a wide geographical area to contribute.

5.3.1 Participants and recruitment

Key stakeholders invited to take part in the co-design process were: 1) NAYP, 2) family members of NAYP, 3) professionals with experience of working with NAYP (including carers, healthcare / education professionals), 4) experts in behaviour change, disability, sedentary behaviour and / or digital health interventions 5) members of the public who wished to contribute. NAYP were aged 12-25 years and had a lifelong disability. All other participants needed to be aged 16 or over. With the exception of the experts, participants needed to live in the United Kingdom (UK). Experts could be recruited worldwide. Additional inclusion criteria for all participants were ability to communicate in English and having sufficient understanding to give informed assent / consent and participate meaningfully in an interview or workshop. The “members of the public” stakeholders were included so everyone with an interest

in this topic had an opportunity to contribute, for example adults with disabilities who are over 25 years of age.

Participants were recruited via open advertisement using a number of strategies including: social media, word of mouth, poster campaign and clinicians sharing information during appointments. The recruitment and online consent procedures are explained in detail in Chapter 3. Briefly, participants completed online consent / assent forms remotely prior to any data collection being undertaken. All who consented to participate in the co-design were contacted via email to invite them to take part in step two, including those who did not contribute to step one. This resulted in new participants contributing to this step who did not participate in step one. There was also some attrition of participants between steps one and two. Details of new participants and attrition are reported in the results. All participants were offered a £10 payment to thank them for their time.

5.3.2 Sample size

The overall minimum sample size was four, combining those participating via virtual workshops and interviews. This low minimum number was chosen during protocol development as potential recruitment rates were unknown. It was assumed that all participants engaged would have valuable lived or professional experience in relation to this subject. Their contributions would therefore be valuable and worthwhile, regardless of how many participants from each stakeholder group had contributed. It was required that all four key stakeholder groups were represented (that is minimum sample was one participant per stakeholder group). There was no maximum sample size stipulated. All participants who responded to the email invite to participate did so.

5.3.3 Data collection

5.3.3.1 Participant characteristics:

Immediately after potential participants completed online consent, an online survey followed to collect the following information: age, email address, stakeholder group, high level location (first three characters of postcode or town/country if outside the UK), gender, ethnicity and employment status. There were also additional questions for participants that were specific to their stakeholder group (Appendix 5). Online consent and the survey were completed prior to workshops / interviews.

5.3.3.2 Workshops and interviews:

Following completion of the online survey, participants were emailed asking them to select a workshop they would like to attend from a range of dates and times or to suggest convenient dates / times when they could be interviewed. Workshops could have between two and 10 participants based on advice relating to conduct of focus groups in qualitative research (248). With the exception of NAYP aged 12-15, all participants could choose whether they wished to participate via a workshop or an interview. NAYP aged 12-15 were interviewed rather than attending a workshop. There was potential for power imbalance to prevent these young people contributing in an open and honest way if they attended a workshop including unfamiliar adults (255, 256). Unfortunately, there were not enough 12-15 year olds participating to hold their own workshop. All workshops included a mixture of stakeholders. There were not separate workshops for different stakeholder groups.

5.3.3.3 Workshop / interview structure:

Interviews and workshops were conducted on Microsoft Teams and were video recorded. Jamboard (Google Jamboard: Interactive Business Whiteboard | Google Workspace) was used to facilitate and capture the outcomes of the prioritisation exercise undertaken. This online whiteboard, provided by google, allowed participants to work collaboratively in real time. The same Jamboard template was used in all workshops and interviews (Appendix 10). To facilitate data analysis and dissemination, participant's initials were used to label their Jamboard contributions. This meant participants could not be identified from downloaded Jamboard data or by anyone viewing the Jamboard online, with the exception of those who also attended the workshop.

Interviews and workshops were facilitated by the first author (MB), who has previous experience of working with children with disabilities and their families and facilitating co-design workshops. This was necessary, as there was not an alternative lead facilitator available to carry out this data collection, however there was potential for the lead facilitator to unintentionally influence participant's decision making due to pre-existing opinions about the likely outcomes. To minimise this risk, this potential bias was openly discussed with participants, and they were encouraged to challenge the facilitator if they felt this was occurring. The lead facilitator also only moved or placed items on the Jamboard that had been directly requested by participants and used feedback from other workshops / interviews to probe or challenge thinking as much as possible to avoid sharing their own opinion.

A member of the research and innovation team at a community NHS Trust was also present in the workshops. They acted as a second facilitator, and did not have previous experience of working with NAYP and their families. They were available to

speak to participants 1:1 outside the online workshop if they felt distressed or worried about anything happening within the workshop. The second facilitator could signpost participants to support if needed. They also made field notes about workshops.

To create a psychologically safe environment, participants were encouraged to respectfully challenge each other if they didn't agree with the decisions made. Participants were asked to speak openly and honestly, even if their opinions differed with the rest of their group and to share why they had a different opinion if they were able to (261).

Prior to the workshops and interviews, two power point presentations were circulated to participants (Appendices 8 and 9). Each presentation included six slides, one for each SOS Framework determinant of sedentary behaviour (118). The SOS determinants were called themes in the presentations and the word "sedentary" was intentionally not used. Use of the word "sedentary" was avoided due to previous research which suggested this could be viewed as a critical / negative judgement of the lifestyle of people with disabilities (246).

Workshops / interview materials were designed to focus on use of images containing objects or symbols, rather than relying on written material alone. This is in alignment with recommendations for undertaking co-design in a virtual environment, as outline by a co-design hub (254). Specifically, the power point presentations and Jamboard templates used images representing each of the SOS framework determinants.

The presentation slides summarised the barriers and facilitators from step one of the co-design in speech bubbles under each SOS determinant image (Figure 11). Facilitators of reducing sedentary time were depicted in green speech bubbles,

barriers were in red speech bubbles. Factors which could be considered either barriers or facilitators (depending on the environment or context) were in amber speech bubbles. Participants could get more detail about each barrier / facilitator on the speech bubble by rolling over it with their curser. However, reading this additional information was optional, and participants could make their decisions just by looking at the text in the speech bubbles. The interactive versions of the presentations are available in supporting digital material, files two and three.

Presentation one showed barriers and facilitators the researchers and public and patient involvement representatives felt were changeable via a digital intervention, categorised by SOS determinant (Appendix 8). There were changeable barriers / facilitators for all six SOS determinants of sedentary behaviour. Presentation two outlined barriers / facilitators that were considered not amenable to change (Appendix 9). Presentations were circulated in advance, so participants had the opportunity to read and understand them prior to the workshop.

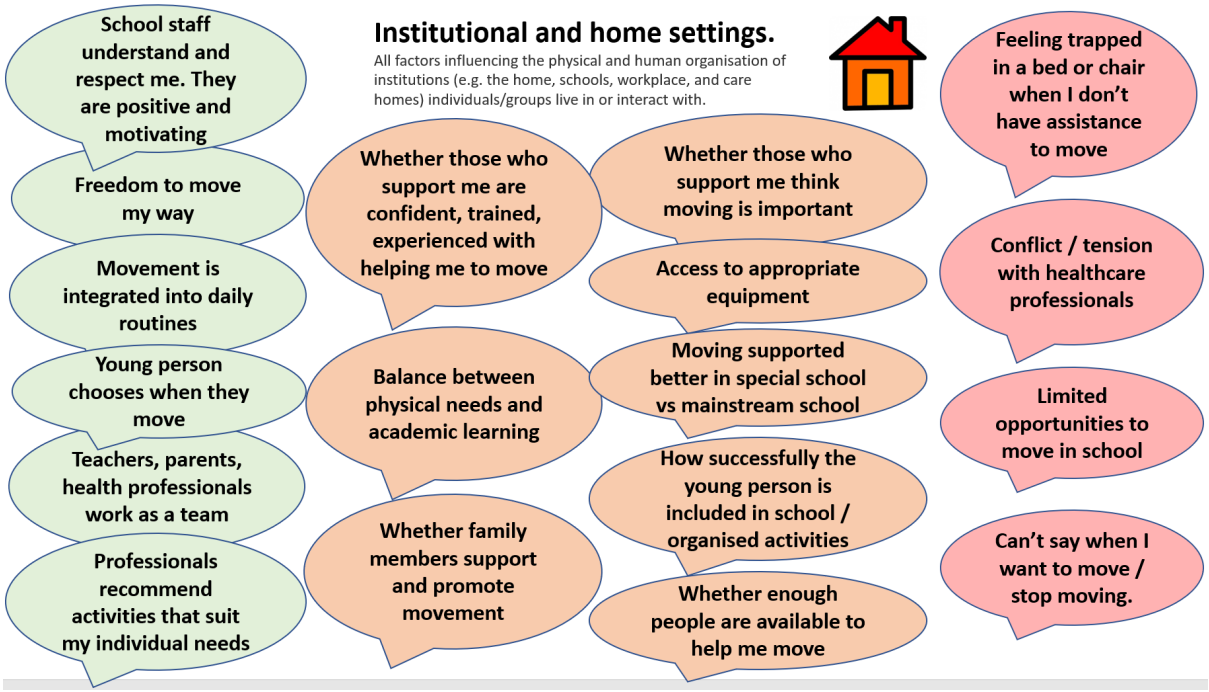


Figure 11 Example of a PowerPoint slide from presentations shared with participants for each Systems of Sedentary Behaviour Framework determinant: barriers / facilitators which are changeable via a digital intervention

Participants were asked to feedback prior to the interview / workshop whether or not they agreed with the researchers about what was or wasn't amenable to change and to rank in advance which themes (SOS determinants) were most amenable to change. They were also asked to select three speech bubbles that they felt were modifiable via a digital intervention, and could be addressed in the intervention from the SOS determinants that they ranked as number one and two.

The first goal of the co-design workshops was for the group to rank the SOS determinants in terms of how changeable they were. Participants then choose specific speech bubbles they felt were changeable from the SOS determinants the group ranked first and second. Finally, the group ranked the speech bubbles they had chosen, to prioritise three speech bubbles from each SOS determinant that they felt

the intervention should address. In interviews, the facilitator discussed reasoning behind the interviewee's decisions with them. To probe their reasoning further, conversations from workshops were shared with the interview to help them to reflect on their choices and consider other perspectives when they weren't in a group environment. Selection of dates for workshops and interviews aimed to maximise convenience for participants. There was no intention to undertake workshops prior to interviews or vice versa, however, the first data collection was via a workshop and not an interview. Table 28 describes the structure of each workshop / interview and the rationale behind each section. Video recordings were saved so reasoning behind each group / participants choices remained accessible, however the completed Jamboard templates acted as the primary raw data set.

Table 28 Structure of step two co-design workshops / interviews and rationale.

Activity	Rationale
Ground rules reminder.	Participants accepted ground rules prior to step 1, which was several months prior to attending the step 2 workshop/interview.
Introductions. Participants advised not to share where they lived / worked / attended school.	Participants familiarised with each other's stakeholder group / motivation for participating.
Ice breaker activity. Participants asked to rank what makes a good TV program by sliding images representing different reasons along a scale on the Jamboard template (Appendix 10)	Allowed participants to share information about themselves and feel more relaxed about contributing to the group (particularly young people) (257). Helped introduce participants to using the Jamboard to rank images that represent themes, as they did in the prioritisation.
Share themes that participants ranked 1 and 2 prior to the workshop. (A ppendix 10)	Transparency about differing opinions / consensus at the beginning of the workshop
Rank 6 themes (SOS determinants) from things we can change most to things we can change east as a group. (Appendix 10)	Discussion of differing perspectives and experiences.
Share speech bubbles that participants chose prior to the workshop. (Appendix 10)	Transparency about differing opinions / consensus between participants
Group selection of 3 speech bubbles for the 2 themes the participants ranked 1 and 2. (Appendix 10)	Discussion of differing perspectives and experiences.
Sharing and discussion of rankings and speech bubbles chosen in previous workshops / interviews. (Appendix 10)	Opportunity to reflect on choices made and hear the perspectives of participants outside this workshop / interview. Opportunity to change selection in light of this. Drew workshop/interview to a close.

5.3.4 Analysis

The ranking of SOS determinants across workshops and interviews was determined using a quantitative process. For interviews, the SOS determinant which was most amenable to change was given a score of one and that which was least amenable to change a score of six. The same scoring was used for workshops, but was based on the whole group's ranking decision. The workshop scores were then multiplied by the number of people in the workshop to weight them. This was to ensure that results weren't biased due to an individual's decision in an interview carrying the same weight as a group decision, which several participants contributed to. Total scores

across interviews and workshops were then calculated. The SOS determinant with the lowest total score was therefore most amenable to change.

To take into account potential differences of opinion between stakeholder groups (for example, young people may have ranked the determinants differently to professionals), separate scores for three stakeholder groups (young people, parents, professionals and experts) were also calculated and compared. Where a workshop contained at least one member of the relevant stakeholder group, scores from that workshop's group decision were used to do this. Professionals and experts were combined as only one workshop included experts.

By the end of each workshop / interview, the two SOS determinants that group or individual ranked as most amenable to change were identified. Three speech bubbles (or barriers / facilitators) that the group or individual felt were modifiable and should be addressed in the intervention were then identified from within the top two ranked SOS determinants. All speech bubbles that were chosen from the top ranked SOS determinants more than once (across workshops and interviews), were included in the next step of the analysis.

A mind map was produced showing the included speech bubbles (barrier / facilitators) and single or double headed arrows were used to show where relationships existed between them. The mind map was shared with the research team and public and patient involvement representatives for feedback. Considering the relationships between the modifiable barriers and facilitators to be addressed in the intervention, it was possible to condense them into five key goals the intervention

would aim to achieve. The key goals were shared with co-design participants for feedback.

5.4 Results

A total of 24 participants were recruited, comprising: 14 professionals, five young people, three family members and two experts. With these participants, five virtual co-design workshops and four interviews were held. Workshops had between two and six participants. Three young people contributed in workshops and two chose to be interviewed. The remaining two interviews were for a family member and a professional. There was one workshop which did not include anyone with lived experience.

There was attrition of 10 participants who took part in step one, but not step two (Table 29). Six of those 10 participants had previously contributed via crowdsourcing and four via virtual co-design workshops. Two new participants took part in step two who did not contribute to step one (Table 29).

Table 29 Change in participant numbers in step two of the 6SQuID in comparison to step one.

Stakeholder group	Attrition (took part in step 1, but not step 2)	New participants
1) Young person aged 12-25 who is non-ambulant.	0	0
2) Family members of non-ambulant children and young people	4	1
Health and education professionals	5	1
4) Experts	1	0
5) Other members of the public	0	0

5.4.1 Participant characteristics

Table 30 provides details of participant characteristics. Professionals formed the largest stakeholder group. A high percentage of participants were female and white-British. However, there was some diversity in ethnicity represented.

Data collected via the online survey (Appendix 5) showed three young people who participated had CP, one had acquired brain injury and one was undiagnosed. One of the participants with CP also had fibromyalgia and osteoarthritis. All the young people lived with their parents. They all reported being sedentary for “most” or “almost all” of the day. They reported having uninterrupted bouts of sitting or lying for between one and seven hours during the daytime. One of the young people who participated via interview used an eye-gaze communication aid and participated with assistance of a carer.

All three family members were parents of a NAYP with CP and lived with them. All of their children had learning difficulties, but were able to express what they wanted to their parents.

The majority of professionals were physiotherapists (n = 10). There were also two occupational therapists, a Physical Education teacher in a school for pupils with special educational needs, and a support worker for young people with disabilities.

Both experts were academic researchers (one from the UK, one international [Australia]).Their areas of interest were sedentary behaviour following stroke and co-design and physical activity and participation of young people with CP.

Table 30 Participant characteristics for step two co-design workshops / interviews.

Stakeholder group / characteristic	**Number of participants (%)**	**Age in years: mean, median, range**	**Gender: Number (%)**	**Ethnicity: Number (%)**	**Employment status / Role: Number (%)**
Young person aged 12-25 who is non-ambulant.	5 (21%)	18.2, 17, 15-22	Female: 4 (80%) Male: 1 (20%)	White – British: 5 (100%)	School/college/sixth form student: 3 (60%) University student: 1 (20%) At home most days (not working): 1 (20%)
Family members of non-ambulant children and young people	3 (13%)	51.7, 53, 48-54	Female: 2 (67%) Male: 1 (33%)	White – British: 3 (100%)	At home most days (not working): 1 (33.3%) Working full time 1 (33.3%) Working part time: 1 (33.3%)
Health and education professionals	14 (58%)	39.7, 39, 27-60	Female: 12 (86%) Male: 2 (14%)	White – British: 11 (79%) White – Any other background: 1 (7%) Black or Black British – African: 1 (7%) Mixed – Any other background: 1 (7%)	Working full time: 10 (71%) Working part time: 4 (29%)
Experts	2 (8%)	35.5, 35.5, 34-37	Female: 2 (100%)	White – Irish: 1 (50%) White – Any other background: 1 (50%)	Working full time: 1 (50%) Working part time: 1 (50%)
Total	24 (100%)	36.4, 35, 15-60	Female: 20 (82%) Male: 4 (18%)	White – British: 19 (79%) White – Any other background: 2 (8%) White – Irish: 1 (4%) Black or Black British – African: 1 (4%) Mixed – Any other background: 1 (4%)	Working full time: 12 (50%) Working part time: 6 (25%) At home most days (not working): 2 (8%) School/college/sixth form student: 3 (13%) University student: 1 (4%)

5.4.2 Participants feedback about step one results

Two communications were received prior to the step two groups commencing, providing feedback about the presentations which summarised the step one results (Appendix 8 and Appendix 9). One participant queried whether more barriers / facilitators from the built and natural environment determinant of sedentary behaviour could be changed by the intervention. For example, campaigning for improved personal care facilities and access to activities such as swimming / soft play. A parent of a young person who was participating indicated that they perceived the step one feedback placed too much emphasis / responsibility on the young person to change, without considering the importance of policy and society changes to facilitate reduction in sedentary time of NAYP. This feedback was shared with participants at the beginning of the step two workshops and interviews.

During the workshops and interviews, the limitations of the intervention being delivered digitally were discussed. It was agreed that although the built environment and policy / societal attitudes are important, the influence a digitally delivered intervention could have on decision makers in these areas would unfortunately be minimal. The feedback from the parent assisted the facilitator to emphasise the opportunity to change behaviour of adult supporters via the intervention. It highlighted that the expectation for change should be placed upon the team who support the young person in addition to the young person themselves.

5.4.3 Objective 1) Identify which of determinants of sedentary behaviour from the SOS Framework were most amenable to change to reduce sedentary behaviour of NAYP.

The results relating to ranking of the SOS Framework determinants of sedentary behaviour from each workshop and interview are shown in Table 31. Psychology and behaviour was the determinant ranked as being most amenable to change via a digital intervention for NAYP and their adult supporters (lowest score of 48). The politics and economics determinant was ranked as least amenable to change via a digitally delivered intervention (highest score of 134). The three determinants which were most amenable to change via a digital intervention were; psychology and behaviour, institutional and home settings and physical health and wellbeing. These determinants fell within a narrow range of 11 points (lowest = 48, highest. = 59). The remaining three determinants had much higher scores (lowest = 83, highest = 134) over a larger range (51 points). This suggests there is a clear divide regarding participants perceptions of the extent to which the first versus the last three determinants were amenable to change.

Table 31 Overall ranking of Systems of Sedentary Behaviour Framework determinants to identify which are most amenable to change.

SOS Framework Determinant:		**Institutional and home settings**		**Psychology and behaviour**		**Built and natural environment**		**Physical health and wellbeing**		**Society and Culture**		**Politics and economics**	
Workshop / Interview	**Number of participants**	**Rank**	**Weighted score**	**Rank**	**Weighted score**	**Rank**	**Weighted score**	**Rank**	**Weighted score**	**Rank**	**Weighted score**	**Rank**	**Weighted score**
Workshop 1	6	4	24	1	6	3	18	5	30	2	12	6	36
Workshop 2	2	2	4	3	6	4	8	1	2	5	10	6	12
Workshop 3	2	2	4	1	2	5	10	4	8	3	6	6	12
Workshop 4	5	3	15	2	10	4	20	1	5	5	25	6	30
Workshop 5	4	2	4	4	16	5	20	1	4	3	12	6	24
Interview 1	1	1	1	2	2	6	6	3	3	4	4	5	5
Interview 2	1	2	2	1	1	6	6	4	4	5	5	3	3
Interview 3	1	3	3	2	2	5	5	1	1	4	4	6	6
Interview 4	1	1	1	3	3	4	4	2	2	5	5	6	6
Total weighted score for each SOS determinant			58		48		97		59		83		134
Rank of SOS determinant from weighted score		2		1		5		3		4		6	

Table 32 shows how SOS determinants were ranked by stakeholder groups. There was consensus across stakeholder groups that the psychology and behaviour determinant was the most amenable to change, with it being placed first or joint first regardless of which stakeholders were contributing. There is a difference of opinion in relation to which determinant should be ranked second. Only one point separated the determinants which were ranked second (institutional and home settings) and third (physical health and wellbeing) in the overall scores. NAYP would chose institutional and home settings to be ranked second, whereas both family members and professionals would argue that physical health and wellbeing should be second, with institutional and home settings being ranked lower (either third [professionals] or fifth [family members]). NAYP are under-represented in comparison to professionals and experts in this study, so it is important to ensure their voice is not lost and that the intervention meets their perceived needs. It is therefore helpful that when looking at the overall rankings from the SOS framework (Table 31) institutional and home settings was ranked second overall across all workshops and interviews. However, the potential for the physical health and wellbeing determinant to be changeable cannot be ignored, as it was ranked third by NAYP and second by family members and professionals.

Table 32 Ranking of Systems Of Sedentary Behaviour Framework determinants to identify which are most amenable to change according to stakeholder group.

Stakeholder group:	**Non-ambulant young people**		**Family Members**	**Professionals and Experts**
Rank	**SOS Framework determinants of sedentary behaviour**			
1	Psychology and behaviour	Institutional and home settings	Psychology and behaviour	Psychology and behaviour
2			Physical health and wellbeing	Physical health and wellbeing
3	Physical health and wellbeing		Society and Culture	Institutional and home settings
4	Society and Culture		Built and natural environment	Society and Culture
5	Built and natural environment		Institutional and home settings	Built and natural environment
6	Politics and economics		Politics and economics	Politics and economics

5.4.4 Objective 2) Select which barriers and facilitators of reducing sedentary behaviours are most modifiable from within the SOS determinants which were most amenable to change.

Based on the results above, barriers and facilitators from speech bubbles in the 1) psychology and behaviour, 2) institutional and home settings and 3) physical health and wellbeing, were included in the next stage of the analysis (that is the three most changeable SOS Framework determinants of sedentary behaviour identified in objective 1). The mind map in Figure 12 shows 15 barriers and facilitators that were chosen as being modifiable via a digital intervention in at least two workshops / interviews, from these three SOS determinants. Barriers and facilitators are colour coded according to the determinant of sedentary behaviour they were selected from (see key, Figure 12). The arrows show where there are hypothesised relationships between these barriers and facilitators and the direction of those relationships. The existence and direction of the arrows were proposed by the first author (MB) and

shared with the research team and a PPI representative with lived experience for feedback. The majority of relationships were uni-directional. For example, a NAYP being successfully included in organised activities (institutional and home settings), influences barriers / facilitators from other determinants (psychology and behaviour, physical health and wellbeing). Being successfully included in an organised activity (institutional and home settings) ensures the level of competition and competitiveness is appropriate and influences whether movement is enjoyable and fun (psychology and behaviour). It influences feeling better due to regular movement (physical health and wellbeing), and addresses NAYP having limited experiences of movement (physical health and wellbeing). Some relationships were bi-directional. For example “limited experiences of movement or sitting up” (physical health and wellbeing) can result in loss of confidence and fear of movement (psychology and behaviour), but feeling scared when moving can also result in NAYP’s experiences of movement being limited (physical health and wellbeing), to relieve their anxiety.

The arrows suggest that in general, addressing barriers and facilitators in institutional and home settings may influence barriers / facilitators related to psychology and behaviour and physical health and wellbeing. However, barriers and facilitators related to psychology and behaviour and physical health and wellbeing may have less influence on institutions and home settings. The mind map suggests there are a large number of connections between the selected barriers / facilitators. This observation highlighted the potential for the selected barriers / facilitators to be condensed into key goals the intervention should address.

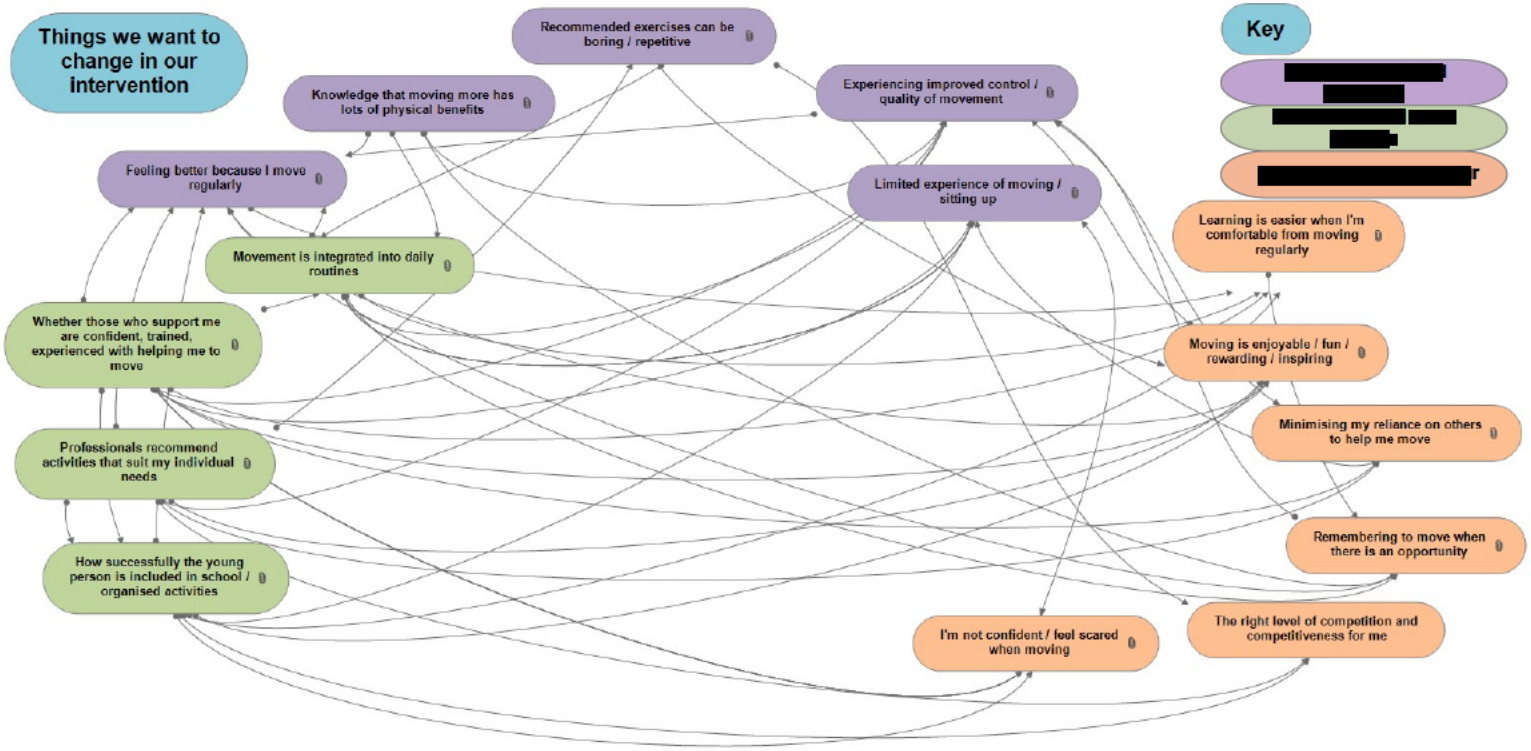


Figure 12 Mind map of the modifiable barriers and facilitators from the three SOS Framework determinants of sedentary behaviour that were most amenable to change (psychology and behaviour [orange], institutional and home settings [green] and physical health and wellbeing [purple]).

5.4.5 Objective 3) Identify key goals of the proposed digital behaviour change intervention using the list of modifiable barriers and facilitators.

Informed by the mind map, the first author (MB) went through a process of grouping similar / linked modifiable barriers and facilitators to identify a smaller, more manageable number of specified goals for the intervention. This lead to the proposal of five key goals. This process was overseen by the research team and a PPI representative, prior to presenting the goals to participants for feedback in step three of the co-design (Chapter 6). Figure 13 shows how the modifiable barriers and facilitators were refined to produce these five key goals. The proposed goals are described in detail in Table 33.

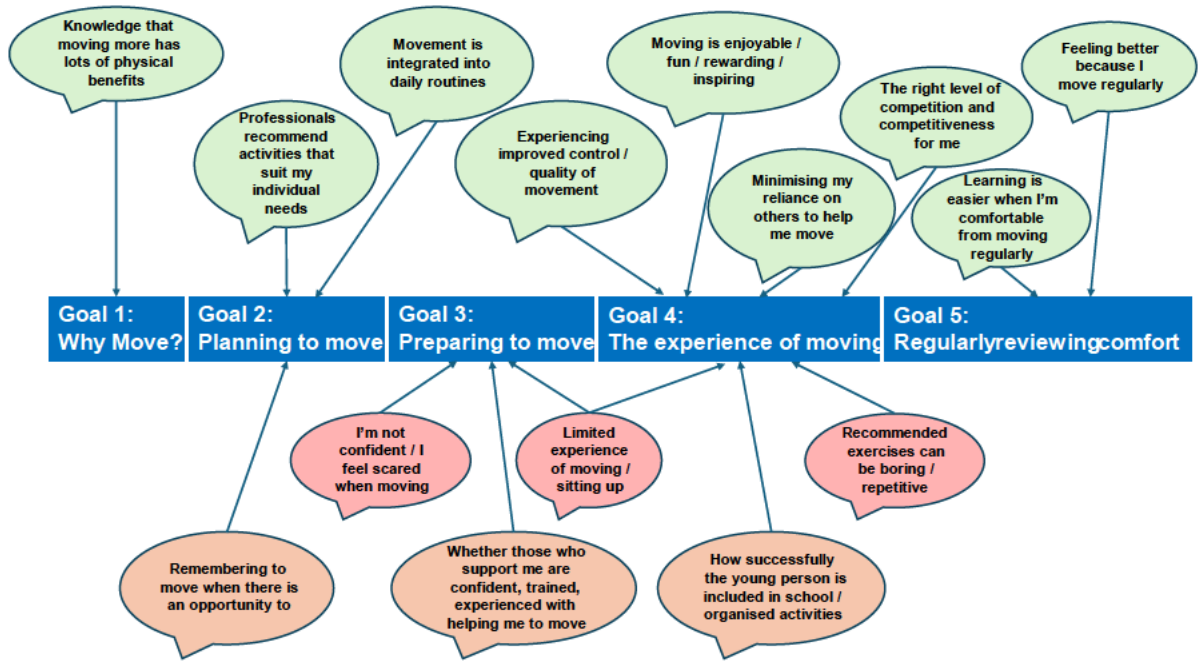


Figure 13 Diagram depicting how modifiable barriers / facilitators were condensed to produce five key goals of the MoveMore intervention. Speech bubble colour codes: facilitators = green, barriers = red, barrier or facilitator depending on context = amber.

Table 33 Proposed goals of the MoveMore digital intervention to support NAYP to reduce sedentary their sedentary time.

Key Goals	Goal description
1. Why move?	To know and understand the benefits of moving more and the risks of sedentary time
2. Planning to move	To identify and plan when and how movement can occur during daily routines. To review regularly
3. Preparing to move	To check the young person feels confident and safe before moving
4. The experience of moving	Young person moves in a way that is fun, enjoyable, rewarding, inspiring.
5. Regularly reviewing comfort	To regularly communicate with the young person about their comfort (regularity to be specified by YP and supporters in their context) and act when discomfort is reported.

For goal 3, preparing to move, it is noteworthy that safety and confidence are different constructs. However, both are required to meet the overall goal of feeling prepared to move. Also, the young person's confidence in this context is not limited to confidence in their own abilities. Their confidence in the skills of the adults assisting them to move is also important and is closely linked to how safe they feel.

For goal 5, comfort was later defined within the MoveMore intervention as being "happy and contented with how your body physically feels. You are free from pain and could stay in this position for longer." During the virtual workshops and interviews, the importance of other people understanding that regular movement maintained comfort for NAYP and could therefore be a facilitator of enhanced learning was discussed. Stakeholders felt this could motivate educational professionals to engage with promoting more regular movement. This was relevant to the "attitudes of others" facilitator category, and the facilitators of "understanding benefits of moving and risks associated with prolonged sitting" and "professionals' beliefs, attitudes, behaviours". Pain is a frequent phenomenon for NAYP (262, 263).

In these step 2 workshops, stakeholders prioritised maintenance of comfort and subsequent enhanced learning as a motivator for moving over other health and wellbeing benefits such as improved sleep / mental health benefits.

5.5 Discussion

This study reports the second step of the co-design of the MoveMore app. In workshops and interviews, participants ranked the SOS Framework determinants of sedentary behaviour (118) that they perceived were most amenable to change via a digital intervention. They selected three SOS determinants they felt the intervention should address: psychology and behaviour, institutional and home settings and physical health and wellbeing. They then selected 15 barriers and facilitators of reducing sedentary behaviour of NAYP that sat within these three SOS determinants that were modifiable via a digital intervention. Next, the modifiable barriers and facilitators were refined to identify five key goals that the MoveMore intervention should aim to achieve: 1) understanding the risks of sedentary time and the benefits of reducing it, 2) planning when and how young people could integrate movement into their daily routines, 3) ensuring NAYP and their adult supporters feel safe when moving and confident about their movement 4) ensuring the experience of movement is fun, enjoyable, rewarding, inspiring and 5) regularly reviewing comfort.

The socioecological model can be used to describe the levels at which interventions act using a hierarchical, rather than systems based model (264). The MoveMore intervention is likely to act at an individual, interpersonal and organisational levels of the socioecological model; which is in keeping with aiming to address the psychology and behaviour and institutional and home settings SOS framework determinants of sedentary behaviour. The MoveMore intervention is unlikely to act at the higher

community or public policy levels of the socioecological model, as SOS determinants such as built and natural environment in communities, society and cultural attitudes and politics and economics were ranked low in relation to being amenable to change via a digital intervention in this study. The physical health and wellbeing SOS determinant has broad scope and could act at any level of the socioeconomic model, however in the context of the goals of the MoveMore app, it is also likely to act at individual and interpersonal levels. Feedback relating to what was / was not considered changeable in the step one results summary demonstrated an appetite amongst stakeholders for interventions which act at higher levels of the socioeconomic model (that is the community or public policy levels), influencing SOS Framework determinants such as the built and natural environment in communities, society and cultural attitudes and politics and economics. Exploring stakeholder perspectives on developing interventions which act on these SOS determinants which operate at higher levels of the socioecological model would be beneficial.

It was noticeable that family members ranked the institutional and home settings determinant lower (fifth) than any other stakeholder group. It is possible that this reflects participants being a self-selecting group, containing parents who may be highly motivated about maximising physical activity for their children and professionals who are seeking strategies to address high levels of sedentary behaviour. As a result, the personal experiences of parents who participated may be that numerous opportunities for movement have been created in home and educational settings for their child already, and that other determinants have greater scope for change. Conversely, professionals may have contact with families and institutional settings with lower levels of motivation to create movement opportunities.

Having observed settings where supporting adults are not actively seeking opportunities to promote movement of NAYP, professionals may have seen more potential for change in the institutional and home settings determinant of sedentary behaviour than family members.

A strength of this study was the involvement of stakeholders in selecting which factors are modifiable. In other studies using the 6SQuID method step one has involved a review (88) and / or stakeholder engagement (87, 89). However, stakeholder involvement in step two, and decision making regarding which factors are perceived to be the most modifiable has not been reported. Empowering participants to lead decision making in this step of the 6SQuID is a unique approach. Prior studies suggest that step two decision making was undertaken exclusively by the research team.

The next step of the co-design (6SQuID step three), involved identifying how to bring about change (or the change mechanism), which will be used to achieve the five key goals identified in step two. The theoretical basis of the intervention was determined in step three. This involved selecting existing theory / theories to inform the theoretical basis of the MoveMore intervention, mechanisms of change and behaviour change techniques. This process was guided by the BCW guide to designing interventions (77). However, decision making about underpinning theory, mechanisms of change and behaviour change techniques was informed by both findings of steps one and two of this intervention co-design, and taking into consideration existing evidence relating to the five goals. Existing evidence relating to the goals is briefly summarised below.

For goal one (understanding the risks of sedentary time and the benefits of reducing it), there is limited evidence about the risks of sedentary time for NAYP specifically (Chapter 2). However, there is knowledge about the risks of sedentary time for the general population, and there is no evidence to suggest those risks are any different for people with physical disabilities (41). Guidelines recommending limitation of sedentary time and the rationale behind them therefore currently still applies to NAYP (6, 26). There is evidence that non-ambulant adults with CP have a higher risk of developing hypertension, cardiovascular conditions, pulmonary embolism, multimorbidity, musculoskeletal / cardiometabolic / pulmonary morbidity, osteopenia / osteoporosis and osteoarthritis than ambulant adults with CP (49). Non-ambulant children and adolescents with CP are also known to have high levels of blood lactate at rest, which reduces considerably after only one bout of 30 minutes of dynamic standing (66), cardiopulmonary endurance of ambulant children with CP is 70% lower than that of their able-bodied peers (234) and children with disabilities who are unable to sit independently or cruise (walk holding furniture) at 24 months are more likely to die in childhood (265). However, a causal relationship between these risks and sedentary time has not been demonstrated. Still, it is a possible catalyst for these observations. There is some research suggesting cardiomyopathy in Duchenne Muscular Dystrophy is associated with physical activity levels in which sedentary time was measured, however, the full methodology has not been published (48).

In relation to goal two (planning to move), parents having time, energy and resources needed to incorporate physical activity in their child's routines daily routines has previously been identified as a barrier to physical activity for children with CP, and engagement and motivation of professionals is a facilitator (57). Data collected in

step one of this co-design highlighted the complexity of planning movement activities for NAYP, which required the young person, their adult supporters, their equipment and an appropriate space for the proposed activity being available at the same time.

There is limited existing evidence relating to goal three (feeling safe and confident about moving). Parents have previously expressed that safety concerns can be a barrier to participation in sports activities for NAYP with complex needs and equipment (57) and have described NAYP becoming more fearful of falls and injuries as they mature (40). However, there is little evidence to date from NAYP themselves that fear of movement and lack of confidence can affect all daily movement routines. It is possible that stigma associated with expressing being fearful is a barrier to NAYP themselves disclosing this information. Previous research has identified fear of injury as barrier to physical activity by participants with spinal cord injury (aged 23-74) (266). In our step one data collection, this barrier was identified by a parent and not a NAYP. Undertaking qualitative exploration with NAYP which focuses on fear / lack of confidence as a barrier to movement in future research would provide insight into NAYP's perspectives of this barrier.

In contrast to goal three, there is considerable evidence relating to goal four (positive movement experiences) (1, 57, 58, 62, 239, 267-269). This evidence supports the concept that fun, enjoyment and socialising with peers is a key facilitator of movement for young people with physical disabilities. This existing evidence was reinforced by the discussions held in our co-design workshops. Participants emphasised the importance of promoting rewarding, inspiring, fun or enjoyable movement via the MoveMore intervention. NAYP needed to feel they could succeed when moving, which required careful planning of school or organised activities where

mixed groups of ambulant and NAYP participated, to ensure NAYP did not feel less successful than their ambulant peers. Several NAYP participating in the MoveMore intervention development described feeling demotivated about movement in childhood because they did not have an opportunity to feel successful when competing against ambulant peers. Goal four is linked closely to goal two (planning to move), as movement plans need to incorporate fun, enjoyment and success. Participants talked about NAYP planning new, inspiring activities that they had chosen as part of the intervention, or adapting existing activities so they were more interesting. They wanted to avoid documenting an existing routine of standing and physiotherapy that NAYP felt were boring, as that is not motivating.

For goal five, evidence shows that 69% adolescents with spinal muscular atrophy and Duchenne and Becker muscular dystrophy regularly experience pain and 50% have chronic pain. Prevalence of pain was the same, regardless of whether participants were ambulant or non-ambulant. Sitting and too much activity were both identified as common exacerbators of pain (262). Twenty-seven percent of non-ambulant children aged three - 10 years with CP report pain (263). Exacerbating factors for them were scoliosis and spasticity. Conversely, another study of children aged 2.5 - 16 years with CP found spasticity was not associated with pain, but was associated with bone and joint complications such as hip displacement, limited range of motion, windswept posture and scoliosis (270). The most frequent location of pain was the hips and feet (263). This evidence supports that regularly reviewing NAYP's comfort and acting to maintain it is important. Workshop participants explained that regular movement and position changes helped them to reduce and manage NAYP's pain, so this could be a good motivation to move. They also spoke about pain

preventing people from moving also. They felt that NAYP were more likely to move if any pain was minimised.

5.5.1 Limitations

Unfortunately, only a small number of family members were able to participate in workshops, relative to the number of NAYP and professionals. The small number of experts was expected. Greater diversity in gender, ethnicity and discipline of professionals would have improved representation of the broader population involved in the design and delivery of care for NAYP. In addition, participants being a self-selecting group who responded to open advertisement introduces selection bias. It is likely that participants have joined the study because they are interested in the topic and they may not be typical representatives of their stakeholder groups.

During workshops, individuals did not rank the SOS framework determinants. Rankings were a group decision following discussion. Each workshop included participants from a mixture of stakeholder groups. Therefore, to analyse differences between stakeholder groups in relation to which SOS determinants were amenable to change (Table 31), the ranking decisions of the mixed stakeholder group attending the workshop was used, provided there was at least one representative of that stakeholder group attending the workshop.

The final barriers / facilitators included in the mind map were selected by participants in the co-design workshops. However there was not an opportunity for co-design participants to subsequently feedback on the development of the mind map during the analysis process. However, the five key goals were shared with participants as part of step three in the co-design, to provide an opportunity for feedback.

5.6 Conclusion

This study described step two of the MoveMore (mobile application) intervention development, following the 6SQuID model. Modifiable barriers and facilitators of reducing sedentary time for NAYP, which could be addressed by a digital intervention, were identified by stakeholders using an established co-design process. Key stakeholders identified which SOS Framework determinants of sedentary behaviour were most amenable to change via a digital intervention. They selected 1) psychology and behaviour,2) institutional and home setting and 3) physical health and wellbeing). They then selected which of the barriers and facilitators linked to these determinants were most amenable to change. This led to the development of five key goals for the intervention, which were used to develop its programme theory in step three of the 6SQuID model.

6 Chapter 6: Step three of the 6SQuID. Identifying the change mechanism.

6.1 Title: Co-designing a digital behaviour change intervention to reduce sedentary time in non-ambulant young people: formulating the programme theory.

6.2 Introduction

The scientific definition of sedentary behaviour is “any waking behaviour characterized by an energy expenditure ≤1.5 metabolic equivalent units (METs) while in a sitting or reclining posture” (3). Reducing sedentary time is important because those who spend extended periods of time sedentary are at higher risk of negative health outcomes. Risks associated with high levels of sedentary time include cardiovascular disease, type 2 diabetes, some cancers and increased likelihood of death (7, 8). Television viewing may be associated with as many as 8% of deaths (all-cause mortality) and 29% of type 2 diabetes incidence in England (8). Physical activity guidelines in the United Kingdom (UK) and worldwide therefore include recommendations that sedentary time is limited (6, 26).

This study relates to the co-design of a digital behaviour change intervention called MoveMore, which is a mobile application (app). The MoveMore app aims to support non-ambulant young people (NAYP), aged 13-25 years, to reduce their sedentary time. NAYP are unable to walk (or only walk short distances indoors using equipment such as a body support walker) due to long term disabilities such as cerebral palsy (CP), spina bifida, muscular dystrophies, traumatic spinal cord / brain injuries or rare conditions. Those who are able to walk short distances often do so as part of a therapy or exercise programme and not as a method of functional mobility.

Valid measurement of sedentary time of NAYP in free-living environments remains challenging (38, 157), however there is consensus that NAYP spend more time sedentary than able-bodied young people (33, 158, 159, 209, 212) and ambulant young people with physical disabilities (33, 158, 159, 210, 215). The MoveMore intervention focuses on 13-25 year olds, because there is some evidence from both device-based and qualitative studies that NAYP's sedentary time increases as they age, with puberty being particularly challenging in this respect (33, 40, 214).

There is an evidence gap in relation to risks associated with sedentary time for NAYP specifically (38, 41, 44). It is assumed that risks would be akin to those experienced by the general population. However, when the complex health needs of this population and their frequent multimorbidity is taken into account (49), risks may be higher. NAYP are therefore likely to have high risk of poor health outcomes associated with sedentary time. There are no evidence-based interventions which aim to reduce sedentary time of NAYP. The MoveMore app is being co-designed to meet this need.

The MoveMore app has been co-designed using the Six Steps in Quality Intervention Development (6SQuID) model (86). Step one of the 6SQuID involved defining and gaining an in depth understanding of the problem from the perspective of stakeholders (Chapters 2-4). Qualitative data were analysed to produce a list of barriers and facilitators of sedentary behaviour in NAYP. In step two, the causal / contextual factors which had the greatest scope for change were identified (Chapter 5). Both steps were completed in partnership with stakeholders including NAYP, family members of NAYP, health, educational and social care professionals and experts in disability, behaviour change and intervention development. Stakeholder

involvement is central to the 6SQuID model and strongly advocated in the recently updated Medical Research Council Guidance for Developing and Evaluating Complex Interventions (73). Stakeholders participated in every 6SQuID step in the MoveMore app intervention development.

Step one of the 6SQuID (Chapters 3 and 4) highlighted that NAYP rely upon people who care for them to support them to move. Family members, carers and professionals who help NAYP to move are therefore integral to the success of the MoveMore intervention and will be included in it as “adult supporters” (AS). Step two culminated in the identification of five key goals the intervention should address (chapter 5). These were : 1) understanding the risks of sedentary time and the benefits of reducing it, 2) integrating movement into NAYP’s daily routines, 3) ensuring NAYP feel safe and confident when moving 4) creating positive movement experiences and 5) optimising comfort.

This study describes the third step of the 6SQuID model, which aims to identify how the intervention will bring about change, or the “change mechanism(s)”. This involves formulation of programme theory for the intervention and selection of established mid-range theories which will underpin the programme theory (271). Programme theory is specific to an individual intervention or programme (271). It explains how the intervention is thought to result in the desired outcomes being achieved, explicitly identifying the targeted active ingredients within the intervention that create change (86, 271). Programme theory also describes the expected outcomes of an intervention and methods of achieving those outcomes (271). Logic models can be used to diagrammatically present programme theory for interventions (73).

It is considered good practice for programme theory to be underpinned by established mid-range theories of behaviour change (73, 77-80, 271), although this is not essential (86). Mid-range theories are not specific to individual interventions, but are not as all-encompassing as grand theories, that apply to multiple domains at a broad, overarching level (271). They therefore form an intermediary between programme theory and grand theory, each one having relevance to a narrow range of specific phenomenon. Examples of mid-range theories include Bandura's self-efficacy theory (272), the Theory of Planned Behaviour (273) and self-determination theory (SDT) (85).

Proposed benefits of referring to mid-range theory or theories include 1) guiding selection of goals or aims for the intervention, 2) enabling explicit description of the intervention's proposed mechanisms of action, 3) informing the intervention's content and delivery, 4) increasing the likelihood of the intervention being effective (75, 76) and 5) providing testable hypotheses that can be explored in empirical research during evaluation (274). However, it is acknowledged that there is insufficient evidence to demonstrate with certainty that theory-based interventions are more effective than those that are not (81). Indeed, the Medical Research Council Framework for Developing and Evaluating Complex Interventions presents theory based intervention development as being one of four possible perspectives that can be used guide intervention development (73). For interventions addressing physical activity and / or diet specifically, interventions based on control theory, motivational interviewing or SDT may be associated with improved effectiveness (81). Regardless of the role established theory plays, development of programme theory is strongly advocated as a core element of intervention development (73, 86).

The Behaviour Change Wheel (BCW), a theory and evidence-based tool for intervention development (77), has been used to guide development of programme theory for the MoveMore app. The BCW tool was selected because it is a comprehensive, evidence-based tool. It incorporates multiple theories, models and frameworks spanning a number of different disciplines (77).

The BCW tool was developed by undertaking a systematic search and evaluation which identified 19 relevant behaviour change frameworks (120). When intervention categories were extracted from these frameworks, it became evident that the categories needed to be divided into intervention functions (activities that change behaviour) and policies (actions of responsible authorities that enable / support interventions) (120). The term intervention “function” rather than type / category was chosen to facilitate being able to utilise multiple intervention functions within one intervention (77). Nine intervention functions and seven policy categories were identified in consultation with behaviour change experts.

The intervention functions and policy categories form two rings around a central hub of the BCW (Figure 5). The central hub contains a behaviour system, which has three components, capability, opportunity and motivation. The behaviour system is therefore known as COM-B (77). Each COM-B component links to specific intervention functions and policy categories in the surrounding rings. The BCW tool provides a systematic intervention development process. The process begins by assisting intervention developers to gain a theoretical understanding of the target behaviours they wish to address by considering which COM-B components influence the target behaviour (77). They can then identify the most appropriate mechanisms,

theories and behaviour change techniques to use to elicit behaviour change and achieve the intended target behaviours.

In this study, the BCW approach was used to understand the behaviours required and the behaviour changes needed to meet the five intervention goals in terms of capability, opportunity and motivation. This facilitated selection of an established mid-range theory to underpin the programme theory. The mid-range theory selected was self-determination theory (SDT) (85). The rationale for selecting SDT as the mid-range theory for the MoveMore intervention is described in the results section. SDT is a broad motivational theory, encompassing six more specific theories (cognitive evaluation theory, organismic integration theory, basic psychological needs theory, causality orientations theory, goal content theory and relationship motivation theory). SDT has three core constructs: autonomy (being able / having volition to choose), competence (feeling capable and effective to achieve outcomes) and relatedness (feeling related to others) (85). It proposes that when the psychological needs of autonomy, competence and relatedness are met, individuals are more likely to be autonomously motivated to maintain a health related behaviour. This is because they undergo a process of internalisation and integration, leading to self-regulation in relation to that behaviour (85). Behaviours are less likely to be sustained when motivation is controlled, i.e. regulated by external factors or controls such as rewards, avoiding punishment, guilt or seeking approval (85).

The concept of motivation is described in different ways in the SDT and the COM-B BCW model. SDT focuses on the quality of motivation, with more intrinsic motivation being achieved when the psychological needs of autonomy, relatedness and competence are met (85). The COM-B model takes a more applied view of

motivation, dividing it into conscious (reflective motivation) and automatic (automatic motivation) processes (77). Reflective motivation relates to analytical decision making, encompassing formation of intentions, setting of goals and consideration of potential outcomes. Automatic motivation encompasses habits and emotional responses. In the COM-B model, motivation interacts with capability and opportunity (77). These differing approaches in the COM-B model and SDT are not conflicting and have been integrated in recent intervention developments (275).

The Theoretical Domains Framework (TDF) (84) describes 14 mechanisms of action that intervention developers can use to change behaviour. The TDF was developed by bringing together 33 different behaviour change theories, which contained 84 constructs. Since publication of the TDF, additional mechanisms of action have been identified via the Human Behaviour Change Project, which features 26 mechanisms of action in its Theory and Technique Tool (276). The three psychological needs of autonomy, relatedness and competence from SDT have also been described as mechanisms of action for behaviour change (123, 127) and were considered in addition to the TDF mechanisms of action in the development of programme theory for the MoveMore intervention.

Selecting appropriate mechanisms of action from the TDF forms part of the BCW intervention development process (77). It facilitates identification of which intervention functions and behaviour change techniques (BCTs) (122) are most likely to be effective (121). BCTs are defined as “an active component of an intervention designed to change behaviour” (77). Following the systematic process described in the BCW intervention development guidance (77) allows explicit description of programme theory and change mechanisms used in interventions. The process

supports the identification of pre-defined mechanisms of action and BCTs which are widely used in the field of behaviour change science.

Indeed, Gardner et al. undertook a review to explore the potential of intervention functions and BCTs used in interventions to reduce sedentary behaviour in adults (124). Only two of the 38 interventions included were delivered online and none of them were delivered via mobile apps. The four most promising intervention functions were education, training, persuasion and environmental restructuring. The most promising BCTs were self-monitoring of behaviour, problem solving, and changing the social or physical environment (124).

These promising BCTs were delivered in interventions in the workplace (14 studies), community (seven studies), online (two studies) or at home (one study). The most frequently used BCTs in apps for adults which aim to reduce sedentary behaviour or increase physical activity / improve diet are self-monitoring, goal-setting and performance feedback (144-146). Problem solving (a promising BCT in Gardner et al.'s review (124)) and goal-setting (frequently used in digital interventions) are quite different techniques. The problem solving technique involves analysis of factors that influence the behaviour and selection of strategies to reduce barriers or increase facilitators, whereas goal setting involves setting a goal to perform a specified behaviour or achieve a specified outcome via a behaviour change (77). With the exception of self-monitoring, the BCTs used in digital interventions were different to the most promising BCTs delivered in more traditional settings.

Self-monitoring tends to be a prominent technique in interventions targeting sedentary behaviour, physical activity and weight management / diet (124, 125, 144-

146). Aldenaini et al. identified self-monitoring was used in 90% of studies aiming to reduce sedentary behaviour or increase physical activity via persuasive technology (125). Their findings indicated that self-monitoring was an effective or partially effective strategy in 79% of the studies (125).

BCTs used within apps to increase physical activity, reduce sedentary time and improve diet of able-bodied children and adolescents has also been explored. Seven of 25 apps in Schoeppe et al.'s review aimed to specifically reduce sedentary time (139). The apps were pragmatic and not underpinned by theory. The most frequently employed BCTs were providing instructions, providing general encouragement, providing contingent rewards and providing feedback on performance. These techniques are all different to those that were highlighted as being most promising in interventions to reduce sedentary behaviour in adults (124). Effectiveness was not explored in Schoeppe et al.'s review, but children and young adults' engagement with the apps was low, leading the authors to suggest there was a need to improve understanding of factors that would affect engagement in this younger population (139).

There are more apps for adults which aim to reduce sedentary behaviour than there are for children or young people (125). In Aldenaini et al.'s review (125), only 5% of persuasive technologies for increasing physical activity and reducing sedentary time were appropriate for children aged 13-17 years, rising to 12% for young adults aged 18-30 (125). Effectiveness of these apps for children and young people were at least 10% lower than the effectiveness of similar apps targeted towards adults (125). Schoeppe et al. (139) and Aldenaini et al.'s (125) conclusions suggest that previous attempts to design apps for young people that target sedentary behaviours have had

limited success in comparison to similar apps for adults, perhaps due to the BCTs being used. Involving young people in development of programme theory may address these previous difficulties and enhance the effectiveness of app-based interventions targeting sedentary behaviours.

The objective of step three of the 6SQuID (86) co-design was to formulate the theoretical foundations of the MoveMore intervention by:

1) identifying the behaviours and behaviour changes needed to achieve the five key goals of the MoveMore intervention with stakeholders. Gaining an understanding of the behaviours and behaviour changes needed in relation to COM-B,
2) using feedback from stakeholders to inform selection of an appropriate mid-range theory to underpin programme theory of the MoveMore intervention,
3) selecting mechanisms of action, intervention functions and BCTs for each intervention goal, which are appropriate to the mid-range theory and desired behaviours,
4) producing a logic model which diagrammatically represents the programme theory for the MoveMore intervention and
5) considering potential unintended outcomes of facilitating the desired behaviours with stakeholders.

6.3 Methods

This study was granted ethical approval by the London - Camberwell St. Giles Research Ethics Committee (Ref: 20/LO/0011). Data collection took place January 2022 – March 2022 via virtual workshops and 1:1 interviews on Microsoft teams. All

UK restrictions due to the Covid-19 pandemic were lifted in February 2022. As it had been uncertain when this would occur, the protocol stated all data collection would be virtual. This allowed NAYP who were at greater risk of illness from Covid-19 due to pre-existing health conditions to participate without needing to travel or meet others face to face. It also facilitated participation of stakeholders from a wide geographical area, including international recruitment of stakeholders who were experts.

6.3.1 Participants and recruitment

The following stakeholders were invited to take part in the co-design: 1) NAYP, 2) family members of NAYP, 3) carers and healthcare / education professionals with experience of working with NAYP, 4) experts in, disability, sedentary behaviour, behaviour change and / or digital health interventions, 5) other members of the public who wished to contribute. The fifth stakeholder group was included to improve rigour by maximising inclusivity. It ensured that people who wished to contribute, but did not fit the criteria for stakeholder groups one-four, were able to join the co-design without having to falsely represent themselves. For example, this fifth group allowed people with disabilities who were over 25 years or ambulant to participate, without stating that that they were a NAYP. NAYP had lifelong disabilities and were aged 12-25 years. All other stakeholders were ≥16 years of age. Experts were recruited internationally. All other stakeholders were recruited from the UK. Participants needed to have sufficient cognitive ability to participate in a workshop / interview and to provide informed consent / assent. Participants needed to be able to able to communicate in English.

The study was advertised via clinicians sharing information in appointments, a poster campaign, social media, word of mouth and a study web page. Participants were

offered a gift of £10 (via bank transfer from the NHS Trust which sponsored the research), to thank them for their contributions.

Recruitment and consent procedures are described in greater detail in Chapter 3.

6.3.2 Sample size

To ensure the co-design continued if recruitment or ongoing contribution to the co-design steps proved challenging, the minimum overall sample size was low (4 participants). It was necessary for there to be one participant from each of the key stakeholder groups. No maximum sample size was required and all participants who responded to the invite were offered an opportunity to contribute.

6.3.3 Data collection

6.3.3.1 Participant characteristics:

Participants completed an online survey to provide demographic information and some additional information that varied according to stakeholder group (Appendix 5).

6.3.3.2 Workshops and interviews:

When participants had provided online consent and completed the online survey, they were sent a selection of workshop dates and times to choose from. If participants were unable to attend any workshops or if they preferred to be individually interviewed, they suggested convenient interview dates / times. In line with advice relating to conduct of focus groups (248) workshops included two - 10 participants. Following the advice of public and patient involvement (PPI) representatives during protocol development and due to the emphasis on theoretical grounding, data collection in this step of the co-design initially only included professionals and experts. Once proposed programme theory had been formulated

and a draft logic model had been prepared, proposals were shared with NAYP and family members of NAYP for feedback and refinement. NAYP aged 12 - 15 years were interviewed rather than being invited to workshops. This approach was taken to ensure they could contribute openly and honestly, without their contributions being negatively impacted by potential power imbalances with other participants (255, 256).

Workshops and interviews were carried out on Microsoft Teams and were video recorded. A data protection impact assessment was followed, which described storage and management of study data.

6.3.3.3 Workshop / interview structure:

A proposed logic model was produced prior to the step three co-design workshops based on data collected in steps one – two. This enabled stakeholders to provide feedback on the logic model in these workshops. An existing logic model (132), was adapted for this intervention. This logic model was designed for complex interventions delivered in multiple contexts. It was deemed appropriate for this digital intervention because the intervention will require adaptation to context and the logic model provides sufficient flexibility for this adaptation to occur.

An online whiteboard called Jamboard (hosted by Google) was used in all workshops and interviews to facilitate collaborative working in real time during workshops. Two templates were created on Jamboard, the first for initial workshops with professionals and experts and a second for NAYP and family members to feedback on the behaviours the app will aim to elicit. Within each workshop participants were identifiable, as they were visible on camera and used their first names. Jamboards were configured to only allow access to those participating in the study. However to

ensure anonymity in the unlikely event of anyone else gaining access, initials rather than names were used to label contributions.

Workshops were facilitated by the first author (MB), who has worked with NAYP and their families as a clinician and facilitated co-design workshops previously. As lead facilitator, there was potential for MB to inadvertently direct participants' discussions due to prior knowledge and opinions on this topic. To mitigate this, it was openly discussed with participants as a potential source of bias. Participants were encouraged to challenge the facilitator freely. The facilitator drew upon conversations from other workshops / interviews or clinical experiences to probe and challenge wherever possible, rather than discussing their own opinions. A second facilitator from the research and innovation team at a community NHS Foundation Trust was also present in workshops and was asked to be mindful of this and to intervene by refocusing the workshop if required. The second facilitator did not have experience of working with young people with disabilities and their families prior to supporting the MoveMore app co-design. They were available to make field notes and to speak to any participants outside of the group if they were concerned about anything or needed signposting to sources of support.

The facilitators strived to create a psychologically safe environment within groups, so participants felt comfortable sharing their views (277). Ground rules were shared which encouraged participants to listen respectfully to each other's views and to accept that others may have different opinions or perspectives to their own.

Table 34 summarises the structure of the focus groups for professionals and experts / NAYP and family members.

Table 34 Structure of 6SQuID step three co-design workshops / interviews and rationale.

Activity	Rationale
Ground rules reminder.	Participants accepted ground rules prior to step 1, so were reminded of them at the beginning of the workshop.
Introductions. Participants asked not to disclose where they lived / worked / attended school.	Participants familiarised with each other's professional roles / background / motivation for participating. Disclosure of location was restricted to preserve confidentiality.
Co-design update. Shared 5 key goals of the intervention and first draft of the intervention logic model.	Remind participants about the aims of the intervention. Share outcome of step 2 analysis (key goals) for feedback. Share proposed logic model which diagrammatically draws together findings of steps 1 and 2 for feedback.
Professionals / experts workshops. For each goal: Identify the behaviours and changes needed to achieve each goal What would motivate NAYP / AS to achieve each goal, what would be the barriers to doing the required behaviours? Are there any possible unintended outcomes from doing the behaviours we discussed?	These data will be analysed using the COM-B tool to inform selection of an appropriate mid-range theory / theories, mechanisms of action, intervention functions, behaviour change techniques. Identify possible unintended outcomes of intervention. Discuss how they could be mitigated.
NAYP / Family members workshops. Present slides for each goal listing the behaviours of NAYP and AS the intervention is intended to elicit for feedback. Discuss possible unintended outcomes raised by professionals / experts and asked about others.	Ensure list of behaviour changes the app is intended to elicit suggested by professionals / experts is in keeping with the views of NAYP and family members. Add any additional behaviour changes that were missing prior to identification of a mid-range theory / theories, mechanisms of action, intervention functions, behaviour change techniques. Discuss unintended outcomes identified with NAYP / family members and mitigations for them. Identify any additional unintended consequences.

Note: NAYP: Non-ambulant young people, AS: Adult Supporters

The five intervention goals were an output of step two of the 6SQuID and had not been seen by participants prior to these step three workshops, where they were shared for feedback. Both video recordings of workshops and the completed Jamboards acted as the raw data set. Suggested changes to the logic model / goals were either made prior to the next workshop or were discussed during it, so participants were aware of them.

6.3.4 Analysis

Raw data from the Jamboards and video recordings were used to produce an intervention matrix table (Table 37). For each goal, the intervention matrix summarised: desired behaviours, who would engage in the behaviours, the change needed to reach those desired behaviours in relation to the six spokes of the COM-B hub (Figure 5), short and long term outcomes and proposed outcome measurement / evaluation measures. Potential unintended outcomes and mitigations were summarised in a separate table (Table 39).

Outcomes and evaluation measures were not discussed in step three workshops. These were added to the matrix by the research team, but were selected based on data collected in steps two and three in relation to what the intervention should aim to change.

To produce the intervention matrix and potential unintended outcomes and mitigations tables, each Jamboard note which was relevant to desired behaviours / changes needed / unintended outcomes and identified a new behaviour / change / unintended outcome or mitigation was summarised and added to the tables. Following this, video recordings were watched again by the first author (MB) who extracted any additional behaviours / changes that were not recorded on the Jamboard and added these to the tables. Potential mitigations of unintended outcomes were also suggested by the research team and a PPI representative as part of data analysis and were added to the relevant table.

The intervention matrix was circulated to members of the research team, who have expertise in theories of behaviour change and motivation and intervention

development. The research team reviewed the data collected individually then met to discuss which mid-range theories may be appropriate to underpin the programme theory. The mid-range theory was selected in a follow up meeting.

Describing the changes needed in relation to each of the COM-B spokes in detail allowed the predominant COM-B components for each goal to be identified. Selection of TDF mechanisms of action for each goal was guided by links between COM-B components and specific TDF mechanisms of action which are described in The BCW Guide to Designing Interventions (77). A predominant SDT mechanism of action was selected for each goal (autonomy, competence or relatedness), with reference to stakeholder data which was summarised in the intervention matrix (85).

A maximum of two intervention functions were selected for each goal, to provide focus and clarity. If multiple intervention functions were used for each goal, programme theory and subsequent evaluation of the intervention would be highly complex. Both TDF mechanisms of action and COM-B components are linked to specific intervention functions in the BCW intervention development guide (77). Selection of intervention functions for each goal was informed by the intervention matrix, these proposed connections and SDT. Several intervention functions, such as coercion and restriction, are not in keeping with the constructs and tenets of SDT and could be excluded (85).

Policy categories were selected using a combination of recommended links from the BCW guide (77), guidance from SDT and consideration of what was possible via a digital behaviour change intervention. For example, legislation and fiscal measures

cannot be delivered via digital behaviour change interventions and are not in keeping with SDT, as they are external rather than intrinsic sources of motivation.

Selection of appropriate BCTs was informed by several resources. The changes needed to achieve the desired behaviours were described by stakeholders in the intervention matrix. Recent work by Carey et al. (121) explored links between mechanisms of action and BCTs in publications relating to design of interventions. The intervention matrix, BCW guide (77), SDT (85) and Carey et al.'s work (121) were drawn upon during decision making. Two classifications of BCTs were used, the behaviour change technique taxonomy (v1) (122) and a classification of BCTs which are specific to SDT (127). Candidate BCTs selected from the taxonomy (122) were assessed using the APEASE criteria (affordability, practicability, effectiveness/cost effectiveness, acceptability, side-effects/ safety, equity) to ensure appropriateness (Appendix 11).

Selection of predominant COM-B components, mechanisms of action, intervention functions, policy categories and BCTs was initially undertaken by the lead author (MB), then discussed with the research team to refine the choices made.

6.4 Results

A total of 19 participants were recruited, including 12 professionals, two NAYP, two family members and three experts. Four co-design workshops were held (three for professionals / experts, one for NAYP and family members) and five interviews were conducted. Each workshop included two - five participants. One NAYP contributed to a workshop with family members of NAYP (including a member of her own family), whereas the younger NAYP chose to be interviewed. One NAYP used a

communication aid and participated in the interview with the support of a carer. The remaining four interviews were with professionals and experts.

6.4.1 Participant characteristics

Participant characteristics are shown in Table 35. The majority of participants were professionals. A high proportion of participants were white British females, however there was some diversity in relation to both sex and ethnicity. Information from the online survey showed both NAYP had CP and lived at home with their parents. They reported spending “most” or “almost all” of the day lying / sitting. The two NAYP reported spending one - two hours and five - six hours sitting or lying without interruption. In this step of the co-design, family members who participated were both parents of the NAYP who participated.

The majority of professionals were physiotherapists, however there was also an occupational therapist, teaching assistant, PE teacher and service manager.

Two of the experts were academic researchers whose work focused on participation and physical activity of young people with CP and co-design of health interventions, including interventions to reduce sedentary behaviour following stroke. One of the academic researchers was an international recruit. The third expert was an experienced advisory teacher for children with physical disabilities.

Table 36 shows how the number of participants from each stakeholder group varied in comparison to step two of the intervention development.

Table 35 Participant characteristics for step three of the 6SQuID.

Stakeholder group / characteristic	Number of participants (%)	Age in years: mean, median, range	Gender: Number (%)	Ethnicity: Number (%)	Employment status / Role: Number (%)
1. Young person aged 12-25 who is non-ambulant.	2 (10.5%)	16, 16, 15-17	Female: 2 (100%)	White – British: 2 (100%)	School/college/sixth form student: 2 (100%)
2. Family members of non-ambulant children and young people	2 (10.5%)	53.5, 53.5, 53-54	Female: 1 (50%) Male: 1 (50%)	White – British: 2 (100%)	At home most days (not working): 1 (50%) Working full time 1 (50%)
3. Health and education professionals	12 (63.2%)	38.1, 35, 28-54	Female: 9 (75%) Male: 3 (25%)	White – British: 10 (83.3%) White – Any other background: 1 (8.3%) Black or Black British – African: 1 (8.3%)	Working full time: 10 (83.3%) Working part time: 2 (16.7%)
4. Experts	3 (15.8%)	39, 37, 34-46	Female: 3 (100%)	White – British: 1 (33.3%) White – Irish: 1 (33.3%) White – Any other background: 1 (33.3%)	Working full time: 1 (33.3%) Working part time: 2 (66.6%)
5. Total	19 (100%)	37.6, 36, 15-54	Female: 15 (78.9%) Male: 4 (21.1%)	White – British: 15 (78.9%) White – Any other background: 2 (10.5%) White – Irish: 1 (5.3%) Black or Black British – African: 1 (5.3%)	Working full time: 12 (63.2%) Working part time: 4 (21.1%) At home most days (not working): 1 (5.3%) School/college/sixth form student: 2 (10.5%)

Table 36 Change in participant numbers in step three of the 6SQuID in comparison to step two.

Stakeholder group	Attrition (took part in step 2, but not step 3)	New participants	Returning participants (took part in step 1 but not step 2)
1) Young person aged 12-25 who is non-ambulant.	3	0	0
2) Family members of non-ambulant children and young people	1	0	0
Health and education professionals	5	2	1
4) Experts	0	1	0
5) Other members of the public	0	0	0

6.4.2 Objective 1) Identifying the behaviours / behaviour changes needed to achieve the five key goals of the MoveMore intervention. Understanding the behaviours / behaviour changes needed in relation to COM-B.

This objective was achieved via production of the intervention matrix (Table 37) from raw data collected in step three. Participants agreed with the proposed key goals of the intervention, however the goal definitions were refined by participants in these step three workshops. The final versions are shared in the intervention matrix (Table 37). A relevant change was suggested for goal three by a family member. They highlighted the importance of the AS feeling confident about assisting the NAYP to move, in addition to the NAYP feeling safe and confident. The word sedentary had been included in the goal one definition. Using this word had been avoided throughout the co-design, due to evidence of people with disabilities perceiving it to be a negative term (43). The phrase “sedentary time” was removed from the goal one definition and was replaced with “spending a long time sitting or lying still”.

Goals two and four involve NAYP planning with AS how they wish to fit more movement into their daily routines and identifying new enjoyable and motivating activities they may wish to do. The professionals / experts raised an important potential barrier to this action planning behaviour. They highlighted possible power imbalances between NAYP and AS on whom they rely. The professionals / experts highlighted that NAYP may find it difficult to request changes to existing routines and to plan new activities, which are likely to involve increased demand on AS. Mitigating actions were discussed across workshops and interviews. Stakeholders agreed NAYP needed to feel empowered to request change. In response, the lead facilitator (MB) proposed that NAYP nominate their AS, so they can choose people they feel comfortable talking to. In addition, MB proposed the NAYP nominating one AS in each setting (for example home / school / community centres) they regularly go to, who would be a “key contact”. It was suggested that the “key contact” would act as the NAYP’s advocate, discussing potential behaviour changes with other AS on their behalf. This would avoid the NAYP needing to express their desired changes in situations where multiple AS may be present, with one or more being resistant to making those changes. The behaviours of key contacts are described in the intervention matrix (Table 37).

Table 37 Intervention matrix for the MoveMore intervention.

MoveMore Goal	**1. Understanding why it is important to move more**	**2. Planning when and how to move**	**3. Preparing to move**	**4. The experience of moving**	**5. Optimise comfort**
Goal definition	To know and understand the benefits of moving more and the risks of spending a long time sitting or lying still.	Identify and plan when and how NAYP can move more during daily routines. Review the plan regularly.	Ensure the NAYP and their AS feel confident about a movement and the young person feels safe before moving.	NAYP having positive experiences of moving.	NAYP and AS communicate about comfort and act to optimise it if needed.
Who? **NAYP / AS**	All	All	All	All	All
Desired behaviours needed to achieve the goal	AS and NAYP : Access small volumes of accessible information received at regular intervals over the course of the intervention. Reflect on how this information relates to them. AS: Assist NAYP to access and	NAYP nominates an AS they trust (key contact) in each setting they go to regularly. Nominated AS confirms whether they can act as a key contact. NAYP shares with key contacts what movements they want to do, when and how they would like to integrate movement into daily routines. AS and NAYP access resources to obtain information about local opportunities or	Key contact discusses NAYP's moving and handling plan with them. NAYP feeds back their views and any requested changes to key contact. Key contact and NAYP negotiate with wider team of AS to accommodate NAYP's requests where possible. NAYP and AS feedback whether the plan is working / needs amending.	NAYP and supporters regularly discuss what movement opportunities the NAYP wishes to explore. NAYP identifies their movement goals with support from AS to make them SMART. Any new actions needed to reach the goals incorporated into movement plan (goal 2).	NAYP and key contact discuss whether NAYP feels discomfort. If so when / where / how frequently. Does moving relieve their discomfort? NAYP and key contact decide and record how they will communicate about comfort, make an action plan for optimising comfort and follow it. This is

MoveMore Goal	1. Understanding why it is important to move more	2. Planning when and how to move	3. Preparing to move	4. The experience of moving	5. Optimise comfort
	understand the information.	hear about the experiences of others. Key contacts share movement ideas / opportunities NAYP may not have considered / be aware of. Key contacts and NAYP negotiate with wider team of AS and accommodate NAYPs movement requests where possible. NAYP and AS create a detailed, comprehensive and flexible plan that NAYP and AS can access. AS / NAYP record adherence to plan. Plan is reviewed and updated when required in consultation with NAYP and key contacts.	Moving and handling plan is regularly reviewed. List of suggestions for when NAYP doesn't feel confident is agreed by NAYP and AS. AS can access information about how to move NAYP and list of suggestions for when NAYP is not confident. Before movement, AS ask NAYP if they feel safe and confident to move. Agreed list of suggestions is referred to if NAYP is not confident about a movement.	Key contact negotiates with wider team of AS on behalf of NAYP to accommodate NAYP's movement requests where possible. AS communicate and collaborate to overcome common barriers to goal achievement wherever possible. NAYP is involved in decision making about their equipment.	reviewed when needed. AS make any onward referrals needed as part of action plan. NAYP and AS monitor and record comfort level in app as appropriate to setting and individual. List of signs that young person is uncomfortable is produced (optional, as appropriate to NAYP and setting). If discomfort is repeatedly reported this is treated as an early warning sign and HCPs need to be involved to identify and address the physical / psychological needs.

MoveMore Goal	1. Understanding why it is important to move more	2. Planning when and how to move	3. Preparing to move	4. The experience of moving	5. Optimise comfort
Change needed in relation to COM-B: **Capability**	**Psychological capability:** Information is made accessible to overcome cognitive impairments / language barriers. Ensuring AS who discuss information with NAYP have the skills and confidence to do this effectively. Challenging beliefs that movement will result in harm, for example if fear of pain is a barrier. **Physical capability:** Information is made accessible to overcome hearing / visual	**Psychological capability:** Knowledge from goal 1. Training materials for key contacts in core concepts needed to deliver the intervention. Knowing how to create the plan in the app. Knowledge of affordable, accessible local opportunities and facilities. Sharing of new ideas to promote movement for inspiration (needs to be individualised, moderated for appropriateness, achievable for AS). Appreciating that small movements can require considerable effort. Input from HCPs to manage risk of new plans.	**Psychological capability:** Training materials for key contacts in core concepts needed to deliver the intervention. Access to moving and handling / postural care plan / checklist that NAYP has co-produced with AS. Empowering / supporting NAYP to be able to feedback how they feel and communicate their preferences, opinions, confidence and perceived safety. (psychological strength). Access to list of actions to take when NAYP doesn't feel confident. AS facilitating movement are sufficiently skilled for NAYP / family to trust them.	**Psychological capability:** Training materials for key contacts in core concepts needed to deliver the intervention. Input from HCPs to advise about new activities / movements and assist with managing risk. Sharing of new ideas to promote movement for inspiration between AS and with other settings (needs to be individualised and moderated for appropriateness). AS have the skills needed to facilitate movement / new activities, so they can do it with confidence. NAYP having confidence to try group activities.	**Psychological capability:** Training materials for key contacts in core concepts needed to deliver the intervention. NAYP has a method of communicating comfort level on an appropriate scale / location of discomfort. AS familiar with non-verbal signs that young person is uncomfortable. An awareness that unpleasant sensations are not always harmful. Reframing of beliefs if indicators of chronic pain are present (context specific).

MoveMore Goal	1. Understanding why it is important to move more	2. Planning when and how to move	3. Preparing to move	4. The experience of moving	5. Optimise comfort
	impairment barriers.	Refer to existing resources such as postural management plans. **Physical capability:** Ensuring equipment is close by and available when needed.	Context specific: Involvement of moving and handling advisors. **Physical capability:** Time to produce the plan in the app. Capacity of HCP's to train supporters in new skills. Equipment is available and appropriate.	**Physical capability:** Capacity of HCPs to train AS to facilitate new movements / activities. Online resources to upskill AS – ideas / advice and training.	
Change needed in relation to COM-B: **Opportunity**	**Social opportunity:** AS talk about information face to face with NAYP. Time delivery of information to coincide with experiences they have or movement tasks (e.g using stander / walker) / in specific lessons when it is more likely to be taken onboard e.g.	**Social opportunity:** NAYP at centre of decision making and has choice. Culture in the setting supports the desired behaviours. NAYP speaks to a trusted person in a private environment. Input from HCPs to recommend appropriate frequency of movement. Communication between AS during transition (e.g. children's	**Social opportunity:** NAYP being supported to regularly communicate their preferences, opinions, confidence and perceived safety and them having the confidence to do so. When NAYP doesn't feel confident, identifying and recording why (context specific). NAYP trusts key contacts. NAYP and family trust the AS moving the NAYP.	**Social opportunity:** NAYP has choice and control over the movements / activities they wish to do, equipment they use and who they do activities with wherever possible. AS have mental capacity to invest time and effort in movement being a positive experience (not feeling rushed / pressurised).	**Social opportunity:** NAYP feels able to share how comfortable they are and is involved in decision making re: action plan to optimise comfort. NAYP speaks to a trusted person in a private environment. All ASs engaged in this goal to facilitate reporting and recording.

MoveMore Goal	1. Understanding why it is important to move more	2. Planning when and how to move	3. Preparing to move	4. The experience of moving	5. Optimise comfort
	health orientated lessons, PHSE vs self-selected timing of access. Release gradually but archive available. **Physical opportunity:** AS and NAYP have time to look at information together Private environment to discuss personal aspirations and for NAYP to ask potentially sensitive / emotive questions. Information available via a range of media formats.	to adult services) improves because plan moves with NAYP through transition points. Flexibility in school timetables. Incorporate activity into routines from a young age. **Social and physical opportunity:** Co-operation of settings and NAYP with engaging in intervention. Maximising opportunities to move in existing routines to assist with supporters' capacity e.g. active travel, floor play with siblings. Marrying up when NAYP wants to move with when AS have capacity to help them. May need flexibility and negotiation. Using feedback about execution of plan to identify barriers / need for review.	**Physical opportunity:** Having time and a private place to regularly discuss how NAYP feels physically and mentally. Allowing time for NAYP to process what movement is going to happen (facilitated by goal 2). AS and NAYP have time, appropriate environment and resources available to follow moving and handling plan and for any actions if NAYP not confident. NAYP involved in deciding when to try new movements and has opportunity to practise challenging movements in a safe environment.	Flexibility in timing / how challenging activity is to accommodate changes in mood / energy levels / pain / co-morbidities etc. School sports more inclusive. Opportunities to work individually, small group or with a specific partner. Being supported to attend activities without a parent e.g., with carer / peer /sibling. **Physical opportunity**: Timely cues / reminders to move / change position when support available to do so. Access to technology that encourages movement e.g. interactive whiteboards / active gaming / VR (optional).	AS may reframe question in a variety of ways to verify validity of answer. Offer non-verbal ways of flagging discomfort / rating comfort. **Physical opportunity**: Opportunities to change location / activity to optimise comfort. Flexibility and choice in resolution options. Timing of question flexible, may be better not to ask immediately after an activity. Range of reporting options available to choose from. Open / closed questions.

MoveMore Goal	1. Understanding why it is important to move more	2. Planning when and how to move	3. Preparing to move	4. The experience of moving	5. Optimise comfort
	Repetition of information to increase retention / opportunities to access information retrospectively. NAYP and AS access the same information for consistency.	**Physical opportunity:** increased frequency of opportunities to move a little. AS and NAYP have time to discuss and plan. Plan is realistic so NAYP and supporters have enough time to complete the activities on it (take into account family members other caring responsibilities). AS nominated from all relevant settings to map movement comprehensively. Reviewing and modifying the plan at transition points to ensure regular movement that is meaningful to NAYP continues in new settings .		Access to appropriate online activities for wheelchair users e.g. yoga / dance videos. Appropriate opportunities and facilities available locally. Opportunities to spend time outdoors. Doing different activities in different settings introduces variety.	AS communicate about who initially responds when uncomfortable, escalation plan if problem is unresolved. Action plan for discomfort needs to account for capacity of AS to act when discomfort is reported. Prevention – use personal care to monitor skin integrity.
Change needed in relation to COM-B: **Motivation**	**Reflective motivation:** AS link information to NAYP's goals and aspirations.	**Reflective motivation:** Intentions as a result of knowledge from goal 1. NAYP at centre of decision making and has choice.	**Reflective motivation:** Feedback from NAYP and supporters about moving and handling / postural care plan so becomes a working document and	**Reflective: motivation:** Involve NAYP and AS in identifying what movements NAYP likes / dislikes doing, what motivates them to move,	**Reflective motivation:** NAYP understand comfort is being discussed and

MoveMore Goal	1. Understanding why it is important to move more	2. Planning when and how to move	3. Preparing to move	4. The experience of moving	5. Optimise comfort
	Information is presented to the NAYP, they don't need to access it. Culture and attitudes promote making effort to share the information. Differing opinions whether NAYP will engage best with key contact they trust / success story delivered by peers / other wheelchair users / voice of authority e.g. exercise professional (above parent / 1:1). Discussion around whether peer interviewers are a voice of authority.	Plan developed around NAYPs goals and aspirations. Supporters are motivated to work towards goal of NAYP moving more. Visibility of one setting contributing to plan in app inspires and motivates other settings. NAYP wants to participate in the chosen activities, finds them engaging / rewarding. When NAYP doesn't want to move, identifying why (context specific). NAYP confident that previous experiences of poor inclusion can be improved upon e.g. PE not equitable. Voice of authority involved in plan production / review.	how safe and confident YP feels. NAYP experiencing a positive outcome when they report a concern helps them to be confident to report again. Context specific: Moving and handling / postural care plan could be incorporated into EHCPs making delivery of it a requirement. **Automatic motivation:** Checks about confidence become embedded. NAYP and AS refer to plan in app less over time as changes in practise are sustained.	appropriate rewards for them. Activities are meaningful to the NAYP. Spending time with friends / family. AS are motivated to work towards goal of NAYP moving more. NAYPs reflections about movement experiences, including evidence of NAYP's progress (e.g. before / after examples), enjoyment level. Receiving feedback about movement from wearable devices. SMART Goal setting (lead by NAYP). Long term aspirations of YP and family.	optimised to promote their movement. NAYP and AS willing and confident to communicate about comfort. AS feel confident to execute comfort action plan. NAYP reflect on their feedback, enabling them to learn or reinforce that moving can increase their comfort. AS experiencing improved learning outcomes / NAYP concentrates better because they are comfortable. NAYP and AS choose when and how often comfort reporting

MoveMore Goal	1. Understanding why it is important to move more	2. Planning when and how to move	3. Preparing to move	4. The experience of moving	5. Optimise comfort
	For NAYP, information must relate to individuals context and age. Make it about the present, not about the future. Context specific information for supporters e.g. family members may be more likely to engage with information they receive from professionals. Have teachers presenting some information.	Feedback about to what extent the plan is being executed. Movement prioritised above other competing activities when possible. Some competing activities will be essential / necessary. Context specific: Plan could be incorporated into EHCPs making delivery of it a requirement. Consider moving focus away from completing a physio program at specific times towards more functional activities. **Automatic motivation:** Plans become embedded. NAYP and AS refer to plan and app less over time but additional movement sustained.		Emphasising that even minimal additional movement is an achievement. Movement being rewarded / acknowledged / celebrating achievement with something meaningful that can't be removed. Experiencing success. AS communicating with NAYP in a way that motivates them to move. Competition at right level (score board of personal best or competing with other NAYP). NAYP being ready to try something new (assisted by goal 1).	occurs, so it is appropriate in local context. Incorporate actions to maintain NAYP's comfort into EHCP.

MoveMore Goal	1. Understanding why it is important to move more	2. Planning when and how to move	3. Preparing to move	4. The experience of moving	5. Optimise comfort
				Knowledge of what other NAYP doing the intervention are doing e.g. photo sharing and how they've improved / what they have achieved (case studies for different levels of functional ability). Sense of belonging and community e.g. Paralympic movement / doing activities with friends / attend focused events such as activity days. Move focus away from a physio program that may be repetitive / boring towards functional activities. NAYP cues supporters to assist them with movements because they want to achieve in a sport.	

MoveMore Goal	1. Understanding why it is important to move more	2. Planning when and how to move	3. Preparing to move	4. The experience of moving	5. Optimise comfort
Outcome – short term	NAYP and supporters gain knowledge of why moving more is important.	Movement plan exists. Record of adherence to plan. Plan is continually updated.	YP feels confident and safe to move. AS feel confident and safe to support movement.	NAYP moves in a way that is fun, enjoyable, rewarding, inspiring. Production of before and after info to show progress (movement rewarding). NAYP achieves the goals they set.	Reduce discomfort experienced by NAYP. May result in NAYP moving more regularly to maintain comfort or moving more because they are comfortable (context specific).
Outcome- long term	NAYP and supporters gain capability and motivation to achieve goals 2-4.	Movement opportunities are integrated into daily routines. Increased repertoire of movement options.	Positive movement experiences for NAYP and AS. Increased trust.	Positive movement experiences lead to increased frequency of movement. Improved health and wellbeing.	Positive movement experiences. Improved likelihood of moving.
Possible outcome measures / evaluation methods	Intermittent multiple choice quiz question Video / text diary (self selected regularity)	Plan created in app Adherence to plan / daily tasks recorded Daily Level of adherence to tasks in the plan	Moving and handling advice section completed in app Suggested actions for when not safe and comfortable completed in app Minimum of daily check of whether YP felt safe and	Accelerometer data Heart rate data Calorie data “New things I’ve tried” records Before / after evidence for integrating movement	Evidence of first comfort conversation recorded in app (may be all that’s required if comfort not an issue) Completion of comfort action plan (context specific)

MoveMore Goal	1. Understanding why it is important to move more	2. Planning when and how to move	3. Preparing to move	4. The experience of moving	5. Optimise comfort
			confident about moving (face scale or simple thumbs up / thumb down) Records / notes made of problems identified, suggestions tried and outcome if YP reported not confident at some point that day via video / text diary	into daily activities – relate to goals Submits a case study to admin Video diary / text	Signs of discomfort list completed (context specific) Preferred rating method and regularity of completion selected (context specific) Chosen rating method completed at locally selected regularity Video diary / text diary (self selected)

Note: NAYP: non-ambulant young people, AS: adult supporters, HCP: health care professional, EHCP: education and healthcare plan.

6.4.3 Objective 2) Selecting a mid-range theory to underpin the programme theory

Gainforth et al.'s "ABC of Behaviour Change Theories" book (278) was used to screen potentially relevant mid-range theories which could underpin the MoveMore programme theory. Taking into account the barriers and facilitators of sedentary behaviour that stakeholders selected for inclusion in the MoveMore intervention in step two of the 6SQuID and data in the intervention matrix, a small number of potentially relevant theories were identified. Potentially relevant theories included Bandura's self-efficacy theory (272), the Theory of Planned Behaviour (273) and SDT (85).

Self-efficacy theory proposes that an individual's belief / confidence in their capability to change their behaviour is the underpinning mechanism of achieving the desired behaviour change (272). The theory describes four sources of self-efficacy: experiencing success personally, observing others experiencing success (vicarious experience), verbal persuasion and manageable feelings of stress, anxiety or vulnerability (emotional arousal), so these emotions do not sabotage the desired behaviour. Self-efficacy theory contributed to the development of the theory of planned behaviour (278). The theory of planned behaviour proposes that intentions are the precursors to undertaking a behaviour (273). It suggests that intentions are determined by the individuals attitude towards the desired behaviour, their perception of whether others believe they should perform the behaviour, whether the individual feels able to perform the behaviour.

Self-efficacy theory (272) and the theory of planned behaviour (273) pre-date SDT and weaknesses in both theories have been identified. Examples include concerns

around their predictive validity and vaguely defined variables that are subsequently difficult to measure (279-281). In light of these limitations and taking into account evidence to suggest SDT may be associated with improved effectiveness for interventions addressing physical activity (81), SDT was the more appropriate mid-range theory.

Prior to identification of the MoveMore intervention's five key goals, stakeholders selected barriers and facilitators they wished to address in the intervention which were relevant to the three constructs / basic psychological needs of SDT (step two, Chapter 5). Choosing when and how to integrate movement opportunities into daily routines and moving more independently, with less reliance on AS were relevant to autonomy. Improving control and quality of movement and confidence levels were related to competence. Successful inclusion in organised activities and trusting AS who are skilled and experienced in assisting NAYP to move were relevant to relatedness. The key goals were formulated based on these barriers and facilitators, and it is therefore unsurprising that the constructs of SDT were also relevant to the behaviours needed to achieve them.

Based on the findings presented in the intervention matrix, the research team concluded that autonomy, self-efficacy and relatedness were important constructs / psychological processes to reach the desired behaviours and goals. Although self-efficacy is not one of the three basic psychological needs of SDT, there is a relationship between autonomy and self-efficacy (282) and competence and self-efficacy. When individuals make autonomous decisions which result in success and achievement, it enhances their sense of competence and increases self-efficacy. The opposite is also true. When individuals perceive a lack of control and choice, they are

less likely to believe in their abilities to change their behaviour, lowering self-efficacy, and the intervention may be less effective for them. Considering that support for the NAYP's feelings of autonomy and competence would facilitate an environment in which self-efficacy can flourish, there was consensus that SDT was an appropriate mid-range theory.

6.4.3.1 Autonomy

Autonomy is described as being able / having volition to choose, and is one of the basic psychological needs described in SDT (85). To achieve goals two – five, NAYP need to have more choice and control over their movement. Autonomy will be necessary for NAYP to populate their movement plan, choosing activities they will enjoy and / or find meaningful. NAYP will require sufficient agency to be able to request to try new activities, to have more control over when (goal two) and how (goal three) they do activities involving movement and to be involved in decision making about their equipment (goal four). NAYP should lead decision making about their movement goals (goal four) and actions that should be taken if they do not feel confident about moving or they feel uncomfortable (goal five). The intervention should enable NAYP to ask AS for support when needed.

6.4.3.2 Self-efficacy

Self-efficacy (belief in capability to change one's own behaviour) originates from Bandura's self-efficacy theory (272). If NAYP have a strong sense of self-efficacy (belief in their capability to change their behaviour in relation to specific tasks or situations), they are more likely to believe they have the ability to increase the

amount they move. They will therefore be more likely to plan to try a new activity or set more ambitious movement goals.

6.4.3.3 Relatedness

Relatedness is a sense of belonging to a social group to which one is emotionally connected (127). Stakeholders identified both desired behaviours and behaviour changes that were tied to feelings of relatedness. Desired behaviours included learning about the experiences of others to support action planning in goal two. For goal four, stakeholders felt NAYP needed knowledge of what other NAYP doing in terms of the intervention, to create a sense of belonging and community. NAYP indicated that enjoying doing activities involving movement alongside peers and family members who may or may not be participating in the intervention was also important to behaviour change.

6.4.3.4 Competence

Although it was not as prominent as autonomy and relatedness in the intervention matrix, competence (feeling capable and effective to achieve outcomes) is also relevant. Competence is one of the basic psychological needs described in SDT (85), and therefore differs from self-efficacy. Achieving goals set as part of the intervention is relevant to this basic psychological need, as is experiencing success, which was listed within the behaviour changes that were needed to achieve goal four. To achieve sustained behaviour change, it is important that NAYP feel confident about their own movement abilities, and trust the abilities of the AS assisting them to move. To establish this trust, AS need to be competent facilitators of movement and NAYP need to perceive them to be competent also.

6.4.4 Objective 3) Selecting mechanisms of action, intervention functions and behaviour change techniques for each goal.

Table 38 summarises the programme theory for the MoveMore intervention, showing the predominant COM-B elements, mechanisms of action, intervention functions, policy categories and BCTs for each goal. For each goal, stakeholders suggested changes in behaviour across all six COM-B components, however, these data were reviewed to select one - two predominant components for each goal.

Eight TDF mechanisms of action were selected in total (Table 38). All three SDT mechanisms of action were relevant across goals two - five, but a maximum of two predominant mechanisms were selected for these goals (Table 38), based on data in the intervention matrix (Table 37). For goal one, only autonomy was relevant in relation to SDT mechanisms of action.

In keeping with the principles of SDT, enablement was the predominant intervention function (goals two - five). Other intervention functions selected included education (goal one), training (goal three) and incentivisation (goal four).

Incentivisation relies on the external motivation of receiving an award (77). It therefore has potential to be in conflict with SDT, which fosters intrinsic rather than external motivation (85). However, cognitive evaluation theory (one of the mini theories within SDT), indicates that the nature of the reward will determine whether it promotes or is detrimental to intrinsic motivation (126). Rewards that support perceived competence and have an informational rather than controlling nature can promote intrinsic motivation (126). Stakeholders consistently advised that acknowledging NAYP's efforts and achievements by providing non-monetary rewards

would promote engagement with the intervention and improve effectiveness. This type of informational reward upon achievement of a goal would support perceived competence and therefore be in keeping with SDT. It was therefore deemed appropriate to include incentivisation in goal four.

Only three policy categories were relevant (guidelines, social planning and communication / marketing), which are broadly in keeping with the tenets of SDT. The content of marketing would need to promote internal rather than external regulation.

Eighteen BCTs from the taxonomy of behaviour change techniques (122) and 14 motivation and behaviour change techniques (127) were included in the intervention's programme theory (Table 38). All selected BCTs were in keeping with SDT. Non-specific reward and social reward BCT's need to be delivered in non-controlling and competence / autonomy supportive manner to ensure they are in keeping with SDT (126). The vicarious consequences BCT included in goal five aimed to change behaviour of AS rather than NAYP. It was included with the intention of AS learning from observing positive consequences of the NAYP moving more frequently (i.e. improved comfort) and therefore changing their behaviour to facilitate the NAYP to move more frequently.

Table 38 Summary of the MoveMore intervention programme theory, showing the predominant COM-B elements, mechanisms of action, intervention functions, policy categories and behaviour change techniques for each goal.

Goal & predominant COM-B elements	**Mechanisms of Action**	**Intervention function**	**Policy category**	**Behaviour change techniques (Taxonomy)**	**Motivation and Behaviour Change Techniques**
1. Why move? **Reflective motivation** (beliefs about good vs bad, self-conscious planning / evaluation)	Beliefs about consequences (accepting outcomes of a specific behaviour) Autonomy*	Education	Communication / marketing	5.1 Information about health consequences 5.3 Information about social and environmental consequences 5.6 Information about emotional consequences	1 Elicit perspectives on condition or behaviour* 3 Use non-controlling, informational language* 5 Provide a meaningful rationale*
2. Planning to move. **Social opportunity** (interpersonal influences, cues, cultural norms) **Physical opportunity** (physical environment, resources, time, location)	Environmental context and resources (aspects of the environment or situation that encourage / discourage independence, skill /ability development, adaptive behaviour, social competence) Social influences (interpersonal interactions resulting	Enablement	Guidelines Social Planning	1.2 Problem solving 1.4 Action planning 2.3 Self-monitoring of behaviour 3.1 Social support (unspecified)	6 Provide choice* 7 Encourage the person to experiment and self-initiate the behaviour* 11 Demonstrate/show interest in the person** 14 Prompt identification and seek available social support** 15 Address obstacles for change*** 18 Promote self – monitoring*** 19 Help develop a clear and concrete plan of action***

Goal & predominant COM-B elements	Mechanisms of Action	Intervention function	Policy category	Behaviour change techniques (Taxonomy)	Motivation and Behaviour Change Techniques
	in change of thoughts / feelings / behaviours) Autonomy* Competence***				
3. Preparing to move (safe / confident). Physical capability (physical skill / strength / stamina) Psychological capability (psychological skill / strength / stamina, knowledge)	Skills (physical and cognitive / interpersonal) Behavioural regulation (managing / changing objectively observed or measured behaviours) Autonomy* Competence***	Training, Enablement	Guidelines Social Planning	1.2 Problem solving 1.4 Action planning 3.1 Social support (unspecified) 4.1 Instruction on how to perform a behaviour 8.1 Behavioural practice / rehearsal	6 Provide choice* 8. Acknowledge and respect perspectives and feelings** 14 Prompt identification and seek available social support** 15 Address obstacles for change*** 19 Help develop a clear and concrete plan of action***
4. Experience of moving Reflective motivation	Beliefs about capabilities (accepting one's abilities) Intentions	Enablement, Incentivisation	Communication / marketing Social planning	1.1 Goal setting (behaviour) 1.5 Review Behaviour goals 2.2 Feedback on behaviour	4. Explore life aspirations and values* 5 Provide a meaningful rationale* 6 Provide choice*

Goal & predominant COM-B elements	Mechanisms of Action	Intervention function	Policy category	Behaviour change techniques (Taxonomy)	Motivation and Behaviour Change Techniques
(beliefs about good vs bad, self-conscious planning / evaluation)	(conscious decision to behave / act in a particular way) Goals (Outcomes individuals wish to achieve) Autonomy* Relatedness**			2.3 Self-monitoring of behaviour 2.6 Biofeedback 3.1 Social support (unspecified) 10.1 Non-specific reward 10.4 Social reward 12.2 Restructuring the social environment	7 Encourage the person to experiment and self-initiate the behaviour* 11 Demonstrate/show interest in the person** 14 Prompt identification and seek available social support** 17 Assist in setting optimal challenge*** 18 Offer constructive, clear, and relevant feedback*** 20 Promote self – monitoring***
5. Optimising comfort Social opportunity (interpersonal influences, cues, cultural norms)	Social influences (interpersonal interactions resulting in change of thoughts / feelings / behaviours) Relatedness** Competence***	Enablement	Guidelines Social Planning	1.2 Problem solving 1.4 Action planning 2.4 Self-monitoring of outcomes of behaviour 3.1 Social support (unspecified) 12.2 Restructuring the social environment 13.2 Framing / reframing 16.3 Vicarious consequences	5. Provide a meaningful rationale* 8. Acknowledge and respect perspectives and feelings** 11 Demonstrate/show interest in the person** 14 Prompt identification and seek available social support** 15 Address obstacles for change*** 19 Help develop a clear and concrete plan of action*** 20 Promote self – monitoring***

Note: Self-determination theory (85) mechanisms of action / motivation and behaviour change techniques: autonomy, relatedness**, competence***.*

Taxonomy of behaviour change techniques, (122). Motivation and behaviour change techniques, (127)

6.4.5 Objective 4) Producing a logic model which diagrammatically represents the MoveMore intervention.

Two versions of the logic model were produced to diagrammatically represent the programme theory of the MoveMore intervention, a scientific and a lay version. The final versions are presented in Figure 14 and Figure 15. The lay version was produced in collaboration with a PPI representative prior to the NAYP and family members workshops, to communicate the ideas in a more accessible format than the scientific version.

Changes made to these logic models to facilitate more effective communication of their meaning in response to feedback from workshops and interviews included:

- making the outer context and inner context boxes different colours to the blue central section to make the distinction between them clearer,
- making separate columns for school staff and carers in the “inner context – moderators” section rather than a shared column, as these are different roles.
- writing health professionals fully rather than using a “HCP” acronym,
- wording of goal five changed from “regularly reviewing comfort” to “optimising comfort”,
- inner context table reformatted to reduce repetition,
- new items added to inner context table or reworded such as “engage with exploring movement opportunities” changed to “being creative about movement opportunities” and “embracing new ideas”,
- “decision making with supporters” was a new item added for young people,
- “approach to risk” was a new item added for adult supporters,

- “YP has increased independence” was in outer and inner contextual outcomes. Changed to “YP has greater participation in day to day activities” in outer contextual outcomes and “YP experiences greater involvement in day-to-day activities in inner contextual outcomes”,
- confidence moved to inner contextual outcomes from outer contextual outcomes,
- in the lay model “Influences”, “Outcomes” and “Our MoveMore app” headings added to make the diagram clearer,
- the word “peers” changed to “friends” in lay model.

These changes aimed to result in clearer and more comprehensive logic models.

To reduce complexity, the logic models do not include the mechanisms of action or BCTs that complement them. The logic models depict the key goals of the intervention, the importance of the relationship between NAYP and their AS, the broad context the intervention sits within (summarising the large number of factors that influence sedentary behaviour of NAYP) and the intended outcomes of the intervention. The models emphasise that many of the moderators and outcomes are contextual and will vary according to local circumstances.

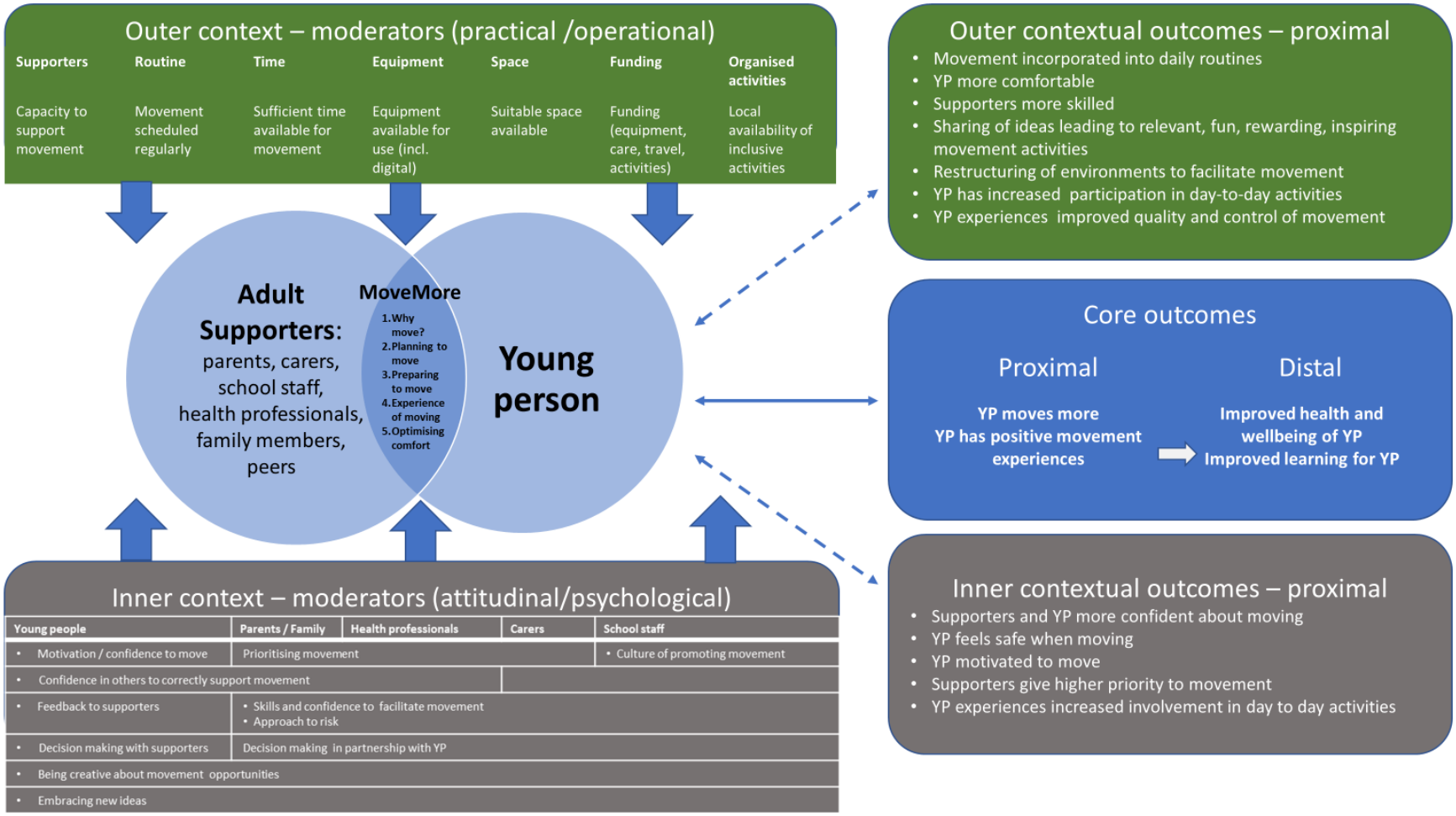


Figure 14 "Scientific" version of the logic model for the MoveMore intervention. YP: Non-ambulant young person. Adaptation of a logic model developed by Mills et al., 2019 (126).

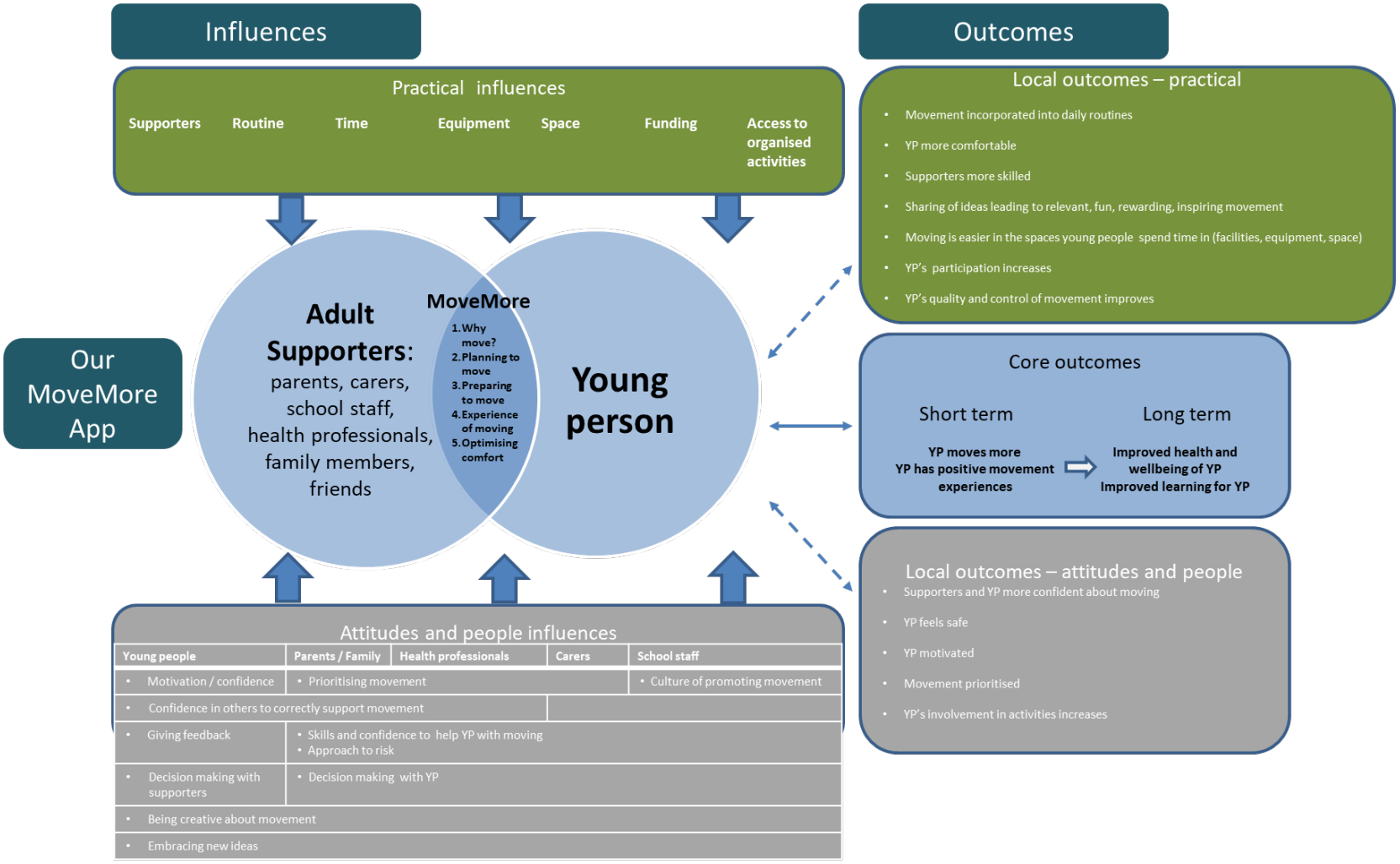


Figure 15 "Lay" version of the logic model for the MoveMore intervention. YP: Non-ambulant young person. Adaptation of a logic model developed by Mills et al., 2019 (126).

6.4.6 Objective 5) Potential unintended outcomes of facilitating the desired behaviours.

Stakeholders were encouraged to discuss potential unintended outcomes of the behaviour changes needed to achieve each goal and how they could be mitigated via a digital intervention. The potential unintended outcomes and mitigations are reported in Table 39.

During the final interview with an expert, the numerous potential unintended outcomes for goal five (optimising comfort) that had been highlighted in previous workshops / interviews were discussed. The interviewee questioned whether goal five (optimising comfort) could be removed from the intervention due to the number of potential unintended outcomes and their complexity. There was strong opposition to this proposal from the NAYP, family members and PPI representatives in the subsequent workshops. It was argued that because comfort has a large influence on movement for NAYP, this goal would be retained and mitigations would be designed in step four of the co-design, (as is the case for goals one – four).

Table 39 Potential unintended outcomes of the MoveMore intervention and suggestions for mitigating them.

Goal	Potential unintended outcomes	Potential mitigation
1. Why move?	NAYP or AS have a negative reaction to information notifications e.g. fear / guilt / feeling of needing to change but not having capability to do so.	Non-threatening language. Careful consideration of content and wording of information. Presented by peers.
	NAYP feels they should tolerate discomfort for health benefits of moving.	Encourage reporting and management of discomfort via information notifications. Present information about differences between normal discomfort experienced following exercise and discomfort which should be reported and managed.

Goal	Potential unintended outcomes	Potential mitigation
2. Planning to move.	Conflict between AS / NAYP in relation to adherence to the plan.	Key contact to advocate.
	Identified that NAYP does not wish to move.	Work with AS and professionals to identify and address individual barriers.
	Identify poor mental health / low mood of NAYP.	AS arrange onward referral for support with mental health.
	Effect on other pupils if increased time devoted to moving more.	Intervention highlights need for increased resources. Consider revising EHCP to meet needs using evidence from intervention.
	Impact on NAYP's education if less time spent learning.	Planning movement activities to minimise disruption and complement existing routines e.g. continue academic work in standing frame, move into a standing frame or walker after personal care when a transfer would already be necessary, consider selecting equipment that facilitates movement activities with fewer transfers such as sit to stand wheelchairs.
3. Preparing to move (safe / confident).	NAYP does not wish to move when it is necessary for them to do so resulting in a best interests arrangement being needed to move them without their consent.	Work with AS and professionals to identify and address individual barriers.
	An out-of-date plan is followed leading to an incident or near miss.	Movement plans have a review date. App flags out of date movement plans. AS ticks to indicate plan is unchanged or NAYP creates new plan if it has changed. Superseded plans are archived with valid date range displayed and cannot be edited.
	Reduction in incidents as greater knowledge and awareness of safety advice.	Positive unintended outcome – no mitigation required.
4. Experience of moving	Movement activities NAYP / AS wish to pursue aren't available / can't be facilitated due to lack of resource / affordability.	Intervention highlights need for increased local opportunities / facilities resources. Consider revising EHCP to meet needs using evidence from intervention. Consider potential for charity / community support to pursue activities or create new opportunities / facilities / provision of equipment.
	NAYP does not wish to move.	Work with AS and professionals to identify and address individual barriers.
	NAYP demotivated by seeing others progress in ways that are unachievable for them.	Categorise stories that are shared with other NAYP accessing the intervention so NAYP are signposted to activities that are appropriate to their abilities.
	Safety concerns if users can communicate with each other.	Moderation of any functions that facilitate communication between users of the intervention.

Goal	Potential unintended outcomes	Potential mitigation
		Limit the level / nature of communication that is possible. Flagging systems for inappropriate content. Any communication in app is visible to all NAYP and AS so there is transparency facilitating the group of AS and the NAYP to self-regulate the content shared. No communication between users of the intervention.
	Managing moderation, bullying / negativity / dangerous activity suggestions.	Moderation of any functions that facilitate communication between users of the intervention. Limit the level / nature of communication that is possible. Flagging systems for inappropriate content. Any communication in app is visible to all NAYP and AS so there is transparency; facilitating the group of AS and the NAYP to self-regulate the content. No communication between users of the intervention. AS use their experiences and skills to assess risk of any activities. Planned activities are visible to all NAYP and AS so there is transparency; facilitating the group of AS and the NAYP to ensure activities planned are safe.
5. Optimising comfort	NAYP needs regular repositioning for comfort but time needed not feasible. NAYP's movement frequency remains unchanged.	Intervention highlights need for increased resources. Consider revising EHCP to meet needs using evidence from intervention. Remove goal.
	NAYP reports discomfort to switch focus away from other activities (e.g. academic work).	Teamworking amongst AS and NAYP to identify and address any inappropriate use of app. Identify and address root cause of inappropriate / excessive reporting of discomfort. Remove goal.
	For NAYP with chronic pain, regular communication about discomfort exacerbates their perception of pain.	Create flexibility in method and frequency of reporting so this can be tailored to individual needs. Remove goal.
	NAYP reports physical discomfort to meet a need for emotional support – attentive /sympathetic / caring responses. Early warning sign of unmet psychological need. Risk of creating external motivations for reporting discomfort.	Teamworking amongst AS and NAYP to identify and address root cause of reporting of discomfort to meet alternative unmet needs. AS arrange appropriate onward referral for support e.g. mental health / safeguarding. Remove goal.

Note: NAYP: non-ambulant young person, AS: adult supporter, EHCP: education and healthcare plan.

6.5 Discussion

This study reports the third step of the MoveMore app co-design, in which the intervention's programme theory was developed. In workshops and interviews, stakeholders identified the behaviours and behaviour changes needed to achieve the five key goals of this digital intervention. Analyses of these data informed selection of a mid-range theory for the intervention (SDT) and selection of 11 mechanisms of action, four intervention functions and 32 BCTs from two differing taxonomies / classifications. Scientific and lay versions of a logic model for the intervention were produced. Finally, potential unintended outcomes of the intervention and suggestions for mitigating them were discussed.

In Gardner et al.'s review (exploring intervention functions and BCTs used to reduce sedentary behaviour in adults) (124), education, training, persuasion and environmental restructuring were the most promising intervention functions. Education and training are both included in the programme theory for the MoveMore app, however persuasion and environmental restructuring are not. Persuasion was perhaps less relevant for NAYP because their motivation to move was not a prominent barrier to reducing sedentary time (chapters 3-4). Social and environmental barriers had greater significance in this population. The digital nature of the MoveMore app makes environmental restructuring inappropriate.

Enablement is the predominant intervention function in the MoveMore app. The enablement intervention function is defined as "increasing means / reducing barriers to increase capability (beyond education and training) or opportunity (beyond environmental restructuring)" (77). This was not listed as one of the most promising intervention functions for reducing sedentary behaviour in adults (124).

This may be due to the enablement intervention function being more relevant to NAYP than the general population. In step one of the co-design it was identified that NAYP need to overcome multiple and complex barriers to reduce their sedentary time, some of which they have little or no control over. In this third step of the co-design, participants highlighted how this lack of control and reliance on others can result in a lack of autonomy for NAYP, which needed to be addressed. In line with SDT (85), overcoming these barriers by enabling NAYP to have more autonomy in relation to when and how they move therefore became a key mechanism of action of the MoveMore intervention.

In contrast to other apps for children and young people which specifically target sedentary time (139), the MoveMore programme theory includes several BCTs which have been highlighted as promising for reducing sedentary behaviour in adults (124). These BCTs include self-monitoring, problem solving and restructuring the social environment. Schoeppe et al. (139) found that children and young people had low engagement with apps specifically targeting sedentary time, however they used different BCTs, such as providing instructions, providing general encouragement and providing contingent rewards. We propose that involving NAYP and other stakeholders in development of the MoveMore programme theory and aligning it more closely to BCTs which are used in more successful interventions for adults (124, 125) will enhance its effectiveness. BCTs which are frequently used in apps aiming to reduce sedentary behaviour or increase physical activity / improve diet (self-monitoring, goal-setting and providing feedback on performance) (144-146) are also included in the MoveMore programme theory.

Evidence describing the BCTs that have previously been used in interventions to reduce sedentary time was helpful to consider in the MoveMore app co-design. However, because NAYP are dependent on adults to support them to move, the MoveMore intervention needs to target multiple individuals. The dynamics of relationships between NAYP and the adults who support them need to be considered. This resulted in additional BCTs being included, for example social support and vicarious consequences.

There are very few interventions for children with disabilities that utilise complex intervention development methodologies or theories of motivation and behaviour change. One example that is also underpinned by SDT is the ParticiPAte CP intervention (63), for ambulant children with CP (eight-12 years of age). This intervention aims to increase participation in physical activity. The ParticiPAte CP intervention focusses on collaborative goal setting and also uses the BCW and TDF in its programme theory, which has been described in a content analysis (123). Similar to the MoveMore intervention, the TDF mechanisms of action for the ParticiPAte CP intervention were social influences, environmental context and resources, intentions, skills, knowledge, and beliefs about capabilities (123). Six of the nine intervention functions in the BCW were included in the ParticiPAte CP programme theory. The enablement intervention function featured strongly, in alignment with that intervention's theoretical basis (SDT) as well as the present MoveMore intervention. The ParticiPAte CP intervention included 32 behaviour change techniques from the taxonomy of behaviour change techniques (122), in comparison to only 18 that were integrated in the MoveMore study.

There are no digital behaviour change interventions for NAYP, however an app for adults who use a wheelchair due to spinal cord injury or lower limb amputation has been has been designed and it's useability and feasibility has been tested (138). The WHEELS app (138) aims to promote a healthy lifestyle by promoting physical activity and healthy dietary, sleep, and relaxation behaviours. It does not specifically aim to reduce sedentary behaviour. However, it is interesting to the compare the programme theory of the WHEELS and MoveMore apps, as they are both digital behaviour change interventions for wheelchair users. The WHEELS app was designed using intervention mapping with stakeholder involvement. The intervention was developed with reference to social cognitive theory (283), the elaboration likelihood model (284) and the transtheoretical model of change (285).Sixteen behaviour change methods were selected from a variety of sources, so they cannot be directly compared with those included in the MoveMore intervention. Behaviour change methods which were aligned with the MoveMore intervention were: self-monitoring, providing feedback, facilitation, consciousness raising and goal setting (138). There were significant improvements in body composition outcomes following the WHEELS app intervention (138). However, it was a single armed feasibility study. A more robust study design with a control group would be required to demonstrate effectiveness of the WHEELS intervention with any certainty.

Examples of other digital interventions to reduce sedentary behaviour that draw upon SDT (85) include an intervention to reduce and interrupt sitting time in office workers, delivered via an individually tailored web-based platform (129) and a media-based based intervention for girls from ethnic minorities, which aimed to increase intrinsic motivation for physical activity (130). The individually tailored web-based intervention

was significantly more effective than a generic web-based intervention and no intervention (129). Sedentary time was measured via a wearable device (ActivPal) and / or self-reported. The media based intervention also significantly reduced sedentary time (measured using a validated self-report tool) and increased intrinsic motivation of the girls from ethnic minorities (130).

In relation to objective 5 of the present study (potential unintended outcomes of the MoveMore intervention), some of the suggested mitigations that were identified would be straightforward to deliver via a digital intervention. Examples include using non-threatening language in information notifications or adding review dates for movement plans and archiving them. However, other potential mitigations would be more difficult to achieve when there is minimal face to face interaction between the research team and NAYP and AS using the MoveMore app. Examples include addressing individual's barriers to movement or identifying the need for referrals for support with emotional / mental wellbeing. With the aim of overcoming these issues, an intervention handbook was produced. The handbook forms part of the materials developed to deliver the intervention (Appendix 12). It provides information to support AS to deliver the MoveMore intervention in a way that is in keeping with SDT and the selected BCTs. The handbook briefly explains in lay terms the intervention development process and highlights the need to empower NAYP via the fostering of their feelings of autonomy, competence and relatedness.

The next step of the co-design (6SQuID step four), will involve developing an implementation plan with stakeholders which outlines delivery of the change mechanisms selected in this step and evaluation of a prototype of the MoveMore app.

6.5.1 Limitations

There were five limitations of this work.

6.5.1.1 Limitation 1)

There was attrition of NAYP and family members between steps two and three of the intervention development. Only two NAYP and two family members participated in step three. The participant information sheets for the study stated that step three involved development of theory. It is possible that deterred participants, perhaps because they did not understand the term, or felt they would not be able to contribute. The email invite for family members and NAYP explained that they would be asked for feedback about proposals that had been formulated in collaboration with professionals and experts. This may have felt tokenistic and created doubt about incorporation of suggested changes. Both NAYP who participated were children of family members who were also participating. It is possible that having parents who were also engaged in the study made it easier for NAYP to contribute to the co-design. Their parents facilitated NAYP's attendance of workshops / interviews and arranged support during them. The involvement of the NAYP's parents also indicates that these families are likely to be interested in this particular topic.

6.5.1.2 Limitation 2)

There was limited diversity within the sample. There was some diversity in relation to gender, ethnicity and discipline of professionals / experts. A more diverse sample would have provided a more telling representation of the target populations. It should also be noted that participants may not be typical representatives of their stakeholder groups because they were recruited via open advertisement. They are therefore a

self-selecting group, introducing selection bias towards people who were motivated to take part. This introduces risk that the perspectives of those participating are not generalisable to the perspectives of those who are less motivated about reducing sedentary behaviour in NAYP.

6.5.1.3 Limitation 3)

NAYP and family members did not contribute to theory development. They fed back on content suggested by professionals and experts. This may have reduced engagement of NAYP and family members in this step (as discussed in limitation 1). NAYP and family members may have had different perspectives in relation to what needed to change to achieve the five key goals in comparison to professionals and experts. To mitigate this, NAYP and family members were asked whether anything was missing from the tables of what needed to change in order to reach the key goals.

When the protocol was formulated, detailed content of co-design workshops was not decided upon and it was felt it there would not be a viable way to develop theory with NAYP and family members. However, the activities professionals and experts did in their workshops / interviews would have been accessible to all participants. Doing the same “input” activities with NAYP / family members and professionals / experts instead of seeking feedback on proposals made by professionals / experts would have strengthened the study. Via the approach taken, we consulted with NAYP and family members rather than collaborating with them. Collaboration is the preferred co-design approach (91).

6.5.1.4 Limitation 4)

In the first workshop, participants focused on the intervention contents rather than the desired behaviours and the behaviour changes needed. The research team met prior to the second workshop to discuss strategies to prevent this occurring again. When these strategies were employed, data became increasingly focused on behaviours and behaviour change.

6.5.1.5 Limitation 5)

Due to time and resource constraints, data extraction from the Jamboards and videos was undertaken by the first author only (MB).

6.6 Conclusion

Drawing from the 6SQuID model (86), this study described the third step of the MoveMore digital intervention (mobile app) co-design. Step three of the intervention development focused on development of programme theory. Stakeholders identified the behaviours and behaviour changes needed to achieve the intervention's five key goals. These data informed selection of the intervention's mid-range theory (SDT (85)) and selection of 11 mechanisms of action, four intervention functions and 32 BCTs from two different taxonomies (122, 127). A logic model based on that used by Mills et al., (132) was produced to depict the programme theory for the intervention. This format emphasised the contextual variations that would influence delivery of the intervention (132) and the importance of the relationship between NAYP and their AS. Stakeholders identified potential unintended outcomes of the intervention and mitigation strategies were discussed. Step four of the 6SQuID will involve using this programme theory to develop and evaluate a prototype app.

7 Chapter 7: Step four of the Six Steps in Quality Intervention Development (6SQuID). Delivery of the change mechanism.

7.1 Pre-face to Chapter 7:

This study describes the fourth step of an intervention co-design which is following the Six Steps in Quality Intervention Development framework (6SQuID) (86). The preceding three steps of this complex intervention development are outlined in Chapters 3 to 6. In the context of this digital intervention development, step four involved a transition from programme theory developed in step three, to writing a software specification and production and evaluation of a prototype mobile application – the MoveMore app.

7.2 Title: Delivering a digital intervention that supports non-ambulant young people to reduce sedentary behaviour: programme theory to prototype evaluation.

7.3 Introduction:

The definition of sedentary behaviour is “any waking behaviour characterized by an energy expenditure ≤1.5 metabolic equivalent units (METs) while in a sitting or reclining posture” (3). Reducing sedentary behaviour is important due to its associations with negative health consequences, such as increased risk of developing cardiovascular disease, type 2 diabetes, some cancers and a higher likelihood of death form any cause (7, 8). There is robust evidence that non-ambulant children and young people spend more time sedentary than able-bodied children and young people (33, 158, 159, 209, 212) and ambulant children and young people with disabilities (33, 158, 159, 210, 215). There is also evidence suggesting that sedentary behaviour of non-ambulant children increases with age (33, 40, 214).

NAYP are therefore at high risk of negative health consequences due to sedentary behaviour. The World health Organisation (WHO) has physical activity and sedentary behaviour guidelines for children and adolescents with disabilities, which state that they should “limit the amount of time spent being sedentary, particularly the amount of recreational screen time” (6). Currently, there are no evidence-based interventions which specifically aim to reduce sedentary time in NAYP (Chapter 2).

The MoveMore digital intervention aims to support non-ambulant young people (NAYP) to reduce their sedentary behaviour, with assistance from their adult supporters. The intervention will be delivered via the MoveMore mobile application. NAYP have long term disabilities such as cerebral palsy (CP), spina bifida, muscular dystrophies, rare conditions or traumatic brain or spinal cord injuries. They are unable to walk, or only walk short distances using equipment which provides support for their trunk or pelvis (i.e. is not handheld).

Development of the MoveMore intervention and app, has followed the Six Steps in Quality Intervention Development (6SQuID) framework (86). 6SQuID is a stepped based approach to intervention development which was designed to support development of public health interventions, but has wider applicability. It draws on existing intervention development approaches such as intervention mapping (79) and the Medical Research Council (MRC) guidance for the development and evaluation of complex health interventions (73), but has a stronger focus on the early stages of development. This study reports the work undertaken in step four of the 6SQuID, which involves working in partnership with stakeholders to produce an implementation plan for the intervention. Identification of resources needed to deliver the plan and any risks and assumptions is also needed. The preceding steps,

detailed in Chapters 2 - 6 include; defining the problem and developing an in-depth understanding of its causes (step one), identifying modifiable causal and contextual factors (step two) and development of the programme theory underpinning the intervention (step three). Programme theory describes how an intervention is expected to achieve its intended outcomes and in what circumstances (75).

Another element of step four of the 6SQuID, is to consider any potential unintended effects the intervention could have. In co-designing the MoveMore app, this was considered in Step three (Chapter 6). The step three workshops involved detailed discussion of what behaviours were needed to achieve the intervention's five key goals. These goals were defined in step two (Chapter 5), and are: 1) understanding the risks of sedentary time and the benefits of reducing it, 2) planning when and how NAYP could integrate movement into their daily routines, 3) ensuring NAYP and their adult supporters feel safe when moving and confident about their movement 4) ensuring the experience of movement is positive and 5) optimising comfort. Participants were prompted to consider potential unintended consequences of the behaviours needed to achieve the goals at this earlier time, allowing them to be taken into consideration and minimised in the proposed implementation plan which was presented to stakeholders during the current step four.

One limitation of the 6SquID framework, is that it does not provide a methodology or resources to direct how to engage stakeholders in step four. However, the Person-Based Approach (83) provides detailed guidance for developing digital interventions in partnership with stakeholders, and has therefore been drawn upon to structure step four of the MoveMore app co-design.

7.3.1 Overview of the Person-Based Approach to intervention development

The Person-Based Approach (83) aims to complement existing theory and evidence based approaches to intervention development such as the MRC guidance for the development and evaluation of complex health interventions (73) and the Behaviour Change Wheel guide to designing interventions (77). This is achieved by deepening understanding of the most effective ways to apply these existing behaviour change models and techniques in the specific context of digital health interventions. Gaining insight into how the intervention can be attractive, persuasive and feasible for the individuals who will use it via in-depth qualitative research involving stakeholders provides this deeper understanding.

The Person-Based Approach involves using qualitative research with stakeholders to produce **guiding principles.** The **guiding principles** have two key elements, **intervention design objectives** and **key features** of the intervention which will achieve the objectives (83). The former summarises context-specific behavioural needs, issues, or challenges to be addressed, whilst the latter succinctly articulates how the design objectives will be achieved. The guiding principles do not replace the detailed mapping of programme theory and selection of behaviour change techniques (BCTs), that was described in Chapter 6. They complement this work by summarising the distinctive elements of the intervention (83).

Once the **guiding principles** have been used to produce a protype of the digital health intervention, the Person-Based Approach recommends using **think-aloud** methods to obtain user feedback about the intervention in iterative cycles. **Think-aloud** methods encourage co-design participants to consider each element of an intervention and vocalise their thoughts about it. This helps researchers to

understand how the intervention might work and provides an opportunity to identify potential problems related to usability or acceptability Suggested changes are recorded in a **table of changes**, facilitating prioritisation of which changes will be done prior to the next iteration of the intervention (taking into account the resources available) and to identify what could be done in future iterations (117).

Yardley et al. (83) outline **guiding principles** which are common to many digital health interventions their team have been involved in developing. They describe three common **intervention design objectives**, which are 1) promoting user autonomy, 2) promoting user competence and 3) promoting a positive experience and sense of relatedness. These common design objectives and their related **key features** were based on the three constructs of Self-Determination Theory (85). Self-Determination Theory also informs the MoveMore intervention (Chapter 6), highlighting the relevance of the Person-Based Approach in development of the MoveMore app.

When considering integration of the Person-Based Approach with the 6SQuID Framework, steps one, two and three of 6SQuID (86) have approximated production of **guiding principles** for the MoveMore intervention. Step one involved gaining in-depth understanding of the needs, views and capabilities of NAYP, which was used to inform and identify **intervention design objectives** (the five key goals) in step two. In Step three, detailed documentation relating to which behaviour change techniques would be used to achieve each **intervention design objective** was produced, however this detailed mapping was not summarised as **key features** of the intervention as is recommended in the Person-Based Approach (83). This is addressed in this step of the MoveMore app co-design.

Building on Steps one -three of 6SQuID, (86) the objectives of this study (step four) were to:

1) describe how data from step three lead to a proposed implementation plan, which describes the MoveMore app intervention's **guiding principles** (including **key features**) and considering resources needed, risks and assumptions.
2) use the **think-aloud** approach, to conduct workshops and interviews to produce a final implementation plan with stakeholders and write a software specification for the MoveMore app,
3) employ the **think-aloud** approach and to evaluate the MoveMore app prototype with stakeholders and present the results in a **table of changes**.

7.3.2 Self - Determination Theory

SDT is a motivational theory which has three primary constructs: autonomy (self-direction), competence (ability and confidence) and relatedness (feeling supported) (85). Users of digital interventions need to be self-motivated to engage with them. Achieving intrinsic motivation (a key concept in SDT) to engage with the intervention by promoting these constructs within it is vital to their success (83).

Participants in the MoveMore intervention co-design previously identified barriers and facilitators of reducing sedentary time for NAYP that they wished to address in the intervention (Chapter 5). The barriers and facilitators they selected were directly related to the constructs of SDT. Examples include minimising reliance on others to assist with movement and integrating movement into daily routines (autonomy), not feeling confident when moving and experiencing improved control and quality of

movement (competence) and having support from people who are trained and experienced in helping NAYP to move and being successfully included in organised activities (relatedness). The MoveMore **intervention design objectives** (five key goals) were written based on these barriers and facilitators. It is therefore logical that in step three, the constructs of SDT were considered important for facilitating the behaviours required to achieve the **intervention design objectives** (Chapter 6). As a result, SDT was chosen as a mid-range theory to inform the MoveMore app intervention development in step three.

7.4 Methods

This study had ethical approval from the London - Camberwell St. Giles Research Ethics Committee (Ref: 20/LO/0011). Data was collected between March 2022 and March 2023. Virtual co-design workshops and 1:1 interviews were held with stakeholders on Microsoft teams. Data collection was all virtual as the study protocol was written when there were social distancing restrictions in place for the Covid-19 pandemic, and it was unclear when they would be lifted. Recruitment was national / international (for experts only) and all those who consented to take part in the co-design were invited to virtual workshops and interviews at every step. There were two data collection cycles of workshops and interviews in this step. The first cycle focused on producing an implementation plan for the intervention (objective 2). The second was an evaluation of a prototype of the MoveMore app (objective 3).

7.4.1 Participants and recruitment

Five stakeholder groups took part in the co-design workshops and interviews: 1) NAYP aged 12-25 with a lifelong disability, 2) family members of NAYP, 3) professionals who were working / had worked with NAYP (for example carers, healthcare / education professionals), 4) experts in digital health interventions, behaviour change, disability or sedentary behaviour and 5) others who wished to participate. Experts could be recruited worldwide. All other participants needed to live in the United Kingdom (UK). With the exception of NAYP, all participants needed to be ≥ 16 years of age. Additional inclusion criteria (for all) were ability to communicate in English and having sufficient understanding to actively participate in an interview or workshop and ability to give informed assent / consent. The “others who wished to participate” group aimed to ensure inclusive recruitment of anyone with an interest in the topic regardless of their motivation. It was highlighted during public and patient involvement (PPI) work that adults with disabilities who are over 25 years of age should not be excluded. This fifth stakeholder group enabled any adult to participate.

A broad recruitment strategy, including clinicians sharing information during appointments, word of mouth, radio interview, social media and a poster campaign and was employed. Recruitment is described in more detail in Chapter 3, as are the online consent procedures. For both cycles of data collection in this step, email invites were sent to everyone who consented to participate in the intervention co-design (including those who had not contributed to previous steps). In the results section, attrition between steps three and four of the MoveMore app intervention development, information about a new participant who joined the co-design for step four and changes in participants between the first and second cycles of data

collection in this step are reported. Following contribution to the co-design, participants were offered a £10 payment for their time.

7.4.2 Sample size

The minimum sample size required for each data collection cycle (from workshops and interviews) was four. It was anticipated that recruitment may be challenging, so this low minimum sample size was chosen. It was expected that participants would have lived or professional experience which was highly relevant to the objectives of the workshops and interviews; therefore their contributions would provide insight to guide the intervention development even if participant numbers were low. However, it was important that the four key stakeholder groups were represented. A minimum sample size of four was selected to ensure there was at least one stakeholder from each key stakeholder group. Having a representative from each of the key stakeholder groups was a condition of successful data collection if recruitment was low. There was no maximum sample size. Everyone who responded to the invite to participate was given the opportunity to do so.

7.4.3 Objective 1) Drafting a proposed implementation plan

A proposed implementation plan was drafted prior to participant involvement, informed by data collected in step three. Outcomes of step three included: 1) selection of a mid-range theory and BCTs that would be used to achieve the five key goals or **intervention design objectives**, 2) a detailed description of the desired behaviours to achieve each goal, 3) changes needed to achieve the five key goals described in terms of the COM-B behaviour change wheel (77, 120), 4) possible unintended outcomes of the intervention for each goal, 5) intended short and long term outcomes for each goal and 6) proposed outcome measures / evaluation

strategies for the outcomes. The data for 2), 3) and 4) were generated by participants in step three workshops. Outcomes 1), 5) and 6) were generated by the research team, informed by participant generated data.

Participants in step three were aware the intervention would be delivered via a mobile app. As a result, step three data included discussion about app content in relation to each goal. The researchers used this data, the selected BCTs and the constructs of the mid-range theory (SDT) to produce a proposed structure for the app. In line with the Person-Based Approach, the proposed structure was in the form of a list of **key features** that could be used to achieve each **intervention design objective** to complete the **guiding principles** for the intervention (Table 42).

The research team identified resources needed and assumptions without participant involvement. Participants identified potential risks of using the app via their discussion about unintended outcomes in step three of the 6SQuID (Chapter 6). Their feedback regarding risks was taken into account when writing the proposed implementation plan.

7.4.4 Virtual co-design workshops and interviews

7.4.4.1 Participant characteristics:

An online survey was completed when participants were recruited to the MoveMore app co-design prior to the step one co-design workshops (Chapters 3 and 4). Information collected included: name, age, email address, gender, stakeholder group, ethnicity, high level location (first three characters of postcode or town/country if outside the UK) and employment status. Additional questions that were specific to the participant's stakeholder group were also asked (Appendix 5).

7.4.4.2 Workshop / interview participants:

In line with guidance relating to conduct of focus groups in qualitative research (248), workshops could include two - 10 participants. Participants chose a workshop they would like to attend from a range of dates and times or provided convenient times when they could be interviewed. To avoid power imbalances having a negative impact on contributions made by NAYP aged 12-15 (255, 256), the co-design protocol stated that they would not attend workshops with other stakeholder groups (for example professionals or experts). However, only one NAYP aged 12-15 years participated in step four. They were comfortable contributing to a workshop with a member of their own family who was also participating. No other participants attended that workshop. All other workshops included a mixture of stakeholders from across the differing stakeholder groups.

7.4.4.3 Workshop / interview structure:

All workshops and interviews were conducted on Microsoft Teams and video recorded. Jamboard - an online whiteboard provided by google - was used as a tool throughout data collection. Jamboard was used to present the proposed app structure during the workshops / interviews and to collect feedback in both data collection cycles in step four. Examples of the Jamboard template from the two data collection cycles are shown in Figure 16 and Figure 17. To ensure Jamboard content remained anonymous to anyone who gained access to it who was not an attendee, participants selected a colour to write in that identified them, or initialled any post it notes. The Jamboard was private – meaning it could only be accessed by people

who had the link. The completed Jamboard templates were the primary data set, however video recordings were saved so detailed discussions about app content remained accessible to the researchers after the workshops.

7.4.4.4 Methodological approach:

In line with the Person-Based Approach (83), a think-aloud approach was used to conduct the workshops and interviews in this step (116). This encourages co-design participants to consider each aspect of an intervention and vocalise their thoughts about it. This helps researchers to understand how the intervention might work and provides an opportunity to identify potential problems related to usability or acceptability.

Workshops and interviews were facilitated by the first author. This was to allow the author to gain experience in using think-aloud techniques (116) as part of their PhD. However, they were aware that their perspectives and preconceived ideas about the app were important to recognise and acknowledge. The participants were encouraged to add to the Jamboard independently using their own words wherever possible, or to do that with the help of a carer. If the facilitator wrote on the Jamboard on a participant's behalf, they ensured they wrote exactly what the participant requested, labelled that data was taken from the video retrospectively or labelled the entry as theirs with an initial if it was an independent contribution. The first author (MB) has experience of facilitating co-design workshops and working with NAYP and their families. A second facilitator from the NHS Research and Innovation team conducting this study was also present, to ensure there was someone available to

speak to participants privately outside the workshop if needed, or signpost them to support.

7.4.5 Objective 2) Producing the implementation plan with stakeholders (first data collection cycle)

In this first cycle of data collection, participants had not seen any of the content presented in advance. This is the usual way of conducting a think-aloud workshop / interview (116). Workshops / interviews in previous steps of this co-design have used images and symbols on the Jamboard to guide discussions, based on advice from a co-design hub who were working on techniques to undertake virtual co-design effectively during the Covid-19 pandemic (254). This theme was continued by giving suggested key features an associated image (Figure 16).

Participants used a tally chart to mark in their selected colour whether the key features should be included in the app (Figure 16). Suggested key features for each intervention design objective (goal) were presented. Participants were encouraged to discuss the pros and cons of each suggestion in the context of the app being used by NAYP, with help from adult supporters. These discussions were recorded on post it notes on the Jamboard (Figure 16). The tally charts were used to prompt discussion about what should be included / excluded in the app and delivery methods. They were not quantitatively analysed.

7.4.5.1 Adult supporters

Data from step one of the MoveMore app co-design highlighted that NAYP's adult supporters (AS) needed to be part of the intervention, because NAYP often need their help to assist them to move. Discussions in step three highlighted potential

issues around selecting which adults should be involved in the intervention and threats to the NAYP's autonomy if there were perceived or actual power imbalances between the NAYP and their AS. A proposal of how interaction between NAYP and AS would be managed was outlined in these step four workshops / interviews.

In line with SDT (83), it was proposed that NAYP select which AS they invite to be involved in the intervention to maximise their autonomy. AS can be family members, carers or health / education professionals. Invited AS can view information added to the app by the NAYP and relevant data from their wearable device via an online dashboard. AS can also contribute to some (but not all) functions of the app. Limitations on what could be edited or contributed to by AS were suggested to uphold autonomy for the NAYP participating.

7.4.5.2 Key contacts

The concept of having a key contact in each place the NAYP visits regularly was also outlined. Their role is to have 1:1 discussions relating to the intervention with NAYP and support them with inputting information into the app / ticking off their activities regularly etc. Key contacts would act as an advocate for the NAYP, providing social support. Social support is one of the selected BCTs included in the intervention (122). Key contacts would communicate with the wider group of AS, avoiding the NAYP needing to negotiate behaviour changes AS needed to make to facilitate the NAYP to reach their goals. This proposal aims to empower the NAYP to request behaviour change of their AS; reducing the risk of the NAYP's voice being lost due to power imbalances between an individual who relies upon the help of their AS and a group of supporting adults. The proposed key features refer to these AS and key contact roles.

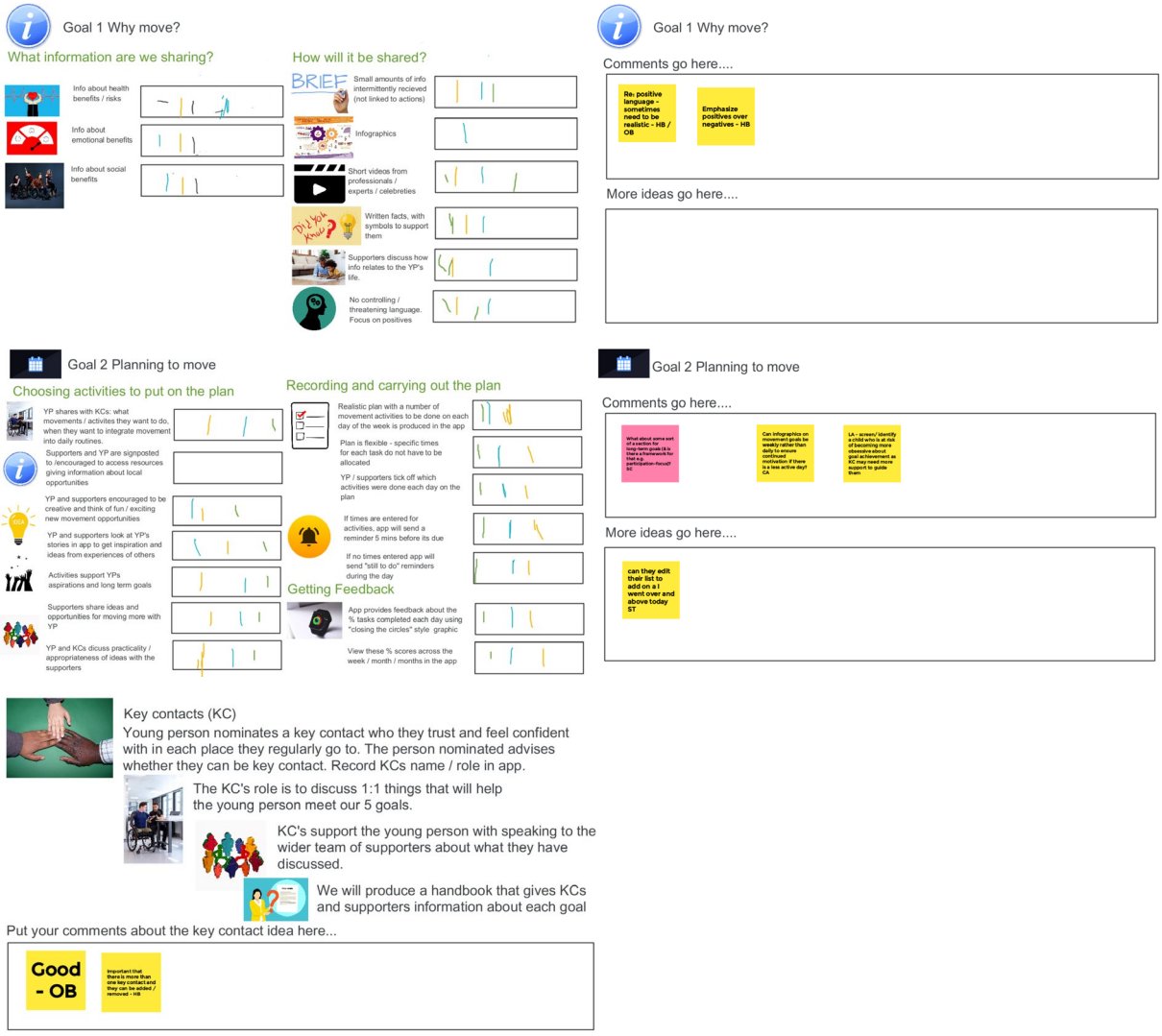


Figure 16 Example of completed Jamboard screens from the step four virtual co-design workshops (first data collection cycle). Note: YP: Non-ambulant young person, KC: key contact.

7.4.5.3 Development of software specification

The research team wrote a software specification detailing the functions and contents of the app using the data collected in the workshops and interviews. If there were either / or decisions to be made for which there was not consensus across groups, researchers were guided by the SDT constructs and behaviour change techniques which had been selected in their decision making. The software specification was

shared with developers, to build a prototype of the app for participants to evaluate in the second data collection cycle.

7.4.6 Objective 3) Evaluating the MoveMore app prototype (second data collection cycle)

The majority of participants contributed to both data collection cycles, however, there was some change in participants between the first and second cycles, which is reported in the results. The app protype was a live and interactive website. Participants could navigate around the protype independently and were able to click on and test functions. Participants were given access to the protype prior to the evaluation workshops / interviews so they could familiarise themselves with it and consider their feedback prior to data collection. When using think-aloud techniques as part of the Person-Based Approach (286), the point of data collection is usually the first time participants have seen the content being presented (as for the first data collection cycle in this step). It was appropriate to share the prototype in advance in this second cycle of data collection; due to the involvement of young people with disabilities who had sensory, communication and mild learning difficulties in addition to their physical disabilities. This gave participants an opportunity to explore the app and formulate their feedback without time pressures. The Person-Based Approach website specifies that sharing materials in advance is acceptable as part of think-aloud processes when participants need time to think (116).

The evaluation workshops / interviews began with sharing the lay version of the logic model for the intervention to inform participants of the programme theory. This version of the logic model was simplified to make it more accessible to lay members of the co-design, with input from PPI reps and feedback from step three. The logic

model includes the five intervention design objectives (goals), a summary of the factors that influence sedentary behaviour of NAYP and the intended outcomes of the intervention (Figure 15).

The software developers attended workshops / interviews. This allowed them to become embedded in the co-design process, hearing participants' feedback and being able to share information about what would / would not be possible in a live version of the app to be used in a feasibility study.

In line with the Person-Based Approach and think-aloud techniques (83), participants discussed each element of the app protype, recording what they liked and what could be improved. Their feedback was recorded on the Jamboard template (Figure 17).

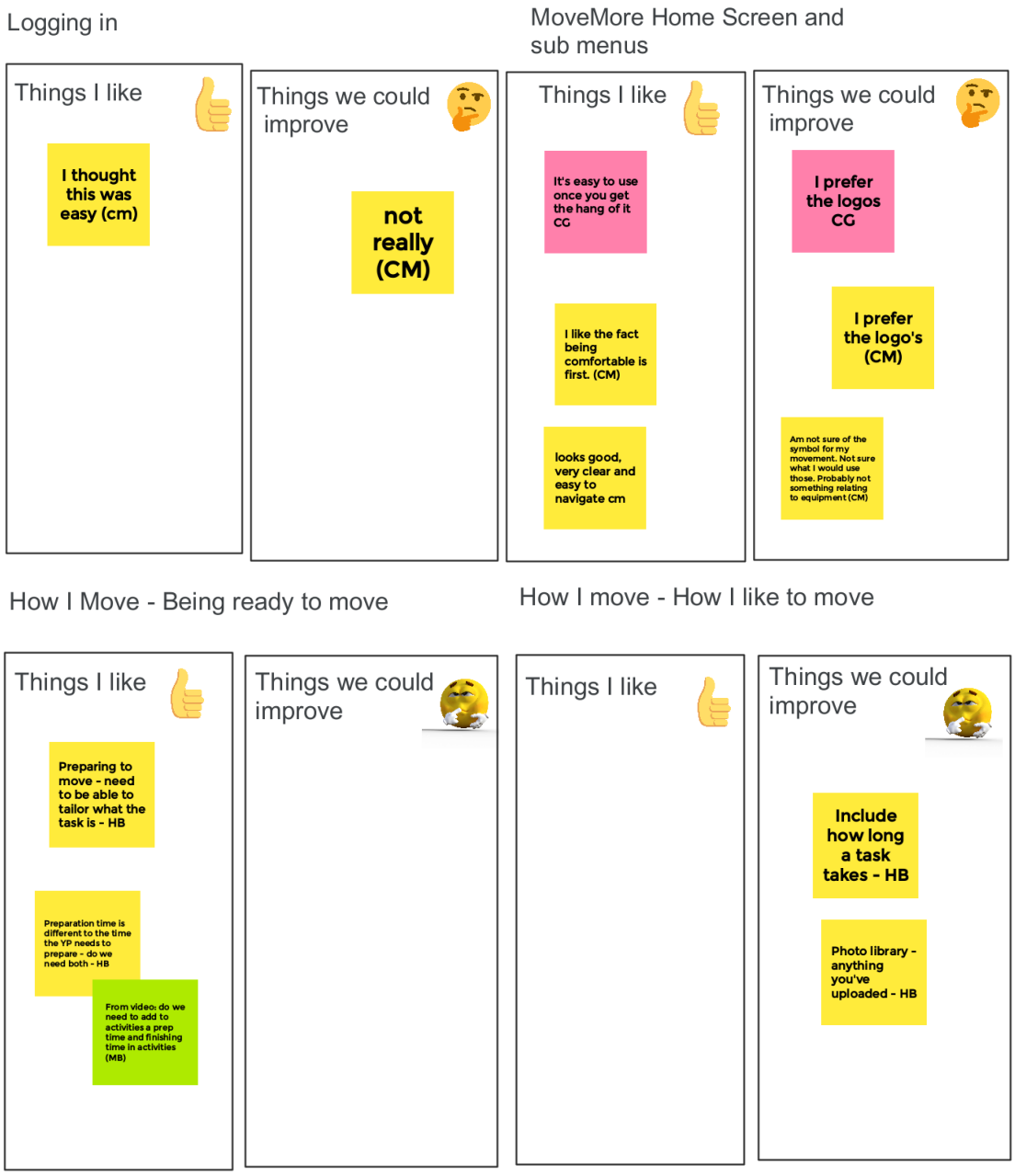


Figure 17 Example of completed Jamboard screens from the step four virtual co-design workshop (second data collection cycle)

Videos recordings of the workshops / interviews were viewed a second time by the lead facilitator. Any content which had not been captured on the Jamboard during the session was added on a green post it note. It was recorded that these notes were added from the video in retrospect (Figure 17).

7.4.6.1 Table of Changes

The Jamboard data was used to populate a table of changes, using a template from the Person-Based Approach (117) (Table 44). The table of changes assists researchers to use stakeholder feedback to identify how to optimise the intervention. The aim is to maximise feasibility, acceptability, motivation for behaviour change, persuasiveness and user experience. The coding framework from the Person-Based Approach (117) has been adopted in the “Reason for Change” column. The codes available are: “essential change for intervention to function”, “important for behaviour change or practical / ethical / safety reasons”, “easy and uncontroversial”, “repeated by more than one participant in the co-design”, “change supported by experience” (for example PPI reps, stakeholders, literature / evidence base), “does not contradict the logic model or guiding principles” or “no change”. The MoSCoW Framework is used in the final column, which stands for “Must do; Should do; Could do; Would like to do”. The MoSCoW Framework is used to prioritise which changes will be done prior to the next iteration of the intervention (taking into account the resources available) and to identify what could be done in future iterations, if those potential changes are supported during feasibility testing (117).

7.5 Results

7.5.1 Participant Characteristics

Fourteen stakeholders participated in total (both data collection cycles) (two NAYP, two family members, seven professionals, three experts). Characteristics of participants who took part in the first and second cycles of data collection in this step are shown in Table 40 and Table 41. Two professionals who took part in the first cycle (producing an implementation plan, objective 2) were not able to participate in the

second (prototype evaluation, objective 3). One professional and one expert who participated in step three of the MoveMore app co-design (Chapter 6) were only able to participate in the second cycle.

Both NAYP contributed to both cycles of data collection via workshops. The 15 year old did workshops with a family member who was also participating. They were not in workshops with unfamiliar adults. Both NAYP were diagnosed with CP and lived with their parents. One communicated using an eye-gaze communication aid with support from a carer. The family members were both parents of NAYP with CP. Their children had mild learning disabilities but could communicate effectively.

Professionals formed the largest stakeholder group. One was a head of physical education in a school for children with special educational needs and another was a Direct Services Manager. The remaining five professionals were physiotherapists. All three experts were academic researchers. They had interests in stroke and sedentary behaviour, physical activity promotion amongst children and adults and co-design and physical activity and participation of young people with CP. One of the experts was an international recruit.

Participants in step four of the MoveMore app co-design, were less diverse than those in steps one-3. The majority were female and white-British. The only stakeholder group with diversity in relation to ethnicity was the experts (Table 40 and Table 41).

Six participants who had contributed to step three of the intervention development did not contribute to this step. One expert took part for the first time in this step (Table 42).

Table 40 Step four participant characteristics for the first cycle of data collection (producing an implementation plan, objective 2)

Stakeholder group / characteristic	**Number of participants (%)**	**Age in years: mean, median, range**	**Gender: Number (%)**	**Ethnicity: Number (%)**	**Employment status / Role: Number (%)**
Young person aged 12-25 who is non-ambulant.	2 (16.67%)	16, 16, 15-17	Female: 2 (100%)	White – British: 2 (100%)	School/college/sixth form student: 2 (100%)
Family members of non-ambulant children and young people	2 (16.67%)	53.5, 53.5, 53-54	Female: 1 (50%) Male: 1 (50%)	White – British: 2 (100%)	At home most days (not working): 1 (50%) Working full time 1 (50%)
Health and education professionals	6 (50%)	42.2, 45, 28-54	Female: 4 (66.67%) Male: 2 (33.33%)	White – British: 6 (100%)	Working full time: 5 (83.3%) Working part time: 1 (16.6%)
Experts	2 (16.67%)	40.5, 40.5, 34-47	Female: 2 (100%)	White – Irish: 1 (50%) Sri Lankan – 1 (50%)	Working full time: 1 (50%) Working part time: 1 (50%)
Total	12 (100%)	40.4, 45, 15-54	Female: 9 (75%) Male: 3 (25%)	White – British: 10 (83.33%) White – Irish: 1 (8.33%) Sri Lankan – 1 (8.33%)	Working full time: 7 (58.33%) Working part time: 2 (16.67%) At home most days (not working): 1 (8.33%) School/college/sixth form student: 2 (16.67%)

Table 41 Step four participant characteristics for the second cycle of data collection (evaluating the MoveMore app prototype, objective 3)

Stakeholder group / characteristic	**Number of participants (%)**	**Age in years: mean, median, range**	**Gender: Number (%)**	**Ethnicity: Number (%)**	**Employment status / Role: Number (%)**
Young person aged 12-25 who is non-ambulant.	2 (16.67%)	16, 16, 15-17	Female: 2 (100%)	White – British: 2 (100%)	School/college/sixth form student: 2 (100%)
Family members of non-ambulant children and young people	2 (16.67%)	53.5, 53.5, 53-54	Female: 1 (50%) Male: 1 (50%)	White – British: 2 (100%)	At home most days (not working): 1 (50%) Working full time 1 (50%)
Health and education professionals	5 (41.67%)	41, 42, 28-54	Female: 4 (80%) Male: 1 (20%)	White – British: 5 (100%)	Working full time: 4 (80%) Working part time: 1 (20%)
Experts	3 (25%)	39.3, 37, 34-47	Female: 3 (100%)	White – Irish: 1 (33.3%) White – Any other background: 1 (33.3%) Sri Lankan – 1 (33.3%)	Working full time: 2 (66.7%) Working part time: 1 (33.3%)
Total	12 (100%)	39.7, 42.4, 15-54	Female: 10 (83.33%) Male: 2 (16.67%)	White – British: 9 (%) White – Any other background: 1 (%) White – Irish: 1 (8.33%) Sri Lankan – 1 (8.33%)	Working full time: 7 (58.33%) Working part time: 2 (16.67%) At home most days (not working): 1 (8.33%) School/college/sixth form student: 2 (16.67%)

Table 42 Change in participant numbers in step four of the 6SQuID in comparison to step three.

Stakeholder group	Attrition (took part in step 1, but not step 2)	New participants
1) Young person aged 12-25 who is non-ambulant.	0	0
2) Family members of non-ambulant children and young people	0	0
3) Health and education professionals	5	0
4) Experts	1	1
5) Other members of the public	0	0

7.5.2 Objective 1) Drafting a proposed implementation plan

Table 43 shows the guiding principles for the MoveMore app intervention, including: intervention design objectives (goals), proposed key features which will address them, the SDT constructs the key features are related to (as defined in the key), the BCTs which will be used to achieve the intervention design objectives (goals) and the SDT constructs they are related to (for motivation and behaviour change techniques). BCTs were selected in Chapter 6.

Table 43 Proposed guiding principles of the MoveMore app, including intervention design objectives (goals), proposed key features, Self - Determination Theory (SDT) constructs related to the key features and behaviour change techniques which will be used to deliver each intervention design objective (goal)

Intervention design objectives (goals)	Key features and their related SDT construct (see key)	Behaviour change technique (Taxonomy of Behaviour Change Techniques (122))	Motivation and behaviour change technique (Teixeira et al., 2020 (127)) and related SDT construct (see key)
1. Why move? Know and understand the benefits of moving more and the risks of spending a long time sitting or lying still.	Share information about health benefits / risks* Share information about emotional benefits* Share information about social benefits* Share infographics* Reference information sources* Information delivered / endorsed by a professional or celebrity* Text to speech function, description of images, subtitles for videos* Short videos from professionals / experts* Written facts with symbols to support them* No controlling / threatening language. Focus on positives* Adult supporters discuss with YP how the information relates to them** Adult supporters and YP have access to the same information** Small amounts of information received intermittently*** Look at the information when the YP is not tired / distracted*** Repeat the same information*** Archive the information received after it's release so it can be revisited***	5.1 Information about health consequences 5.3 Information about social and environmental consequences 5.6 Information about emotional consequences	1 Elicit perspectives on condition or behaviour* 3 Use non-controlling, informational* language 5 Provide a meaningful rationale*
2. Planning to move Identify and plan when and how YP	Young person discusses with key contacts what movements / activities they want to do* YP and adult supporters encouraged to be creative and think of fun / exciting new movement opportunities* Plan is flexible - specific times for each task do not have to be allocated*	1.2 Problem solving 1.4 Action planning 2.3 Self-monitoring of behaviour	6 Provide choice* 7 Encourage the person to experiment and self-

Intervention design objectives (goals)	Key features and their related SDT construct (see key)	Behaviour change technique (Taxonomy of Behaviour Change Techniques (122))	Motivation and behaviour change technique (Teixeira et al., 2020 (127)) and related SDT construct (see key)
can move more during daily routines. Review the plan regularly.	Adult supporters and YP are signposted to /encouraged to access resources giving information about local opportunities** YP and adult supporters look at YP's stories in app to get inspiration and ideas from experiences of others** Adult supporters share ideas and opportunities for moving more with YP** YP and key contacts discuss practicality / appropriateness of ideas with the adult supporters** Realistic plan with a number of movement activities to be done on each day of the week is produced in the app*** Activities support YPs aspirations and long term goals*** YP identifies when they want to integrate movement into daily routines YP / adult supporters tick off which activities were done each day on the plan*** If times are entered for activities, app will send a reminder 5 mins before its due*** If no times entered app will send "still to do" reminders during the day*** App provides feedback about the % tasks completed each day / week using "closing the circles" style graphic*** View these % scores across the week / month / months in the app***	3.1 Social support (unspecified)	initiate the behaviour* 11 Demonstrate/show interest in the person** 14 Prompt identification and seek available social support** 15 Address obstacles for change*** 18 Promote self – monitoring*** 19 Help develop a clear and concrete plan of action***
3. Preparing to move Ensure the YP and their adult supporters feel confident about a movement and the young person feels safe before moving.	Key contacts and YP discuss how YP is helped to move* YP feeds back their views and any requested changes to key contact* Adult supporters understand if YP needs processing time prior to moving and factor it in to routines** Ask YP if they feel safe and confident to move prior to moving** YP helps produce a list of suggestions for when they don't feel safe / confident to move in the app** Follow the list of suggestions if the YP is not confident about a move**	1.2 Problem solving 1.4 Action planning 3.1 Social support (unspecified) 4.1 Instruction on how to perform a behaviour 8.1 Behavioural practice / rehearsal	6 Provide choice* 8. Acknowledge and respect perspectives and feelings** 14 Prompt identification and seek available social support**

Intervention design objectives (goals)	Key features and their related SDT construct (see key)	Behaviour change technique (Taxonomy of Behaviour Change Techniques (122))	Motivation and behaviour change technique (Teixeira et al., 2020 (127)) and related SDT construct (see key)
	Minimum daily check of whether YP felt safe and confident about moving (face scale in app) (frequency can be selected)** View these ratings scores across the week / month in the app** YP & key contact discuss with supporters any changes and what is possible*** YP helps produce a guide in the app explaining how they move. Language simple with option to include photographs*** Guide includes details of specific equipment needed for each move in each setting*** Guide includes a review date and there is marked as expired if it hasn't been reviewed*** Encourage practising challenging movements in a safe environment with skilled supporters***		15 Address obstacles for change*** 19 Help develop a clear and concrete plan of action***
4. The experience of moving The YP having a positive experience of moving.	YP regularly discusses movement opportunities they wish to explore* YP sets max. 3 short term and one long term SMART movement goals with key contacts* Key contacts discuss how goals relate to YP's aspirations* Goals focus on participation and activities not impairments* An equipment list for each setting, including what YP likes / dislikes about each item, whether they feel it meets their needs* List of prompt questions for YP to capture their voice during equipment assessments / decision making* YP records movement goals in app with key contact** YP and key contacts discuss working towards the goals with supporters (overcoming barriers)** YP can link with another YP with username only to message them. Age displayed. YP who are linked can message each other** Other user needs to accept / decline. Acceptance can be reversed** Supporters and YP can access messages / flag concerns**	1.1 Goal setting (behaviour) 1.5 Review Behaviour goals 2.2 Feedback on behaviour 2.3 Self-monitoring of behaviour 2.6 Biofeedback 3.1 Social support (unspecified) 10.1 Non-specific reward 10.4 Social reward	4. Explore life aspirations and values* 5 Provide a meaningful rationale* 6 Provide choice* 7 Encourage the person to experiment and self-initiate the Behaviour* 11 Demonstrate/show interest in the person**

Intervention design objectives (goals)	Key features and their related SDT construct (see key)	Behaviour change technique (Taxonomy of Behaviour Change Techniques (122))	Motivation and behaviour change technique (Teixeira et al., 2020 (127)) and related SDT construct (see key)
	Messaging is moderated** Photos from before / after sheet can be shared with linked YP** Medal table can be shared with linked YP** Add new activities to reach the goals to the movement plan (see planning to move)*** Feedback from wearable device divides YPs waking day into "moving" vs "not moving" time*** Record what YP could do when goal was set and their progress with goals (use journal function)*** Complete before / after sheet in app for completed goals to recognise progress (can include photos)*** When a goal is achieved, a new one can be set*** YP can send a story of an activity / achievement to admin for publication*** Health professionals assess new activities to manage risk and advise on facilitation*** Bronze, silver, gold medal for first 3 goals achieved, enter level 2 and repeat*** Medal table: number of medals at each level*** Medals unlock an experience story / or info notification*** Experience rewards can be offered locally for goal achievement (not inactive screen time)***	12.2 Restructuring the social environment	14 Prompt identification and seek available social support** 17 Assist in setting optimal challenge*** 18 Offer constructive, clear, and relevant feedback*** 20 Promote self – monitoring***
5. Optimising comfort YP and adult supporters communicate about comfort and act to improve it if needed.	Choose from a range of open questions / face scale / switch / thumbs up / down to rate comfort level* Key contact and YP select frequency of recording comfort in app (minimum weekly if doing goal 5)* Does moving / changing position relieve the discomfort? Yes / no check box* Include movement / change of position as an action in comfort action plan where appropriate* Deliver messages about comfort as part of “Why Move?” goal including: • Not all discomfort is harmful / abnormal*	1.2 Problem solving 1.4 Action planning 2.4 Self-monitoring of outcomes of behaviour 3.1 Social support (unspecified)	6 Provide choice* 5 Provide a meaningful rationale* 8. Acknowledge and respect perspectives and feelings** 11 Demonstrate/show

Intervention design objectives (goals)	Key features and their related SDT construct (see key)	Behaviour change technique (Taxonomy of Behaviour Change Techniques (122))	Motivation and behaviour change technique (Teixeira et al., 2020 (127)) and related SDT construct (see key)
	• Explanations of expected / normal discomfort vs discomfort that needs action* • Pressure sore prevention - encourage skin checking and regular position change* • Challenge "no pain no gain"* • Share with adult supporters and YP under reporting of pain in YP with disabilities evidence* Key contact explains to YP reason for discussing comfort: optimising it may help to promote their movement** Is discomfort an issue for this YP? Yes / no check box. If no, exclude goal 5** If yes, discuss when, where, how frequently, what makes worse / better etc with key contacts. Checkbox for this conversation having happened** Option to include a list of signs the YP is uncomfortable** YP and key contacts discuss how and how often / when to communicate about comfort*** Comfort ratings viewed across the week / month in the app*** Frequent reporting of discomfort is flagged as an early warning sign*** Healthcare professionals complete any new referrals needed*** Health professionals support identifying and addressing physical / psychological needs where there are early warning signs*** Make action plan in app for improving comfort with key contact, discuss with supporters*** Include who initially responds to reporting of discomfort, who ongoing discomfort is escalated to*** Takes into account variability in supporters capacity to act*** Include flexibility as context / circumstances may require different responses e.g. options to try but not no fixed order***	12.2 Restructuring the social environment 13.2 Framing / reframing 16.3 Vicarious consequences	interest in the person** 14 Prompt identification and seek available social support** 15 Address obstacles for change*** 19 Help develop a clear and concrete plan of action*** 20 Promote self – monitoring***

Intervention design objectives (goals)	Key features and their related SDT construct (see key)	Behaviour change technique (Taxonomy of Behaviour Change Techniques (122))	Motivation and behaviour change technique (Teixeira et al., 2020 (127)) and related SDT construct (see key)
Functions / delivery strategies crossing multiple intervention delivery objectives (goals)	App users are reminded to check and update plans / lists at the frequency they select for each goal during set up* Key contacts and YP talk about goals / information/ complete rating scales / journals / create plans somewhere private** Journal function: YP / supporters upload video / text / audio to feedback about goals 3, 4 and 5 (only YP & supporters can access)*** Consider referring to existing documents / routines e.g. postural management plans / moving and handling risk assessments / education healthcare plans to produce plans and lists*** Export any plans / lists into postural management plans / moving and handling risk assessments / education and healthcare plans*** Plans and lists are quick and easy to edit so they can be kept up to date. All supporters / YP can edit.	1.4 Action planning 2.4 Self-monitoring of outcomes of behaviour 3.1 Social support (unspecified)	8. Acknowledge and respect perspectives and feelings** 11 Demonstrate/show interest in the person** 19 Help develop a clear and concrete plan of action*** 20 Promote self – monitoring***

Note: SDT constructs: : autonomy, relatedness**, competence***. Text with no * = no direct link to SDT constructs. YP: Non-ambulant young person*

7.5.2.1 Resources

The research team identified resources needed to deliver the intervention. Stakeholders were not involved in this process. The resources identified are listed below:

- Time (NAYP and AS)
- Access to the internet (NAYP and AS)
- A device on which to access the app / online dashboard.
- Wearable device with blue tooth connectivity (NAYP only)
- Safe moving and handling equipment
- Training in how to carry out moving and handling tasks safely (AS)
- Rehabilitation equipment (e.g. standing frames / walkers / tricycles / wheelchairs / hand cycles / arm cranks)
- Accessible environments which facilitate movement
- Resources specific to activities NAYP select to do (materials / equipment / transport / finance)

7.5.2.2 Risks

The largest assumption being made and the greatest risk to the intervention's success is availability of these resources. Data collected in steps one and two of the co-design suggested having time to support NAYP to move is a considerable barrier for AS, which could not be modified by this intervention. This is a risk to the intervention's effectiveness. Environmental accessibility and financial support were also considered non-modifiable barriers to movement (Chapter 5).

Wearable devices can be realistically provided as part of a research study, but funding this could be more challenging following translation into practice. Providing devices on which to access the app and internet access as part of a research study

or in practice would be costly and less realistic. There is a risk that lack of access to internet / devices has potential to introduce inequality, as only families who already have access to these facilities will be able to access the digital intervention.

There is an assumption that NAYP and AS will be motivated to engage in the intervention. Engagement of PPI reps and co-design participants in this intervention development indicates that there are NAYP and AS who would engage with the intervention (including being motivated to making time to do so), but how widespread adoption would be is unknown and introduces risk.

7.5.3 Objective 2) Producing an implementation plan with stakeholders (first data collection cycle)

Four workshops were held at the implementation planning stage. The workshops included two - four participants. Two of the workshops did not include anyone with lived experience.

Table 44 shows data collected on the Jamboard in relation to each intervention goal and the AS / key contact concept. The impact this feedback had on protype development is also summarised.

Table 44 Data collected on the Jamboard during workshops to produce an implementation plan with stakeholders. Text in square brackets added to give context to quotes

Intervention design objectives (goals)	**Intervention design objectives (goals)**	**Impact of feedback on prototype development**
1. Why move? Know and understand the benefits of moving more and the risks of spending a long time sitting or lying still.	NAYP 1: *"Re: positive language - sometimes need to be realistic."*	Incorporated
	Family member 2: *"Emphasize positives over negatives."*	Incorporated
	Professional 2: *"Care to avoid bombarding with too much information as may not suit everyone."*	Incorporated
	Professional 4: *"Can you link* [to] *a reference link so that people can access who want it as not all user will want to access them."*	List with links to be made available for those who wish to access it
	Expert 1: *"Perhaps the option for an 'on/off' switch for certain topics (e.g. pain), so a participant can choose whether or not to access some information."*	Not incorporated: complex to filter out some content for specific users when content gradually released to all
	Expert 2: *"How will we make the information age appropriate for everyone?"*	Will be considered when info drafted
2. Planning to move Identify and plan when and how young people can move more during daily routines. Review the plan regularly	NAYP 1: *"Reminder times need to be flexible and can be set individually."*	Incorporated
	"Prefer closing the circles weekly not daily."	Incorporated
	Family member 2: *"Don't need what's left reminders* [i.e. activities still to be completed]- *could be annoying."*	Reminders optional – can be turned on or off
	"Could the [activity] *reminder give an equipment prompt- to take everything you need."*	Equipment needed for an activity can now be added to on the plan
	Professional 2 *"Screen/ identify a child who is at risk of becoming more obsessive about goal achievement as key contact may need more support to guide them."*	Not incorporated: external support for KC not part of intervention
	Professional 3: *"Can they edit their list to add on a I went over and above today."*	Incorporated
	Professional 4 *"Can infographics on movement goals be weekly rather than daily to ensure continued motivation if there is a less active day?"*	Incorporated
	Professional 5: *"For "closing circles" feedback - maybe have option to turn off numbers and just see the shape. Or give option to not use it."*	Incorporated

Intervention design objectives (goals)	Intervention design objectives (goals)	Impact of feedback on prototype development
	Professional 6: *"Could we use existing material from tic tok / you tube / existing bloggers."*	(option to turn off numbers) Not incorporated: relevant content too focused on MVPA, not in keeping with intervention aim of replacing sedentary time with LPA
	Expert 1: *"What about some sort of a section for long-term goals (& is there a framework for that e.g. participation-focus)?"*	Incorporated long and short term goals, no framework to avoid goal setting becoming complex for adult supporters
3. Preparing to move Ensure the young person and their adult supporters feel confident about a movement and the young person feels safe before moving.	Professional 2:*"Make sure the guide to moving is dated - like an up to date risk assessment as the equipment or plan to move may no longer be appropriate."*	Incorporated
4. The experience of moving The young person having a positive experience of moving.	NAYP 1: *"Agreed to choose medals or stars* [not both]*."*	Goal achievement certificates became the only reward mechanism for simplicity.
	"Might not need prompt questions re: equipment [to capture NAYP's voice]*. This usually is OK."*	Not incorporated: in conflict with other feedback
	"Would be better if it [interaction between NAYP using the app] *could be face to face not virtual / anonymous."*	Not incorporated: safeguarding risks and option for anonymity needs to be maintained
	"Liked the idea of being able to share progress onto other social media sites."	Incorporated: YP can choose to share exported goal certificate on social media
	"Liking achievements [of other NAYP using the app] *would be OK."*	Incorporated
	Family member 2: *"Re: risk assessment of new activities doesn't have to be health care professional - change wording to someone appropriate."*	Incorporated
	"Goals function is function is optional."	All functions optional

Intervention design objectives (goals)	Intervention design objectives (goals)	Impact of feedback on prototype development
	"Maintenance goals might be an option to make sure things don't stop."	NAYP can write a maintenance goal as their short / long term goal
	"Before / after sheet may not work for maintenance goals."	Before / after fields optional
	Professional 1: *"Messaging* [between app users] *needs to have a complete opt out for people who don't want to do it."*	Incorporated. Messaging limited to between adult supporters and NAYP only via journal apart from NAYP liking each others stories.
	Professional 2: *"Give examples of participation goals - what do you want to do with whom."*	Incorporated
	"You could like or endorse a story rather than have to chat to each other." [relating to young people communicating with each other in the app]	Incorporated
	Professional 3: *"Equipment - what do I like about it, what does it allow me to do?"*	Incorporated
	Professional 4: *"Use young people's stories to include examples of goals."*	Not incorporated: stories and goals sections not linked in prototype build
	"List of equipment in app and prompts for voice of the child for equipment assessment & what does the young person have in place & their thoughts around the equipment."	Incorporated
	"Can YP chose between medals or stars as rewards."	Goal achievement certificates became the only reward mechanism for simplicity
	"Can words/phrases be flagged for moderation, but not all comments need moderating?" [relating to young people communicating with each other in the app]	Messaging limited to between adult supporters and NAYP only via journal apart from NAYP liking each others stories. Moderated via a flagging system
	Professional 5: *"Tic toc challenges."*	Not incorporated: Can't maintain anonymity Safeguarding risks
	Expert 1: *"I wonder if the social element takes away from the main goal of the app? And with a risk/cost analysis, is it worth it?!? Just posing the question, it could be amazing!!!"* [relating to young people communicating with each other in the app]	Incorporated: messaging limited to between adult supporters and NAYP only via journal apart from NAYP liking each others stories

Intervention design objectives (goals)	Intervention design objectives (goals)	Impact of feedback on prototype development
5. Optimising comfort Young person and adult supporters communicate about comfort and act to improve it if needed.	Family member 2: *"Action planning for comfort may / may not be relevant."*	Incorporated: all functions optional
	Professional 2: *"Need to have a health care worker or KC who knows the child to guide whether movement pain is discomfort or red flag pain."*	Not incorporated: YP selects KC and adult supporters for autonomy
	"Think about how to export information to existing postural management plans and whether the KC can devote enough time to catch up with the young person regularly (daily)."	Incorporated: adult supporters can export from online dashboard
	Professional 4: *"Really like the discussion about different types of discomfort."*	Positive feedback
	Professional 5: *"Bone density and fracture risk needs to be discussed."*	Will be considered when goal 1 info drafted
	Professional 6: *"Option to write individualized descriptions for the 5 faces to explain what each one means with the KC (check with HCP)."*	Written descriptions added to faces scale but not individualized
	"Don't use word red flag or a red flag image for this - on warning system."	Incorporated
	"Change wording of red flag boxes so if they have persistent pain team look for a deterioration rather than steady reporting of a low score being an issue."	No red flag boxes to be included
Key contacts	NAYP 1 *"Good."*	Positive feedback
	NAYP 2: "*Good idea.*"	Positive feedback
	Family Member 1: *"Like the idea that the key contact is chosen by the young person."*	Positive feedback
	Family Member 2: *"Important that there is more than one key contact and they can be added / removed."*	Incorporated
	Professional 1: *"Sounds sensible / realistic to ensure success and that the young person selects them."*	Positive feedback
	Professional 2: *"I really like the idea of a key contact that the YP knows and trusts - communication is the key."*	Positive feedback
	"Could there also be a contact a KC can discuss the role with, do we assume if they work with children they are Safeguarding trained."	Not incorporated: handbook will explain KC role. External support for KC not part of intervention. Adult supporters do not have to have had safeguarding training (could be family members). YP controls adult supporters for

Intervention design objectives (goals)	Intervention design objectives (goals)	Impact of feedback on prototype development
		autonomy. Moderated flagging system in place for journal where adult supporters can communicate with NAYP. Journal visible to all adult supporters -no private messaging.
	Professional 3: *"Great to have a key person yes."*	Positive feedback
	Professional 4: *"This is a really good idea. Having someone to communicate with that the YP trusts, could be key to success!"*	Positive feedback
	Professional 5: *"This sounds a good idea having someone to lead on using the app."*	Positive feedback
	Professional 6: *"As I understand it that sounds like a good idea."*	Positive feedback
	Expert 1: *"Sounds great! Love that there's one per key location. Some skills ideas for KCs too if they're needing to negotiate with a wider team?"*	Positive feedback Skills ideas not incorporated: handbook a resource for KC. External support for KC not part of intervention

Note: NAYP: Non-ambulant young person, YP: young person KC: key contact, MVPA: moderate to vigorous physical activity. LPA: light physical activity.

There was only one instance of participants in different groups offering contradictory feedback. This related to NAYP being able to comment on what they did or did not like about their items of equipment and what they would like to change. One NAYP did not feel this was necessary, as they had no personal experiences where this would have been helpful to them. Two professionals in different workshops supported the NAYP being able to write about what they like / dislike about their equipment. Empowering NAYP to have a voice in decision making around their equipment is in line with the SDT construct of autonomy, so the support professionals gave to include this was upheld.

As feedback and suggestions generally complemented each other, it was possible to incorporate most feedback in the software specification and prototype. In some instances, changes made were in line with what the participant suggested, but were not exactly what they suggested (Table 44).

A software specification was written based on the results from initial workshops and interviews to allow building of an interactive prototype app.

7.5.4 Objective 3) Evaluating the MoveMore app prototype (second data collection cycle)

Four workshops and one interview were held in the second cycle of data collection. The workshops included two - four participants. One workshop did not include anyone with lived experience. The interview was with an expert.

The results of the prototype evaluation are presented in the table of changes from the Person-Based Approach (117). A section of it is presented in Table 45 below as an example of its content. The full table of changes is available in Appendix 13.

Positive and negative feedback was shared in the prototype evaluation workshops. As expected at this prototype stage, suggestions for improvements outweighed positive feedback in this first iteration of the intervention. There was sufficient flexibility and resource to incorporate almost all changes rated “Must do”; “Should do” or “Could do” in the live app ready for feasibility testing. On discussion with the broader team following the evaluation workshops, there was insufficient resource for some items and they were consequently rated “Would like to do”. These ideas can be considered in future iterations.

There were only two examples of conflicting feedback. One was in relation to whether it would be helpful for NAYP to be able to write about what they did or did not like about their equipment. The decision to retain this feature was based on its inclusion being in keeping with the autonomy construct of SDT. The second conflict was around whether appearances should be kept simple using fewer colours and images, or whether more colours would be more engaging / exciting and could be useful to illustrate different activity types that had been completed in the feedback functions of the app. As stakeholders with lived experience consistently supported simple appearances, it was decided not to add additional colours / images or add complexity by making the appearance of the app tailorable.

Completing the table guided future work with the software developers, to produce a live version of the app ready for use in a feasibility study.

Table 45 A section of the table of changes, using the Person-Based Approach table of changes template (111).

Intervention Element	**Positive Comments**	**Negative Comments / Things to mprove.**	**Possible Change**	**Reason for Change**	**Agreed change / No change (NC)**	**MoScoW**
My Movement: Menu screen		Professional 2: *"The sub menu and the main menu are very similar so easy to forget you are in a sub menu and there are other lists to return to. Use a logical flow - my activity first then diary plan"*	Change appearance of main menu and sub-menu so it's clear where you are in the app.	EXP (stakeholder), NCON	Place icon of the submenu you are in at the top centre of the submenu screen with submenu items below it.	C
My Movement: My Activities	NAYP 2: *"I like the option to choose from the list"*	NAYP 2: "*You could have an option to include a visual of the activity. Less words, more pictures"*	Add option for photo upload for each activity.	EAS, EXP (stakeholder) NCON.	Add photo upload here	S
	Family member 1: *"Useful to have the list of equipment. Once set up would be easy to use. Easy to understand how to use"*	Family member 1: *"Who will be responsible for adding all the activities. Some people will be motivated, others may not"*		NC. Key contacts will support NAYP to add activities via their app only. Risk of NAYP losing autonomy if AS's can add activities via AS dashboard without involving them, which is key to the theoretical underpinning of the intervention.	NC	
	Professional 1: *"Very flexible and can be added to easily"*	Professional 2: *"Can we have a few activities as an example to choose- eg walking, motomed, swimming and then add other activities that they complete"*	Produce a drop down list of suggested activities, but can also add your own.	EAS, NCON	Standard list of activities that can be chosen and put onto plan, plus	S

Intervention Element	Positive Comments	Negative Comments / Things to mprove.	Possible Change	Reason for Change	Agreed change / No change (NC)	MoScoW
					able to add your own.	
	Professional 4: *"Opens up conversations about what activities young person enjoys as it allows for open input, not selecting from a set list"*	Professional 4: *"Can we add PDF attachments to activities e.g. therapy programmes?"* Researcher comment: *"Does AS needs to be able to upload any PDFs from the AS dashboard, and can do from YP's app?"*	AS able to upload documents related to a particular activity.	EXP (stakeholder)	NC – could threaten autonomy as NAYP has no control over content of uploaded program. AS can't edit activities section.	
	Professional 7: *"Nice that the activities aren't just exercise focused"*	Expert 3: *"I think engagement might drop off for this section - it's a lot. Can it be linked with outlook calendar?"* Expert 3: *"Reduced touch points would be better - the less the user has to do the better"*	Link with "My Plan" so a new activity can be added from my plan and will get listed here automatically.	EXP (stakeholder), NCON	New activity can be added from my plan and gets listed here automatically.	C
	Expert 1: *"Likes that activities can be added in plan or my activities"*	Expert 3: *"Are there 'push notifications' with the app? It might be difficult to remember to do the planned activities without a reminder"*		NC. Reminder can be set for an activity from "My Plan" to trigger a notification.	NC.	
	Expert 1: *"Adding activities is straight forward"*	Expert 3: *"The summary of what was input popped out of the screen - what does it look like in the app?"*		NC. Summaries appear in app also. Can submit if info correct, or press cancel or the cross in top right corner,	NC	

Intervention Element	Positive Comments	Negative Comments / Things to mprove.	Possible Change	Reason for Change	Agreed change / No change (NC)	MoScoW
				which takes you back so you can edit the info.		
		Researcher comment: *"May need multiple places for an activity"*		NC. Place is added in "My Plan" rather than "My Activities". The same activity could be done at school in the morning then home in the afternoon on the plan.	NC	
		Researcher comment: "Does AS need to be able to add activities from dashboard, not just the app?"		NC – could threaten autonomy as NAYP has no control over content uploaded by AS. AS can't edit activities section from dashboard.	NC	
My Movement: My Plan	Family member 1: *"Like the idea of reminders!"*	Family member 2: *"Good* [for NAYP] *to be able to navigate around independently* [using i gaze]*"*	Build integration with communication aids	EXP (stakeholders), NCON.	NC. Not possible within project resources (time and funding).	W
	Professional 1: *"The details that can be added are great, the journey it shows could be really motivating"*	Family member 2: *"Do you get reminders about which activities you still need to complete?"*		NC. Option to set a reminder to complete an activity for each activity added to the plan.	NC	
	Professional 1: *"Could help create routines for people which will*	Professional 1: *"Think some young people are going to need a lot of support to add information"*		NC. Team of key contacts to support NAYP with creating	NC	

Intervention Element	Positive Comments	Negative Comments / Things to mprove.	Possible Change	Reason for Change	Agreed change / No change (NC)	MoScoW
	help them physically and mentally"	Professional 1: *"Keeping activities up to date will need someone to help YP to do it. YP may get demotivated about the app if its not being done"*		and updating plan. Giving AS ability to add to plan via dashboard reduces NAYP's autonomy. AS can tick activities in plan as complete from AS dashboard.		
	Professional 2: *"I like the summary page to confirm what you have put in"*	Professional 2: *"Can we make the 'Add' and plus sign a stronger colour green/blue as it looks greyed out so I did not try to click on it"*	Change colour of "Add" button.	EAS, EXP (stakeholder), NCON	Change colour of "Add" button to bold colour from theme colours used in app.	S
	Professional 4: *"The recurring function when adding an activity is very useful & will make scheduling activities easier"*	Expert 3: *"Would be better to be able to click you've done the activity from the plan list for the day without opening the activity"*	Developer suggestion: "Will be able to tick you've done an activity from the notification for that activity"	EXP (stakeholder), NCON.	Able to tick activities as complete directly on the plan without clicking on the activity first. AS's able to tick as complete from "Timeline" view of movement plan.	S
	Professional 7: *"Ability to edit then tick an activity if you did it on a different day to when you originally planned is helpful"*					
	Expert 1: *"It's intuitive!! Adding*					

Intervention Element	Positive Comments	Negative Comments / Things to mprove.	Possible Change	Reason for Change	Agreed change / No change (NC)	MoScoW
	activities is straight forward"					
My Movement: How much am I moving?	NAYP 1: *"Like bonus activities"*	NAYP 2: *"Can understand bar charts well. Would like being able to see history of tasks completed in a bar chart too as it gives you more information than just the circle view."* Family member 1: *"Would be useful to be able to look at different days"* Professional 1: *"Closing the ring, comparing days, weeks and months to see patterns and challenges and to work out why they are happening"* Professional 2: *"Use multiple circles to show day-by-day or week-by-week or month-by-month"* Professional 4: *"Being able to review activity break down by day will allow overview of patterns when less activities are completed."* Professional 6: *"Detailed breakdown?"*	Be able to see patterns of % completed activities and bonus activities over time more clearly in app and AS dashboard. This could be multiple circles or bar charts, as preferred by NAYP 2.	IMP, REP, EXP (Literature – self monitoring behaviour change technique), NCON	To show patterns over time in a bar chart via app and AS dashboard.	S
	NAYP 2: *"I like the circle and how you can go back and fourth between dates"*	Professional 4: *"Add a flag for "reasons why I couldn't move today" e.g. school holidays, illness, hospital admission etc."*	Add being able to add a barrier into the movement plan, and what dates that barrier affected movement.	IMP, EXP (stakeholder)	NC. Not possible within project resources (time and funding).	W

Intervention Element	Positive Comments	Negative Comments / Things to mprove.	Possible Change	Reason for Change	Agreed change / No change (NC)	MoScoW
			This is then is written on the ring in “How much am I moving” also, if relevant dates selected.			
	Family member 1: *“My daughter really liked the pink! Too many colours on this screen could be off putting. One colour was nice”*	Professional 6: *“How to celebrate achievements and activities”* Professional 7: *“Would be good to have the bonus activities more celebrated as previous groups suggested”*	Make bonus activities more celebratory by using a present icon to represent them. Goals can be set around planned activities to gain certificates or achievements shared via the “My Stories” or publishing to the “Stories Collection”	IMP	Present icon used to celebrate bonus activities.	S
	Family member 2: *“Adding bonus activities is clever”*	Expert 1: *“Add quick date range selection in addition to date range. e.g. last week, last month as on AS dashboard”*	Add quick select options on AS dashboard to see last day, week, month etc.	EAS, NCON	Quick select option added to AS dashboard.	C
	Professional 7: *“This screen really focuses on what has been achieved”*	Expert 1: *“Change naming of my progress so its clearer what it is and the difference between moving minutes and my progress”*	Change to “How much am I moving?” to match original software spec.	EAS	Function name changed to “How much am I moving”	S
		Expert 1: *“Link my progress and moving minutes together, not toggle between”* Expert 1: “*Date selection stays when moving between my moving minutes / my progress”*	Under “How much am I moving” have “Completed Activities” and “Moving Minutes”. Date range is just selected once and data is shown in	EXP, NCON	To change titles in app and AS dashboard. Single date range to show date for both in AS dashboard only for this project. To add to app in the future.	C

Intervention Element	Positive Comments	Negative Comments / Things to mprove.	Possible Change	Reason for Change	Agreed change / No change (NC)	MoScoW
		Expert 3: *"More colourful would be more engaging. Different activities could be different colours"*		NC – In conflict with positive feedback from Family member 1 – who felt single colour was good.	NC	
		Expert 3: *"Have you looked at Garmin Connect?"*	Use wearable activity recognition to automatically tick off activities.	NC – not possible within project resources to investigate automating this section with activity recognition.	NC	C
		Facilitator comment: *"If you select not to see the percentage figure it should be remembered for future visits to that page"*	App remembers for future visits to this page if user selects not to see the percentage figure.	EAS, NCON	Percentage figure won't be shown again once user selects not to display it unless they change this setting. EAS, NCON	S
My Movement: My Equipment	NAYP 1: *"Like that can write what you do / don't like about equipment"*	Professional 2: *"Options of addition of 2 equipment pieces for a single activity eg standing - using the wheeled stander at school and static at home"*	Able to add more than one item of equipment to an activity.	EXP (stakeholder), NCON	NC - not possible within project resources. To add in future.	W
		Professional 4: *"Add pictures for positioning in certain pieces of equipment like a postural management plan"*	Facilitate this this by making it possible to upload more than one image per item of equipment.	EXP (stakeholder), NCON	NC - not possible within project resources. To add in future.	C
		Professional 4: *"Add who purchased the equipment, user manuals /*	Add upload of docs to AS dashboard for these items.	EXP (stakeholder), NCON	NC - not possible within project	C

Intervention Element	Positive Comments	Negative Comments / Things to mprove.	Possible Change	Reason for Change	Agreed change / No change (NC)	MoScoW
		service date for adult supporter dashboard" Professional 4: *"Add service history and instruction manuals for each pieces of equipment on the adult dashboard"*			resources. To add in future.	
		Expert 3: *"Icons would work well rather than detailed images. Garmin and Strava do the gear listing very well"*		NC – detailed image allows upload of NAYP's posture in the equipment.	NC	
My Movement: Moving Minutes	NAYP 2: *"I like the bar charts that show how many minutes I have moved when wearing the fitbit. I can understand bar charts better when collecting more information."*	NAYP 1: *"Not sure if I will be able to see the watch as screen is small"*		NC – minimal use of watch screen needed as relevant data is automatically moved into the app. May be needed for checking battery level but AS's can support this.	NC	
	NAYP 2: *"Looking back at what I have done will help me move more"*	Family member 2: *"Need to think about orthotics / wrist straps obstructing the fitbit"*	Problem solving in feasibility study.	IMP, EXP (stakeholder), NCON.	Identify any change necessary in feasibility study.	W
	NAYP 2: *"Seeing moving minutes will motivate people to move more"*	Family member 2: *"May pick up heart rate increases when [name] gets excited and interpret them as movement"*		NC- to be assessed in feasibility study by comparing activPAL™, fitbit accelerometer data and paper diaries.	NC	

Intervention Element	Positive Comments	Negative Comments / Things to mprove.	Possible Change	Reason for Change	Agreed change / No change (NC)	MoScoW
	Professional 2: *"I like the moving minutes feedback"*	Expert 3: *"Can fitbit be used to enter the activities, rather than it being manually added in this app"*	Developer comment: Explore this and pulling activities from the fitbit also, can manually add activities or pull from Fitbit data.	EXP (stakeholder), NCON	NC – not possible within project resources to investigate automating this section with activity recognition.	C

Note: Text in square brackets [ ] added to give context to quotes. ESS: Essential change for intervention to function, IMP: important for behaviour change or practical / ethical / safety reasons, EAS: Easy and uncontroversial, REP: repeated by more than one participant in the co-design, EXP: change supported by experience, for example of public and patient involvement reps, stakeholders (including those with lived experience, health / education professionals, experts), literature (evidence base), NCON: does not contradict the logic model or guiding principles, NC: No change, plus justification of why, M: must have, S: should have, C: could have, W: would have (if resources available), AS: Adult supporter, NAYP: Non-ambulant young person, YP: Young person, KC: Key contact.

7.6 Discussion

This study has described the fourth step of the MoveMore intervention development, following the 6SQUiD model (86). This involved transitioning from a logic model and programme theory for the MoveMore digital behaviour change intervention to having completed an evaluation of a prototype app with stakeholders. This was achieved in three stages: 1) proposing an implementation plan based on previous data collection and theory, 2) co-design workshops and interviews in which stakeholders fed back on the proposal to inform writing of a software specification, 3) workshops and interviews to evaluate the prototype app. The evaluation produced a list of prioritised changes using a table of changes template from the Person-Based Approach to digital intervention development (83). The changes will now be incorporated into the live app in preparation for feasibility testing, which is step five of the 6SQuID model.

Step four of the 6SQUiD involved consideration of potential risks and unintended consequences associated with the intervention. This included considering potential exacerbation of health inequalities by being more beneficial to those who are affluent or well educated. The greatest risk to adoption of the MoveMore intervention is whether the required resources are available. As for the majority of digital interventions, access to the internet and devices is necessary, creating potential for inequality. It is estimated that 7% of households in the UK lacked access to the internet in 2023 (287). This is a relatively small number of households overall, however it rose to 23% in households with a combined annual income of <£10.4k (287). Only 10% of households do not have access to a smartphone in this same income bracket, so it is possible the intervention could be accessible via a smartphone (287). Reassuringly only 4% of children do not have access to the

devices they require for school in households with one - two children, suggesting a greater proportion of households with children have internet access than in the general population (287). However, this rose to 24% of children when there were four children in the house (287). Limited internet and device access therefore has potential to result in the MoveMore intervention exacerbating health inequalities. Exploring opportunities to minimise this risk by signposting potential adopters to local and national third sector opportunities aiming to reduce digital inequality by providing internet or device access would be beneficial.

At present, the MoveMore app only integrates with Fitbit devices. The wrist worn Fitbit collects both heart rate and accelerometery data. Currently, only the heart rate will be used to estimate the “moving minutes” that are visible to the NAYP as self-monitoring feedback, as this avoids issues relating to atypical movement patterns. Usefulness of the Fitbit accelerometer data will be assessed as part of feasibility testing. It may be used to improve accuracy of the “moving minutes” feedback in future optimisation, if it is deemed helpful. In the feasibility study, a thigh worn ActivPal will also be worn for one week pre and post intervention. This provides the research team with additional data showing time spent sitting, lying and standing and the amount of physical activity undertaken in those positions. The ActivPal device does not integrate with the MoveMore app, so this information won’t be visible to NAYP as self-monitoring feedback. However, the ActivPal data will improve accuracy of sedentary time measurement pre and post intervention for the research study.

An additional consideration for the MoveMore intervention is NAP’s access to wearable devices. Approximately 35% of the UK’s adult population currently own and regularly use a smartwatch or wearable fitness tracker (288). This figure is likely to be

much lower amongst NAYP, as the feedback provided is not adapted for wheelchair users. It is feasible that health or education facilities could provide wearables for NAYP who could benefit from the MoveMore intervention, however this would increase the cost of delivering the intervention. To facilitate translation, additional wearable devices could be integrated with the MoveMore app in the future, so NAYP can use it with a wider range of wearable devices.

Incorporating all feedback and suggestions from the implementation planning workshops / interviews (objective 2) resulted in the software specification being detailed and complex. Making multiple functions tailorable by the individual, such as when they are reminded about each aspect of the app and the option to select how and when they wish to rate their comfort and confidence with moving increased the complexity of building and using the app. Feasibility study data will demonstrate which tailorable features and behaviour change functions NAYP engage with; providing an opportunity to reduce complexity of the app without having a negative impact on user experience or effectiveness.

In workshops / interviews participants suggested key contacts may need external support with undertaking their intended role. Examples included supporting key contacts to manage NAYP who may become overly fixated on achieving their goals, how to approach conversations about comfort and support with goal setting. To minimise cost of delivering the MoveMore intervention, providing individualised support for key contacts is not currently included. The intention is for key contacts to refer to the handbook (Appendix 12) and resources within the app to guide them. Participants' feedback suggests assessing whether individual support for key contacts is needed for successful implementation should be an important aspect of

feasibility testing. This is an example of how early stakeholder involvement can anticipate implementation challenges, as described in the updated Medical Research Council Framework for the Development and Evaluation of Complex Interventions (73). The framework recommends early consideration of the intervention's implementation strategy during feasibility testing and early consideration of the economic impact any changes may have (73). Building individual support for key contacts into future iterations of the intervention would have resource implications. Evaluation of this specific aspect of the intervention may need to be included in the intervention refinement process, comparing outcomes when key contacts do or do not receive individual support.

Other digital interventions that have employed think-aloud interviews and a table of changes as part of a Person-Based Approach to intervention development include development of the "BP: Together" intervention to support self-monitoring of blood pressure for people who have had a stroke (289) and the "Active Brains" intervention, which aims to reduce cognitive decline in older adults with or without pre - existing cognitive impairments (290). Both used these techniques to optimise a prototype prior to live deployment, as we have done with the MoveMore intervention prototype. Only the intended end users (older adults) participated in the "Active Brains" intervention development, however a management team including PPI reps, clinicians, academics and charity partners met quarterly (290). As in our MoveMore intervention development, the "BP: Together" project included a wider group of stakeholders in their data collection. Qualitative data was collected from partners and family members of participants and healthcare professionals (289). The authors highlighted the value of including family members who support patient care (289). A

second table of changes was produced following feasibility testing of the “Active Brains” intervention (290). This allowed the researchers to compare this second table with the first (which related to the prototype intervention) to confirm that issues raised in the first iteration had been resolved in the second. This will be a useful approach to take following feasibility testing of the MoveMore intervention.

The next (fifth) step of the 6SQUiD involves testing the intervention on a small scale. Following the incorporation of changes identified in this prototype evaluation, a small single armed feasibility study will assess usability and acceptability of the MoveMore intervention. The protocol for this study is shared in Appendix 14 and ethical approval has been granted. This mixed methods evaluation of use of the live app in the community will combine quantitative data collected within the app with qualitative data from interviews with NAYP and AS. This work will inform the next iteration of modifications for the app prior to undertaking a study to assess the intervention’s effectiveness (step six).

Step two of the 6SQuID identified several barriers to reducing sedentary behaviour which could not be modified via a digital intervention, including time, environmental accessibility, access to equipment and financial support. The feasibility study will provide early evidence of whether: 1) these barriers will continue to impede behaviour change, 2) there is capacity to increase movement despite these barriers, or, 3) whether the MoveMore intervention addresses any of the barriers through collaboration and innovation. Recruitment to the feasibility study will be the first indication of motivation amongst NAYP and AS to engage with a digital intervention of this nature.

7.6.1 Strengths and weaknesses

The wide range of stakeholders included in the MoveMore intervention development and the involvement of PPI reps in decision making throughout the process is a strength of this study. The range of stakeholder groups provided varied feedback due to their differing priorities and perspectives. Differences of opinion between differing stakeholder groups was infrequent, allowing the majority of feedback to be incorporated into the intervention. This increases the likelihood of the live version being acceptable, useable and feasible for all stakeholders. In addition, complementing the structure of the 6SQUiD model (86) by incorporating tried and tested tools from the Person-Based Approach (83) is a strength of this work. The 6SQuID model lacked methodological detail in step four. Using techniques recommended in the Person-Based Approach addressed this weakness, ensuring evidence-based intervention development methods continued to be used throughout the MoveMore app co-design.

Whilst there are several strengths to this study, there are some limitations related to virtual data collection, attrition, extent of stakeholder involvement and risk of bias. Firstly, virtual data collection restricted the type of activities that could be undertaken during workshops. However, it allowed wide geographical representation and avoided potentially vulnerable NAYP needing to attend or travel to meetings. Second, attrition over the course of the 6SQUiD co-design steps resulted in a small number of NAYP and family members being involved at this stage. This attrition also resulted in reduced diversity in this cohort which is a concern. Recruitment to the feasibility study will provide an opportunity to involve a more diverse group of participants in testing of the live app. Third, stakeholders were only consulted about intervention content and

not resources needed or assumptions made when producing the proposed implementation plan. Finally, workshops and interviews were facilitated by the lead author (MB), who had preconceived ideas about the contents of the intervention. Although they acknowledged this and took measures to reduce the risk of their perspectives influencing participants feedback, it is inevitable that this introduces some risk of bias.

7.7 Conclusion

This study described step four of an intervention co-design, following the 6SQuID model and supported by methods and tools from the Person-Based Approach. This involved developing an implementation plan for the MoveMore digital behaviour change intervention using a previously developed logic model and programme theory with input from stakeholders and PPI reps. The plan was used to produce a prototype mobile application and online dashboard which aims to support NAYP to reduce their sedentary behaviour, with assistance from their AS. To inform a first iteration of optimisation, the prototype was evaluated by stakeholders in virtual workshops using think-aloud methods to produce a table of changes. These prioritised changes will now be incorporated into a live version of the MoveMore digital intervention ready for feasibility testing.

8 Chapter 8: General discussion

8.1 Overview

The overarching aim of this PhD was to co-design a new digital behaviour change intervention in the form of a mobile application (or app) to support non-ambulant young people (NAYP) with long term disabilities to reduce sedentary behaviour. This aim was underpinned by three objectives.

1. To establish quality of existing evidence by undertaking a systematic search and review of the literature relating to sedentary behaviour and NAYP.

2. To explore using crowdsourcing, a novel and innovative digital data collection methodology, to engage with stakeholders as part of the Six Steps in Quality Intervention Development model.

3. To co-design a new digital health intervention with stakeholders, that aims to reduce and break up sedentary behaviour by promoting light physical activity (LPA). To achieve this using a combination of stepped, theoretical and partnership approaches to intervention development.

The Six Steps in Quality Intervention Development (6SQuID)(86) model has guided the work undertaken in this thesis. Studies undertaken to complete steps one - four of the 6SQuID have been presented. The chapters progressed through the four steps of the intervention development sequentially.

First, this discussion outlines the original contributions to knowledge this thesis makes. This is followed by a summary of the key findings, how they relate to existing literature and the implications of them. Strengths and weaknesses of this body of work are discussed and finally directions for future research are proposed.

8.2 Original contributions to knowledge

Scope of evidence relating to sedentary behaviour of children and young people with physical disabilities has been explored previously (38, 157). However, these scoping reviews did not incorporate critical appraisal to assess risk of bias. The systematic search and review that was undertaken in this thesis, is the first review that includes appraisal of quality of this body of literature. It is also the first review to focus specifically on literature relating to non-ambulant participants.

Using crowdsourcing (113) to engage stakeholders in intervention development is innovative and in its infancy. There are only a small number of published examples of this methodology being attempted (242, 243, 291). These were published just prior to or in parallel with the data collection undertaken via crowdsourcing that is presented in this thesis. This thesis contributes to the understanding of use of crowdsourcing (including associated challenges) in the field of intervention development. It raises questions about why engagement was low amongst NAYP and their family members, when engagement has been more successful in previous intervention developments involving young people (242, 243, 291).

Undertaking virtual co-design workshops via Microsoft teams and use of the Jamboard interactive whiteboard is also an innovative methodology. Virtual data collection was necessary due to the Covid-19 pandemic. Researchers needed to rapidly adapt to virtual methods and this work is an example of knowledge being gained about the strengths and weaknesses of virtual data collection during that period. This data collection method was accessible to NAYP and their family members, reducing barriers to participation in research that they have previously experienced (240).

Previous qualitative literature has explored barriers and facilitators of physical activity (184, 239, 292-297), or physical activity and reduction of sedentary behaviour (40, 53, 57, 218, 298) that children and young people with physical disabilities experience. However, sedentary behaviour has not been discussed independently of engagement in physical activity, or in relation to NAYP specifically. In step one of the 6SQuID, stakeholders were asked to identify barriers and facilitators of moving more and sitting or lying less for NAYP. In relation to moving more, it was clarified that the focus was on low intensity movement undertaken frequently during daily routines and *not* on more vigorous exercise that would raise heart rate for example. When a list of barriers and facilitators had been generated, step two of the 6SQuID went on to use this new knowledge to identify which barriers and facilitators were modifiable via a digital intervention, from the perspective of stakeholders.

Finally, steps three and four of the 6SQuID culminated in production of a prototype of the first theory-based behaviour change intervention which specifically aims to support NAYP to reduce sedentary behaviour (the MoveMore app). An intervention handbook was also produced (Appendix 12) and the prototype intervention was evaluated to inform a first iteration of optimisation.

Key findings in relation to this new knowledge and how they relate to existing literature is presented below.

8.3 Key research findings and relationships to existing literature

Results of the systematic search and review showed that there are methodological weaknesses in the majority of studies providing quantitative evidence relating to sedentary behaviour in NAYP. Three existing qualitative studies and two scoping

reviews were of good quality. The remaining 48 (largely quantitative) studies were of fair quality. Fifteen publications were excluded due to being poor quality.

How sedentary behaviour / time was defined and measured was an issue across the quantitative studies. A key finding of the review was that there are no validated methods of measuring sedentary time of NAYP in free-living environments at present. There are promising lab based studies which analysed raw data from multiple wearable devices (173, 208). This issue related to the measurement of sedentary behaviour in NAYP reduced the quality of existing quantitative observational studies that have been undertaken to estimate sedentary time in this population. Despite these weakness, there was consistency across observational studies indicating that there are high levels of sedentary time in NAYP in comparison to typically developing children and young people (33, 158, 159, 209, 212) and ambulant young people with physical disabilities (33, 158, 159, 210, 215).

Associations between sedentary behaviour of NAYP and their physical function and age are likely. Those who are older (33, 40, 210, 214) with greater functional difficulties (39, 158, 159, 210, 214, 216) are likely to be more sedentary. The same relationship between sedentary behaviour and age is also present for able-bodied children and adolescents (27, 299).

Qualitative studies identified multiple social, environment and cultural influences on sedentary behaviour of NAYP, however these papers did not focus on sedentary behaviour in isolation (40, 57, 218). Sedentary behaviour and physical activity were being discussed. The studies in Chapters 3 and 4 of this thesis are the first example of qualitative work exploring sedentary behaviour of NAYP in isolation. In research on

physical activity and sedentary behaviour of able-bodied children aged 0-6 years (300), participants did not make a distinction between barriers and facilitators of physical activity and sedentary time. This was also observed in data collected for step one of the MoveMore app co-design. Although participants were asked to focus on barriers and facilitators of doing light physical activity or sitting less or lying more, the barriers and facilitators identified were similar to those identified in previous research which explored physical activity alone (58, 239) or a combination of physical activity and sedentary behaviour (40, 53, 56, 57, 218).

For able-bodied children aged 0 – 6 years, factors influencing both sedentary behaviour and physical activity included: the child themselves (preferences, health and lifestyle, development, downtime), home (parental roles, siblings and peers, environment); childcare away from home; parent – childcare provider interactions; environmental factors; safety; and weather (300). These participants and NAYP who participated in step one of the MoveMore app intervention development reported that interpersonal relationships with adults and peers had a strong influence on sedentary behaviour. Our data suggests that for NAYP, it is essential to consider these interpersonal relationships in order to facilitate behaviour change, due to NAYP's reliance on assistance from adults to help them to move.

Safety was another common theme for able-bodied children (300) and NAYP in the present research. For able-bodied children, concerns were often related to appropriate supervision in relation to safeguarding and limiting high risk activities such as sports and tree climbing. In our data relating to NAYP, there were concerns about availability and correct use of moving and handling equipment, confidence and skills of carers, and risks of injury due to pre-exiting conditions and co-morbidities.

Due to their limited opportunities for independent movement, risks were different for NAYP in comparison to able-bodied children. Indeed, in our study, categorising the barriers and facilitators of sedentary behaviour for NAYP into the six determinants of sedentary behaviour set out in the Systems of Sedentary Behaviour (SOS) Framework (118) showed that the majority of barriers and facilitators (17) were related to physical health and wellbeing.

Weather was not a key theme for NAYP, whereas it was for able-bodied children (300). This may be because there are fewer opportunities for NAYP to do outdoor activities due to barriers related to environmental accessibility and appropriate facilities.

Literature relating to barriers and facilitators of sedentary behaviour of able-bodied adolescents largely focuses on school environments (301, 302). Barriers identified at school included lesson structure, environment / structure of the classroom and recreational areas, curricular pressures and increased sedentary behaviour outside of school as a result of school-related factors such as homework and travel time (302). Changes in classroom layout / furniture, uniforms, pedagogical changes, hands-on learning, outdoor lessons and equipment, more breaks and compulsory physical activity were deemed to be facilitators (302). Comparing these findings with our data, the broad themes of improving environments, access to equipment and competing academic pressures were similar between able-bodied and NAYP. However, specific barriers / facilitators and what would need to change in terms of an intervention were particular to each population. Again this is likely to be due the restrictions in independent movement faced by NAYP.

Overall, comparing the barriers and facilitators of sedentary behaviour between able-bodied and NAYP highlights that there are similar broad themes, however the barriers / facilitators themselves are specific to NAYP due to their differing needs and lived experiences. Our data show multiple requirements need to be met to create each movement opportunity for NAYP. The requirements include (but are not limited to): trained AS being present to assist at a time the NAYP is also available, having an appropriate space available and having access to the equipment needed at that same time. As a result, reducing NAYP's sedentary time is complex. Interventions designed for able-bodied children and young people are therefore unlikely to be applicable or effective in NAYP. The systematic search and review undertaken in this thesis confirmed that there are no interventions that have been designed to reduce sedentary behaviour of NAYP, identifying a need for NAYP tailored interventions to be developed.

Zvolanek et al. have previously reported that schedule limitations and travel logistics are the primary barriers to participation in research for participants with CP and their carers (240). It was intended that using crowdsourcing as the primary data collection tool in the MoveMore app intervention development would overcome those barriers, boosting recruitment and participation of NAYP and their family members.

Crowdsourcing was a novel approach for intervention development at the time of data collection in this thesis. However, some studies have been published that were also engaging young people in crowdsourcing as an intervention development tool at a similar time (242, 243, 291). These studies utilising crowdsourcing successfully engaged 127 – 257 participants to contribute to the development of digital interventions for asthma, to boost physical activity for those with low income and to

develop a safer dating app. As for the MoveMore app intervention development, a range of stakeholders were recruited, including young people.

However, recruitment to the crowdsourcing platform as a vehicle to contribute to the MoveMore app intervention development was much lower than in these other studies (242, 243, 291). This might be partially due to NAYP making up a very small proportion of the population in comparison to populations relevant to the existent studies. However, our recruitment activities were targeted to reach NAYP and their family members. The number of people in our study who completed consent forms and opted to contribute via crowdsourcing in preference to a virtual workshop was only a little lower than the number of participants reported in these other studies employing crowdsourcing (89 people). However, the number who actually contributed to the crowdsourcing platform was far lower (12) and was mostly health and educational professionals or experts. A number of hypotheses of why this was the case were proposed. It is likely that the timing of data collection (in parallel with lockdown for the Covid-19 pandemic) had a significant impact, particularly as people with disabilities were a vulnerable group and therefore experiencing greater restrictions. They were also struggling with loss of access to vital services and equipment at this time. Many families of young people with disabilities felt they were abandoned by health and care services (250). Also, many activities of daily living moved to online delivery mechanisms, for example school, work and healthcare appointments. It is possible that potential participants were spending large periods of time online and did not wish to engage in further online interactions. In addition to these potential reasons for lack of engagement, there may be further learning when considering the drop in numbers between providing consent and contributing on the

platform. A gateway questionnaire needed to be completed prior to accessing the crowdsourcing conversation. It is proposed that opening the platform with a shorter gateway questionnaire and posting fewer, simpler questions in the crowdsourcing conversation would have improved engagement of those who had consented.

Prioritisation of which SOS Framework determinants of sedentary behaviour would be most modifiable (via interventions of any nature), has not been undertaken for able-bodied children and adolescents or those with disabilities prior to the study reported in Chapter 5. When the SOS Framework was developed, there was a 92% consensus that for the general population, the institutional and home settings determinant of sedentary behaviour should be the highest priority for research, but this was not specific to intervention development (118). Stakeholders in the MoveMore app intervention development ranked this as the second most modifiable determinant. Psychology and behaviour was ranked first, and physical health and wellbeing third.

Which specific factors within each SOS Framework determinant would be most modifiable for youth in the general population has been explored (118). The largest number of factors were within the institutional and home settings determinant and related strongly to screen use and internet access. Opportunities to be outdoors, pet ownership, housing type and family commitments / expectations also featured. Within the psychology and behaviour determinant, self-efficacy and modelling behaviour of others featured, alongside levels of sedentary behaviour and physical activity, eating habits, school attendance and modes of transport. Finally, in the health and wellbeing determinant, physical fitness and skills, energy level and mental health were the only factors identified as modifiable. When compared with the 15 barriers / facilitators

stakeholders identified for inclusion in the MoveMore intervention (Chapter 5), our findings highlight the differing needs of NAYP to the general population. Surprisingly, screen use did not feature as a modifiable barrier / facilitator for NAYP, whereas this was prominent for the general population. The lack of autonomy experienced by NAYP was not necessarily due to their own self-efficacy. It was more related to a lack of control over their movement opportunities and routines. Physical skills and abilities featured more strongly for NAYP, as they are a major barrier. Adult supporters' abilities to effectively facilitate rewarding movement opportunities was an important factor for NAYP, which is not relevant for youth in the general population.

Based on data collected in the co-design workshops, Self - Determination Theory (SDT) (85) was selected as the most appropriate mid-range theory to inform the MoveMore intervention. SDT has previously been employed in digital interventions which reduced sedentary time in able-boded people across a range of age groups (129-131). It has also been employed in the ParticiPAte CP intervention for ambulant children with cerebral palsy which aimed to enhance physical activity goal performance and increase habitual physical activity (63). As for the MoveMore app, the ParticiPAte CP intervention was developed using the Behaviour Change Wheel (BCW) model (77). The MoveMore app featured four of nine possible intervention functions described in the BCW, whereas ParticiPAte CP featured six. In keeping with SDT, both interventions had strong emphasis on the enablement intervention function.

There are few behaviour change interventions for people with disabilities for which programme theory has being described in detail (303). ParticiPAte CP and the WHEELS app intervention (138) are examples which have relevance to the

MoveMore intervention; in relation to the population targeted (77) or the digital delivery mechanism (138). It is noteworthy that although neither specifically address sedentary time, they both focus on promoting physical activity. The WHEELS app promotes physical activity as well as healthy dietary, sleep, and relaxation behaviours. It was underpinned by social cognitive theory (283), the elaboration likelihood model (284) and the transtheoretical model of change (285) rather than SDT. However, there were similar themes amongst the behaviour change techniques (BCTs) selected for MoveMore, including self-monitoring, providing feedback, facilitation, consciousness raising and goal setting.

A review of physical activity interventions for people with disabilities identified goal setting, problem solving, self-monitoring of behaviour, social support, instructions on how to perform the behaviour and graded tasks as being the most commonly used BCTs (303). The MoveMore intervention employs all but the graded tasks technique, which has less relevance to reducing sedentary behaviour. The most effective techniques for increasing physical activity were self-monitoring of the behaviour, monitoring of behaviour by others without feedback and feedback on behaviour (303). Self - monitoring and feedback on behaviour are both incorporated in the MoveMore app, however, “monitoring of behaviour by others without feedback” is not.

Using the Person-Based Approach (83) to produce and evaluate a prototype app has provided the feedback needed to complete a first iteration of optimisation of the intervention prior to feasibility testing. Using the MoScoW framework (“Must do; Should do; Could do; Would like to do”) (83) to prioritise feedback from the evaluation has made it is clear which changes will be incorporated prior to feasibility testing. The Medical Research Council advises that refinement of interventions (ideally with

stakeholder involvement) can take place both within phases of complex intervention development and during transition from one phase to another (73). This first early evaluation took place during transition from the intervention development to the feasibility testing stage. Feedback was sought from stakeholders to inform refinement of the intervention prior to a live deployment of the app in a feasibility study.

8.4 Implications

The gaps in the literature in relation to NAYP and their sedentary behaviour highlight that NAYP are an underserved group in relation to research in comparison to able-bodied children and young people or ambulant young people with disabilities. This may be because the challenges faced by young people with disabilities who wish to participate in research, such as travel to and scheduling of research activities (240), are accentuated for those who need to use a wheelchair for mobility. Overall, more robust measurement methods of sedentary time have been established for ambulant young people with disabilities (304-309). There is more information about patterns of sedentary time (178, 310-314) and cardiovascular risks associated with patterns of sedentary behaviour (51, 315) in ambulant young people with disabilities. There are also more interventions to increase physical activity available to them (59, 63, 151, 269). It is important that these inequalities are addressed.

All steps of the MoveMore co-design have highlighted that any intervention to reduce sedentary behaviour in NAYP needs to aim to change behaviour of adults who support the NAYP in addition to the NAYP person themselves. Interventions that target NAYP in isolation are unlikely to be effective. Most NAYP who participated lacked autonomy to create movement opportunities independently because they rely upon assistance to move or to access activities. Those who could self-propel and

transfer in and out of their wheelchair independently had greater autonomy, but still needed support to overcome barriers related to transport, environmental accessibility and finance to access the movement opportunities they were most motivated about.

Describing the MoveMore intervention in terms of its intended mechanisms of action and BCTs communicates its active ingredients to researchers in the field of intervention development in a common language. Defining the active ingredients in this way allows evaluation of the contribution each active ingredient makes to the intervention's overall effectiveness. This process also facilitates future optimisation. Using a common language to describe the present intervention enables comparison with other interventions. The logic model and guiding principles complement this description by providing broader context and outlining intended outcomes.

Based on the protype evaluation undertaken in this thesis, a large number of changes have subsequently been made to the MoveMore intervention in a first round of optimisation. This has improved the quality of the live version of the MoveMore app which will be used in subsequent feasibility testing. It is expected that this early optimisation will increase the efficiency of the feasibility testing stage of the intervention development (step five of the 6SQuID) by reducing the amount of change required in the next iteration of optimisation.

In order to robustly evaluate efficacy of the MoveMore intervention, it will be necessary to validate a device-based measure of sedentary time for NAYP in free-living environment. A measure that reflects all three elements of the definition of sedentary time, wakefulness, posture and energy expenditure is needed.

This thesis and other recent literature (242, 243, 291) demonstrate that crowdsourcing has potential as a data collection tool in intervention development. However, this thesis demonstrates that careful consideration is needed to maximize engagement in such a methodology. Our experiences of using crowdsourcing to engage NAYP and their families indicate that it should not be relied upon as the only data collection tool, but it may be a helpful contributor to a triangulation method. Groups of stakeholders who experience barriers with communication and use of technology may find crowdsourcing difficult to access. Those who are accustomed to digital communication, perhaps within their professional role may have greater confidence to engage in this way. Drawing from the present findings, researchers who wish participants to volunteer specific data on a narrow topic are advised to use a traditional survey rather than crowdsourcing. When researchers have freedom to pose only a small number of simple, open questions and allow participants to lead the direction of conversations that follow, crowdsourcing is more likely to be successful.

8.5 Strengths

Throughout this body of work, we aimed to adopt a person - centred approach to study design that empowered people with disabilities to participate. When undertaking previous research involving children and young people with disabilities and their families, scheduling, time constraints, environmental access, communication difficulties and complexities of managing long-term conditions have been barriers to participation. In this body of work, we explored using digital data collection tools to overcome these barriers. Participants were offered a choice in how they wished to participate (crowdsourcing, virtual workshop or virtual interview).

There was a clear preference for contributing via virtual workshops and interviews. This offered participants an opportunity for face-to-face interaction with the researchers or researchers and other participants, which was not possible via crowdsourcing. It also reduced health-related risks in comparison to meeting in person during the Covid-19 pandemic. It removed the need to travel, which subsequently reduced time commitments. NAYP could participate from home, eliminating concerns about accessibility of unfamiliar environments. If participants did not feel confident about attending a workshop with others, or the proposed dates / times were inconvenient, they could opt to do a 1:1 interview. Several NAYP preferred 1:1 interviews to attending a workshop. By offering the option of participating in a 1:1 interview, a participant with a communication aid was able to contribute to all steps of the intervention development.

Having meaningful stakeholder involvement at every step of the intervention development is a strength of this work. The research team strived to ensure engagement was at the highest level possible on the ladder of participation and engagement (91). For example, step two of the 6SQuID was at the highest level of devolving. Decision making in relation to which barriers / facilitators of sedentary behaviour should be addressed in the intervention was in the hands of the stakeholders.

In addition to stakeholder involvement in the MoveMore app intervention development, there has been consistent public and patient involvement (PPI) throughout. A lay member of the study's steering group committee has been involved at all stages and there have been additional PPI activities at other stages. The lay member of the committee has contributed to development of the systematic search

and review and co-design protocols and acted as a third reviewer for the review. They contributed to a research ethics committee meeting, supported recruitment via their own networks and joined the thesis author (MB) for a local radio interview. They assisted with analysis by coding anonymised transcripts from the step one co-design workshops / interviews and provided feedback relating to the barrier / facilitator lists and power point presentations shared with participants prior to step two. Their input was central to a decision not to remove goal five (optimising comfort) due to concerns around unintended consequences. They suggested production of the lay version of the logic model and provided feedback in relation to it. During meetings with the app developers, they provided input and feedback in relation to prototype development. They remain involved in piloting the live version of the app and other elements of the feasibility study protocol at present.

Other PPI activities have included: production of an engagement video featuring NAYP (supporting digital material, file 1), selecting appropriate icons for the apps various functions, a photo shoot to produce appropriate photographs to be used in the handbook (Appendix 12) and to accompany information notifications from the app and sharing the protype at an accessible sports event to raise awareness of and engagement with future stages of the intervention development. The photo shoot was necessary due to poor availability of realistic stock images of NAYP. Stock images appeared to feature able-bodied children and young people who had been photographed in a wheelchair. They were not representative of NAYP.

Using the 6SQuID model has provided a clear structure for designing the MoveMore app intervention. As a PhD candidate learning about intervention development, the clear sequential steps were a useful guide. Combining theoretical and partnership-

based approaches gives this intervention development a strong foundation to build upon. Using a variety of established tools, frameworks and approaches at different steps in the process has strengthened its evidence-based nature.

A rigorous, systematic search of the literature was undertaken. The review had four sub-questions, making it a broad exploration of what is known about sedentary behaviours of NAYP. Critically appraising the relevant literature using published tools provided an in depth understanding of current knowledge in this field and highlighted gaps. Two reviewers independently screened the results of the database searches and critically appraised included articles to add rigor.

In step one of the intervention development, (identifying barriers and facilitators of sedentary behaviour for NAYP), qualitative data was collected using two different methods (crowdsourcing and virtual co-design workshops) to allow triangulation. Detailed thematic analysis was undertaken involving multiple coders with differing perspectives. People involved in coding included PPI representatives who are wheelchair users, healthcare students and advanced clinical practitioners and members of the research team. The results of the analysis were fed back to stakeholders prior to the step two co-design workshops / interviews, providing an opportunity for respondent validation.

It is proposed that early evaluation of the prototype MoveMore app by stakeholders prior to feasibility testing will improve efficiency of optimisation.

8.6 Limitations

When planning intervention development workshops / interviews for each step of the 6SquID model, the model occasionally lacked depth detail in relation to methodology.

When this was experienced, the researchers drew on additional tools and literature, for example the Theoretical Domains Framework (84), the BCW (77) and the Person-Based Approach (83).

Recruitment was more challenging than predicted, particularly recruitment of NAYP and family members. There were limited opportunities for face-to-face engagement with potential participants in relevant settings or at events due to a national lockdown during the Covid-19 pandemic. Subsequent poor engagement with data collection via crowdsourcing resulted in virtual workshops and interviews becoming the primary data collection method. There was also attrition of all stakeholder groups as the steps of the intervention development progressed. Some attrition was expected. However, low recruitment of NAYP and family members at the outset resulted in only a small number of NAYP and family members involved in the prototype evaluation. It was not possible to re-open recruitment due to time, governance and funding constraints.

A laboratory-based study was planned and a protocol written (Appendix 6) to compare sedentary time measurement in NAYP via a thigh worn ActivPAL, heart rate and accelerometer data collected via a wrist worn device and metabolic gas exchange. This study would have contributed towards validating device-based measures of sedentary time for NAYP, which could be used in subsequent research , including interventional studies. Unfortunately, it was not possible to undertake this study as the United Kingdom (UK) entered lockdown prior to applying for ethical approval. The measures would still need validating in a free-living environment prior to being used in an efficacy study, but this would have given an indication of their validity.

During development of programme theory, NAYP and family members were engaged at a lower level of the ladder of engagement, “consulting” (91); whereas professional and experts were engaged at the higher level of “involving”. This resulted from decision-making during protocol development, when it was unclear what activities stakeholders would undertake in step three workshops. In step three workshops / interviews, professionals and experts provided feedback about the behaviours and behaviour changes needed to achieve the five key goals. This data were analysed and summarised in the form of a list of behaviours the intervention was intended to elicit from NAYP and adult supporters. This summary was presented to NAYP and family members for feedback and discussion of any potential unintended consequences. NAYP and family members were not involved in generation of the behaviours and behaviour changes data.

8.7 Directions for future research

The next step (step 5) of the 6SQuID is feasibility testing. Ethical approval has been granted to undertake a single armed, mixed methods study to test the feasibility of the MoveMore intervention and elements of the protocol, for example recruitment rates and appropriateness of methods and outcome measures. Twelve NAYP have been recruited to participate. Data collection will open when work to incorporate changes identified in the table of changes (Chapter 7) is completed. Quantitative data will include device-based measurement of sedentary time using both a thigh worn ActivPAL4 and a wrist worn Fitbit. The Karvonen formula and data from the Fitbit will be used to calculate individual heart rate thresholds between sedentary behaviour and light physical activity. This allows “moving minutes” to be fed back to participants

in the MoveMore app, showing how long they spend above their sedentary heart rate threshold. An activity diary will also be kept.

Participants will be interviewed about their experiences of using the intervention after 12 weeks. Use of each function of the app and the online dashboard via which adult supporters access the intervention will be analysed. The protocol is presented in Appendix 14.

At present, NAYP with moderate to severe learning difficulties are excluded from participating in the feasibility study, as the outcome measures are inappropriate for this group. For example, those with moderate to severe learning disabilities would not be able to provide detailed user experience feedback via a post intervention interview. However, the MoveMore intervention has potential to be beneficial for this group, even if adult supporters are the primary users of the intervention. Improving awareness, planning, communication, goal setting and monitoring in relation to movement amongst adult supporters could lead to reduced sedentary behaviour for the NAYP, even if the NAYP has less active involvement in this process. Future studies focusing on NAYP with learning difficulties would be beneficial once translation of the MoveMore app is established.

Chapter 2 highlighted that prior to assessing efficacy of the MoveMore app, validation of appropriate device-based sedentary time measures for NAYP is needed, in both laboratory and free-living environments. These measures need to capture both the postural and energy expenditure elements of the definition of sedentary behaviour (3). To achieve this, data from a variety of devices may need to be combined and classified using machine learning and algorithms (173, 208). This approach may

prevent active sitting / lying and static standing being misclassified as sedentary time. Validating device - based sedentary time measures in free-living environments is challenging (316). Direct observation is rarely employed (316). This creates risk of misinterpretation when data from differing sources is incongruent. Ethnographic studies could have potential to overcome these challenges. Direct observation of a small number of participants over several days, with simultaneous monitoring of physiological markers such as heart rate and collection of raw accelerometer data from multiple devices could result in development of feasible and valid methods to measure sedentary time in NAYP.

Longitudinal research is needed to understand the impact high levels of sedentary time has on the health of NAYP and the factors that influence it. Children with CP have higher levels of systemic inflammation than adults in the general population (232), greater dysautonomia (elevated blood pressure, heart rate, respiratory rate and low blood oxygen saturation / body temperature) than able-bodied children (50) and children and adolescents with disabilities are at higher risk of developing cardiovascular disease than their able-bodied peers (233). However, it is not known whether there is a causal relationship between sedentary behaviour and these health outcomes for NAYP. Prospective cohort studies, which intermittently measure sedentary time across life span, would be valuable to understand relationships with non-communicable long-term conditions and mortality. Exploring associations between sedentary time in NAYP and cardiovascular and metabolic outcomes such as blood pressure, incidence of stroke, cardiac arrest, and incidence of type II diabetes would be valuable to quantify risk.

Additional evidence-based interventions to reduce sedentary behaviour in this population need to be developed. Digital interventions have limitations (317), for example it is not possible to influence some of the SOS Framework determinants of sedentary behaviour, such as politics and economics, or the built and natural environment. They also have potential to broaden health inequalities for those without devices or internet access (135). It would be valuable to be able to compare interventions delivered via different mechanisms, for example, to compare the efficacy of digital and face-to-face interventions.

The 6SQuID model has been used before to develop digital health interventions previously. For example it has been used to produce an intervention to encourage a healthy lifestyle in women attending screening or clinics for breast cancer (87). However, there are alternative co-design methods that focus specifically on production of digital or e-health interventions. The Person-Based Approach (83), which was used in step four of our MoveMore app intervention development, is one example. Another is the Centre for eHealth Research & Wellbeing Roadmap, which is in the process of being updated at present (318). These differing models and frameworks have similar underlying principles, including securing stakeholder involvement and identification of clear objectives and active ingredients, but there are variations in their detailed processes. Prior to initiating a digital intervention development, it is advisable to review the most recent frameworks and models available in detail. This allows selection of an approach that suits the nature of the intended future intervention and the population it targets.

It is recommended that where crowdsourcing (113) is used as a data collection tool in intervention development, this is always alongside an alternative data collection

method to safeguard against low engagement. Using it for triangulation of data collected by more traditional methods, such as face-to-face interviews or focus gorups, for example, is ideal. It may be more suited to collect data from professionals or experts than those in small populations with clinical conditions. However, further exploration of this hypothesis is needed, to test whether there are similar observations when questionnaires and crowdsourcing activities are simplified.

Since this intervention development was conducted, a new Behaviour Change Technique Ontology has been published (319). The ontology builds upon the original behaviour change technique taxonomy (122), aiming to improve interoperability by facilitating clear communication and collaboration between researchers and others who may be describing the active elements of interventions. It is intended that the ontology will be dynamic, being adapted as knowledge advances (319). Following feasibility testing of the MoveMore intervention, it would be beneficial to use data collected to revisit the BCTs selected and map them across to the new ontology and adapting them if needed. This is to ensure the intervention remains up to date and is in keeping with the new ontology.

8.8 Conclusion

This thesis has reported how the first four steps of the 6SQuID model (86) has been used to co-design the MoveMore app, a digital behaviour change intervention. The MoveMore app aims to support NAYP to reduce their sedentary behaviour, with assistance from their adult supporters.

A systematic search and review was undertaken to write a best evidence synthesis, describing the quality of existing evidence relating to sedentary behaviour of NAYP.

The review highlighted significant gaps in knowledge and understanding. Weaknesses in measurement of sedentary time in NAYP were identified. The weaknesses had an impact on accuracy of sedentary time estimates in observational studies describing patterns of sedentary behaviour and associated risks for this population. The review confirmed that there are no evidence-based interventions which specifically aim to reduce sedentary behaviour in NAYP.

Step one of the 6SQuID (defining and understanding the problem) was comprised of this review and qualitative engagement with stakeholders. An in depth understanding of sedentary behaviour of NAYP was gained. Fifty-two barriers and 35 facilitators of sedentary behaviour of NAYP were identified. Engagement of stakeholders was more successful via virtual workshops and 1:1 interviews than via crowdsourcing. However, data collected via crowdsourcing was useful for triangulation of data collected via virtual workshops and interviews.

In step two, stakeholders decided upon which barriers and facilitators should be addressed in the intervention. They selected 15 barriers and facilitators which were both influential and modifiable via a digital intervention.

Programme theory was developed in partnership with stakeholders in step three. Their contributions informed the selection of SDT (85) as the mid-range theory which informed the intervention. SDT (85) and the BCW guide to developing interventions (77) informed selection of 11 mechanisms of action and 32 BCTs. The programme theory for the intervention was represented diagrammatically in a logic model.

In step four a prototype of the MoveMore app was produced with and evaluated by stakeholders. Changes proposed in the evaluation have resulted in a first iteration of

optimisation prior to feasibility testing, strengthening the MoveMore app's acceptability and usability. The MoveMore app is the first intervention to be developed that specifically aims to reduce sedentary behaviour in NAYP by promoting LPA.

Feasibility testing (step five of the 6SQuID) is the next step towards translating the MoveMore app into practice. Prior to evaluating effectiveness of the intervention, validated methods of measuring sedentary time in NAYP in free-living environments need to be established. When validated and acceptable measurement methods are available, further research is needed to accurately quantify sedentary time in NAYP and confirm relationships between sedentary behaviours and influencing factors such as age and gross motor function. Longitudinal studies to assess the impact that high levels of sedentary time have on health outcomes when NAYP reach adulthood are needed.

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10 Appendices

Appendix 1 DoMore study recruitment materials

Examples of recruitment materials for the DoMore Study (in which the MoveMore app was co-designed).

Posters



NHS
Birmingham Community Healthcare
NHS Foundation Trust

DO MORE

SCAN TO ACCESS WEBSITE:

DO MORE

Does a child or young person in your family use a wheelchair?

Could they benefit from being more active?

Would you like to be involved in research?

Want to help other wheelchair users to improve their lifestyle too?



HANNAH DINES

Hannah Dines is supporting the #DoMore study. She is a cyclist with the GB cycling team and a race runner at World level. Hannah has cerebral palsy. She represented Great Britain at the Paralympics in Rio.

GET INVOLVED!

Join the #DoMore study via our online workshops or a virtual focus group. Help researchers to design software that tracks wheelchair users' body movements and supports them to move more.

VISIT do-more.org.uk, **EMAIL** domore.study@nhs.net or **CALL** 07701371838

SUPPORTED BY NIHR | National Institute for Health Research

Sport Inspired

#DoMore

IRAS ID: 271259
v0.3 03/10/2019

UNIVERSITY OF BIRMINGHAM

NHS
Birmingham
Community Healthcare
NHS Foundation Trust

DO MORE

DO MORE

Do you work with children or young people who use a wheelchair?

Could they benefit from being more active?

Would you like to be involved in research?

Want to help wheelchair users to improve their lifestyle?

SCAN TO ACCESS WEBSITE:



HANNAH DINES

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Copyright and acknowledgments: The design of the DoMore logo was drafted by members of the West Midlands Clinical Research Network's Young Person's Steering group and produced by David Mark, Clever Together Ltd. The poster was designed by David Mark, Clever Together Ltd. The image was provided by Hannah Dines with her permission for it to be used on recruitment materials for the DoMore study.

Social media posts:

How will the DoMore study help?
We want to empower children and young people who use wheelchairs to be in control of their health and wellbeing. We are co-designing a programme that supports them to move more, in partnership with them and their family members.
Visit our Website:
https://do-more.org.uk



What is the DoMore study about?
The #DoMore study is about working in partnership with children and young people who use a wheelchair, their family, health and educational professionals and experts to co-design a programme that supports young people who aren't able to walk to move more.
Visit our Website:
https://do-more.org.uk



How will the #DoMore study help?
Reducing and breaking up sedentary time can help to prevent poor health. We are co-designing a programme that supports young people who aren't able to walk to move more in partnership with them.
Visit our Website:
https://do-more.org.uk



What is the DoMore study about?
The #DoMore study is about working in partnership with children and young people who use a wheelchair, their family, health and educational professionals and experts to co-design a programme that supports young people who aren't able to walk to move more.

Visit our Website:
https://do-more.org.uk



Who is the DoMore Study for?
With your help, we are developing software for computers, tablets or mobile phones to support children and young people aged 12-25 with long term disabilities, who are unable to walk (or only walk with the assistance of a body support walker), to move more.
Visit our Website https://do-more.org.uk



It's amazing to have Hannah Dines supporting the #DoMore study! Hannah is a cyclist with the GB cycling team and a race runner at World level. Hannah has cerebral palsy. She represented Great Britain at the Paralympics in Rio!

Visit our Website https://do-more.org.uk



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Appendix 2 DoMore study participant information sheets

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DO MORE

NHS Birmingham Community Healthcare NHS Foundation Trust

Information Sheet for 12-15 year olds

Hi! I'm Marilyn Bradbury. I'm a researcher who works with young people who find movement difficult. I want to help young people who use wheelchairs to be **healthy**, by supporting them to **move more**.

I would like your help.

I want to help **young people** who have a **disability** and use a **wheelchair** because they are unable to walk to **spend less time being sedentary**. Being sedentary means you are awake, but using very little energy. This includes:

- Time on your phone
- Watching TV
- Playing video games
- Reading

Spending long periods of time being sedentary reduces fitness, and can increase the risk of:

- Obesity
- Heart disease
- Mental health issues

The **aim** of this study is to **develop a programme** to encourage young people who are unable to walk due to their disability to be **active more regularly** through their day. The programme will include an **app** on a tablet.

There are two ways you can help with developing the programme. You can choose which one to do.



You can take part in **anonymous** workshops **online** at anytime

or

You can come to virtual **focus groups** online at a specific time



You can log in and out of the online workshops at any time. You write answers to questions and you can read and respond to other peoples answers. There are 3 workshops or focus groups you can take part in that help me to: 1) understand the problem 2) decide how the programme can best support young people to move regularly 3) decide how the support should be delivered. Each workshop or focus group will happen at different times. I would like you to participate in all 3 if you can.

How taking part will help

You know what its like to be a young person with a disability. I haven't had the same experiences as you. Your involvement with developing the app will mean it is much more likely to work well. I want the programme to help lots of young people like you to have healthy lifestyles in the future.

IRAS ID: 271259
Patient information sheet for 12-15 year olds_v4 23/07/2020

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NHS Foundation Trust

Will anyone else know I've taken part?

People in the same focus group as you will see who you are, know your first name and may repeat what you say. No one other than your family, the researchers and/or the other people in a focus group will know you have participated, or what you have said unless you want to tell them about it. Everything you say on the online workshop will be anonymous. The only reason we would break your confidentiality and share your identity is if we were concerned about a risk of harm to you or someone else, or if any criminal activities were discussed.
When we share the results of the study, we will use some quotes, but it won't say who said them.

Do I need to worry about anything?

There will be ground rules about how young people taking part should speak to each other in the online workshops and the virtual focus groups, to make sure everyone taking part respects each others opinions. In the online workshop, there will be a button you can use to report any comments you think break these ground rules, and the workshop will be monitored by the researchers.

There will only be young people aged 12-15 contributing to the online workshop or focus groups you will take part in. Older people with disabilities and other adults like parents, carers, health professionals and teachers can take part too, but they will have separate workshops or groups to take part in.

It's up to you whether you want to take part. It's OK if you don't want to. Even if you say yes now and later you change your mind - that's OK.

What if I have some more questions?

If there is anything else you would like to know I'm happy to help. You can contact me (or ask your parent/guardian to) using these details:

Marilyn Bradbury,
HEE/NIHR Clinical Doctoral Research Fellow
Medical Directorate
Research and Innovation
Birmingham Community Healthcare NHS Foundation Trust
Trust Headquarters
3 Priestley Wharf
20 Holt Street
Birmingham
B7 4BN
Tel: [redacted] E-mail: domore.study@nhs.net
Twitter: @marilynpaedsahp
Website: Do-more.org.uk



Paralympian Hannah Dines supports the #DoMore study. Marilyn and Hannah would like to thank you for taking time to read this leaflet, and for your help.

IRAS ID: 271259
Patient information sheet for 12-15 year olds_v4 23/07/2020

Research Title: **Developing an intervention to reduce sedentary behaviour in non-ambulant young people with long-term disabilities (DoMore).**

Chief Investigator: **Mrs Marilyn Bradbury, HEE/NIHR Clinical Doctoral Research Fellow, Birmingham Community Healthcare NHS Foundation Trust**



I'm Marilyn Bradbury. I would like to invite you to be involved in my research project. To help you to decide whether to take part, this form explains what you would need to do. Please take time to read the information and contact me if you have any questions. It can be helpful to talk to your friends and family about the research project when you are deciding whether to participate.

What is the study about?

Previous research has shown that young people with disabilities do less physical activity than able-bodied young people. Supporting them to increase their physical activity has, therefore, been identified as a high priority for research.

I want to help young people who use a wheelchair and are unable to walk due to their disability, to spend less time being sedentary. Being sedentary means you're awake, but using very little energy. This includes:

- Time on your phone
- Watching TV
- Playing video games
- Reading

Spending long periods of time being sedentary reduces fitness, and can increase the risk of obesity, heart disease and mental health issues.

Aim of the study

The aim of this study is to develop a programme to encourage young people who are unable to walk due to their disability to be active more regularly through their day. The programme will include an app on a tablet

Different groups of people will be getting involved with developing the programme. The groups are: young people who are unable to walk as a result of their disability, family members of young people with disabilities, professionals who work with young people with disabilities, experts / academics who are interested in disability, physical activity or using technology in health care and other interested parties. You and your family may be able to take part.

Why do you want my family and I to take part?

Young people who use a wheelchair most of the time and are unable to walk, or only walk short distances using a body support walker are being invited to take part. They need to be 12 - 25 years old, have a long term disability, live in the UK and be able to communicate using English language online or in a focus group and have enough understanding to be able to answer the questions asked.

All family members or carers (aged 16 and above) of children and young people who are unable to walk due to a long term disability can also take part.

What will we need to do?

There are two ways you and/or your family can help with developing the programme. You can choose which one to do.



You and/or your family can contribute to an anonymous workshop online at anytime

You and/or your family can come to virtual focus groups online at a specific time.



If you are participating, you will be asked to complete a consent form online. You will be emailed a copy of your consent form.
You and/or your family will need to agree to accept the ground rules about how people participating should speak to each other in the online workshops and at the virtual focus groups, to make sure everyone taking part respects each others opinions. After giving your consent to take part, you/your family members will be asked to:

- provide some basic information about yourselves, including your diagnosis if you have a disability.
- complete a short survey before you contribute to the workshop.

There will be 3 steps you can contribute to that help me to:
1) understand the problem
2) decide how the programme can best support young people to move regularly
3) decide how the support should be delivered.

I would like you to participate in all 3 if you can. Each step will happen at different times.

The online workshop will open for approximately 2 weeks at each step. There will be several questions you can respond to at each step. You don't have to respond to them all. You can spend as much or a little time as you choose to on the online workshop. Online, you will be able to see other people's responses to the questions, and there is a button to agree or disagree with what they have written. You can write a reply about what they have written too. You will not be able to tell who has written each response. There is a ground rule that asks you not to use your name, or give too many details about yourself that could allow someone to know who you are.
There will be 2 focus groups held at each step; one for 12-15 year olds, and a second for all participants over 16. Between 3 and 10 people will be in each focus group. Focus groups will last for 45 – 90 minutes.

If someone writes something that upsets or offends you, or you feel would allow you to know who that person is, you can flag what they have written, and it will be removed either permanently, or until the platform administrators have reviewed what was said and edited it if needed.

Young people aged 12-15, young people aged 16-25, family members / carers, professionals and experts and other interested parties will write on 4 separate platforms. Once you have participated in one step, I will email to invite you to the next step, unless you ask me not to.

Focus group attenders will receive a £10 shopping voucher as a thank you for coming.

Do we have to take part?

No. It is up to you and/or your family members. Your healthcare will not change whether you decide to take part or not.

What if we change our minds about taking part?

You can pull out at any stage and it won't change the care you receive. We will still use any information we have already collected, but it will remain anonymous.

When will it be and how long will it last?

This part of the study (developing the programme) will begin in October or November 2020 and last for 6-8 months.

What are the benefits of taking part?

- The programme will be designed using the information everyone who participates has given us. This means its much more likely to work well, and you will have helped us to achieve that.
- You will have contributed to a new digital treatment, that 20 young people with disabilities will use in our small study to test it.
- I hope that lots of young people will use the programme in the future, helping them to live healthy lifestyles, and you will have helped them with this.

What are the disadvantages of taking part?

There is a small risk of participants becoming upset, distressed or offended by the content of discussions in the online workshop or in the focus groups. The ground rules and ability to flag any content you feel should be removed will help to reduce the risk of this happening.

Families participating need to find time for contributing to the online workshop or virtual focus groups. Groups may be held in school or working hours.

Will anyone else know we are taking part?

If you take part in a focus group, confidentiality cannot be assured, because the other participants will know your first name and see you on the video. Participants are asked in the ground rules to avoid making comments that could identify them. No one other than you, the researchers and the other people at any focus groups you attend will know you have participated unless you want to tell them about it. Everything you say in the online workshop will be anonymous.

When we share the results of the study, we will use some quotes, but it won't say who said them. All electronic information will be encrypted (which means it won't be readable by anyone who shouldn't see it) and/or password protected. Any information kept on paper will be transported in the same secure way as health records, and will be kept in a locked filing cabinet that is only accessed by the researchers.

How many others are taking part?

Its hard to know how many people will sign up to the online workshop, we hope lots of people will! Please share this information and our website link: https://do-more.org.uk/welcome with any friends or family you think would be interested in participating.

Will it affect my normal healthcare?

The study is not related to your routine healthcare. This will not change as a result of your participation.

What happens when the study is finished?

You will be able to keep up with what's happening and find out the results of the study via our website (**do-more.org.uk**). The programme we design together will be produced and there will be a small study to see if it can be used in the NHS and what the young people think of it. The results will be used to write presentations and to publish in a medical magazine so we can share what we find out with other young people with disabilities and other professionals.

Who is organising and funding the research?

Birmingham Community Healthcare NHS Foundation Trusts are responsible for running the study in accordance with existing research legislation and guidelines. The study is funded by the National Institute for Health Research and Sport Inspired charity.

Who is reviewing the research?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable ethical opinion by a research ethics committee. It has also been reviewed by the National Institute for Health Research, the study steering group and an expert fellowship collaborator who holds a highly regarded academic post in childhood disability and has considerable clinical and research experience.

How have patients and the public been involved in this study?

Members of the West Midlands Young Persons Steering Group, public and patient involvement representatives who are non-ambulant young people, parents of young people with disabilities and adults attending a day centre for people with cerebral palsy have been involved in developing the research. The young Persons Steering Group and public and patient involvement representatives have lived experience of long-term disability. A lay member sits on the study steering committee.

The public and patient involvement representatives have been involved in developing the participant information sheets and adverts for the crowdsourcing platforms, and have contributed to production of the website. They will assist with disseminating the adverts via relevant networks they are members of, opportunities in their local communities and face to face activities where possible.

Will my data be kept confidential?

Birmingham Community Healthcare NHS Foundation Trust is the sponsor for this study based in the United Kingdom. They will be using information about you obtained from you in order to undertake this study. Birmingham Community Healthcare NHS Foundation Trust will act as the data controller for this study. This means that they are responsible for looking after this information and using it properly. Birmingham Community Healthcare NHS Foundation Trust will keep the identifiable information collected for 5 years after the study has finished.

You can find out more about how Birmingham Community Healthcare NHS Foundation Trust will use your information, or raise a complaint about how your personal data has been handled by contacting their Data Protection Officer:

- **Tel:** 0121 466 7033
- **Email:** bchc.dpo@nhs.net
- **Address:** Data Protection Officer, Corporate Affairs, Birmingham Community Healthcare NHS Foundation Trust, 3 Priestley Wharf, Holt St, Birmingham. B7 4BN

If you are not satisfied with their response or believe they are processing personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). Tel: 0303 123 1113, www.ico.org.uk)

We will use your name, email address, NHS number and your contact details to contact you about the research study, and to oversee the quality of the study. This information will only be used for the DoMore study. It will not be used for any other purpose. Clever Together will have access to all information you enter online via the study website. They have a strict privacy policy for handling this information, that you can access via the study website. Two weeks after the study ends Clever Together will delete all the data they hold relating to this study. Your consent form will be transferred to a representative at Birmingham Community Healthcare NHS Foundation Trust. Your anonymised responses will be retained by the researcher team.

Individuals from Birmingham Community Healthcare NHS Foundation Trust, Clever Together (who are hosting the online workshop) and regulatory organisations may look at your research records to check the accuracy of the research study.

The only people in Birmingham Community Healthcare NHS Foundation Trust who will have access to information that identifies you will be people who need to contact you to audit the data collection process or the research and innovation team who are archiving the study information when the study has finished.

The people who analyse the information will not be able to identify you and will not be able to find out your name, your NHS number or your contact details. However, if you attend a focus group, the researchers running the group will be aware of your name and appearance, and may later analyse the data.

Birmingham community Healthcare NHS Foundation Trust Research and Innovation Team will securely store identifiable information about you from this study for 5 years after the study has finished. Clever Together will only keep the information they have for 14 days after the end of the workshop.

Under the General Data Protection Regulation (GDPR), some of the personal data which will be collected from you is categorised as "sensitive data" (e.g. your name and contact details). The processing of this data is necessary for scientific research in accordance with safeguards. This means that study has gone through an ethical committee to ensure that the appropriate safeguards are put in place with respect to the use of your personal data. Personal data will be processed on the public task basis. Individuals' rights to erasure and data portability do not apply if you are processing on the basis of public task. However, individuals do have a right to object. If you withdraw from the study, we will keep the information we have already obtained.

To safeguard your rights, we will use the minimum personally-identifiable information possible.

Clever Together will pass data collected during the study to Birmingham Community Healthcare NHS Foundation Trust securely.

We would need to break confidentiality and share identifiable information with external agencies if we think there is a risk of harm to you or others at any point in the study, or disclosures of criminal activity are made. In this case we will follow the Trust's Safeguarding Policies and inform appropriate staff or agencies.

What is said in the recordings of the focus groups will be typed up by the researchers. They will remove anything that might identify you.
If you would like further information about how your data is managed in health research, please follow the link below:
https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/

What if there are any problems?

It is very unlikely, but if during the study any concerns about clinical care, criminal activity or safeguarding concerns are highlighted, the researchers have to share this information with the relevant authorities.

Some people may feel anxious about taking part in the online workshop or virtual focus groups. Participants will be signposted to appropriate local support services on the study website and during focus groups if required.

What if I want to complain?

Please speak to the research team initially if you are worried about the study (tel: 07701371838, email:domore.study@nhs.net). If you wish to formally complain, you can contact customer services (formerly the patient advice and liaison service) at Birmingham Community Healthcare NHS Foundation Trust using the details below:

Anne Pemberton (Patient Experience Manager) or Zarina Mansuri (Advise and liaison officer), Birmingham Community Healthcare NHS Trust Customer Services
Moseley Hall Hospital, Alcester Road, Moseley, Birmingham, B13 8JL
Tel:
e-mail: contact.bchc@nhs.net

What if I want to find out more about the study?

If you have questions about any aspect of the study that are not answered by this information sheet, please contact Marilyn Bradbury, HEE/NIHR Clinical Doctoral Research Fellow, Medical Directorate, Research and Innovation, Birmingham Community Healthcare NHS Foundation Trust, Trust Headquarters, 3 Priestley Wharf, 20 Holt Street, Birmingham, B7 4BN. Tel: 07701371838. E-mail: domore.study@nhs.net

Thank you for taking time to read this information.

Professionals / Experts and Other Interested Parties Participant Information Sheet

Version 3 (23/07/2020) IRAS Project ID: 271259

Research Title:	**Developing an intervention to reduce sedentary behaviour in non-ambulant young people with long-term disabilities (DoMore).**
Chief Investigator:	**Mrs Marilyn Bradbury, HEE/NIHR Clinical Doctoral Research Fellow, Birmingham Community Healthcare NHS Foundation Trust**

I'm Marilyn Bradbury. I would like to invite you to be involved in my research project. To help you to decide whether to take part, this form explains what you would need to do. Please take time to read the information and contact me if you have any questions.

What is the study about?

Previous research has shown that young people with disabilities do less physical activity than able-bodied young people. Supporting them to increase their physical activity has, therefore, been identified as a high priority for research.

I want to help young people who use a wheelchair and are unable to walk due to their disability, to spend less time being sedentary. Being sedentary means you're awake, but sitting or lying down and using very little energy (less than 1.5 metabolic units). This includes:

- Time on your phone
- Watching TV
- Playing video games
- Reading

Spending long periods of time being sedentary reduces fitness, and can increase the risk of obesity, heart disease and mental health issues.

The aim of this study is to develop a programme to encourage young people who are unable to walk due to their disability to spend less time being sedentary, and to be active more regularly through their day. The programme will include an app on a tablet.

Different groups of people will be getting involved with developing the programme. The groups are: young people who are unable to walk as a result of their disability, family members of young people with disabilities, professionals who work with young people with disabilities, experts / academics who are interested in disability, physical activity or using technology in health care and other interested parties. There are two ways you can help with developing the programme. You can choose which one works best for you.

Why do you want me to take part?

Health and education professionals who work with young people who use a wheelchair and are unable to walk (or only walk short distances using a body support walker) are being invited to take part.

Experts in sedentary behaviour, paediatric disability, behaviour change, or digital health interventions and other interested members of the public (aged 16 and above) are also being invited to participate.

The young people the programme is being developed for will be aged 12 - 25 years old and have a long term physical disability. These young people are parting in this study too. Young people with learning and physical disabilities can take part if they have enough understanding and communication to answer the questions. Family members (aged 16 and above) of young people with disabilities who are unable to walk can also take part. Please feel free to tell people you work with about the study, so they can participate too, or share this link to the study website with them: https://do-more.org.uk/welcome.

Children and young people who are under 16 and do not have a long term disability that prevents them from walking are unfortunately unable to participate.

What will we need to do?
If you are participating, you will be asked to complete a consent form online. You will be emailed a copy of your consent form.

You will need to agree to abide by the ground rules about how people participating should interact with each other both in the online workshop and the virtual focus groups, to make sure everyone taking part respects each others opinions. After consenting to participate, you will be asked to complete some basic information including your name, age, email address, first 3 characters of your postcode (or town/country if you are outside the UK), gender, ethnicity, employment status and job role. You will be asked to complete a short survey before you contribute to the workshops or the virtual focus groups (you can't contribute to both).

There will be 4 steps you can contribute to that help me to: 1) understand the problem 2) decide how the app can best support young people to move regularly 3) form an evidence and theory based foundation for the programme, 4) decide how the support should be delivered. I would like you to participate in all 4 if you can. Each step will happen at different times. There will be 2 focus groups held at each step; one for 12-15 year olds, and a second for all participants over 16 (apart from step 3, which won't include 12 – 25 year olds with disabilities or family members). Focus groups will last for 45 – 90 minutes. The online workshops will open for approximately 2 weeks at each step. There will be several questions you can respond to at each step. You don't have to respond to them all. You can spend as much or a little time as you choose to on the online workshop.

In the online workshop, you will be able to read other people's responses to the questions, and there is a button to agree or disagree with what they have written. You can write a reply

about what they have written too. You will not be able to tell who has written each response. There is a ground rule that asks you not to use your name, or give too many details about yourself that could allow someone to know who you are. If someone writes something that upsets or offends you, or you feel would allow you to know who that person is, you can flag what they have written, and it will be removed either permanently, or until the platform administrators have reviewed what was said and edited it if needed. Young people aged 12-15, young people aged 16-25, family members / carers, professionals and experts and other interested parties will write in 4 separate workshops.

Once you have participated in one step, I will email to invite you to the next step, unless you ask me not to.

Focus group attenders will receive a £10 shopping voucher as a thank you.

Do we have to take part?
No. It is up to you.

What if I change my mind about taking part?
You can pull out at any stage. We will still use any information we have already collected.

When will it be and how long will it last?
This part of the study (developing the programme) will take place between October and November 2020 and last for 6-8 months.

What are the benefits of taking part?

- The programme will be designed using the information everyone who participates has given us. This means it's much more likely to work well, and you will have helped us to achieve that.
- You will have contributed to a new digital treatment, that 20 young people with disabilities will use in our small study to test it.
- I hope that lots of young people will use the programme in the future, helping them to live healthy lifestyles.

What are the disadvantages of taking part?

There is a small risk of participants becoming upset, distressed or offended by the content of discussions in the online workshops or in the focus groups. The ground rules and ability to flag any content you feel should be removed will help to reduce the risk of this happening.

Participants need to find time for contributing to the online workshops or virtual focus groups. Groups may be held in school or working hours.

Will anyone else know I am taking part?
If you take part in a focus group, confidentiality cannot be assured, because the other participants will know your first name and see you on the video. Participants are asked in the ground rules to avoid making comments that could identify them. No one other than you, and the researchers and other people at any focus groups you attend will know you

have participated, unless you want to tell anyone else about it. Everything you say in the online workshop will be anonymous. If you participate online, Clever Together (the company hosting the online platform) will transfer your name to the research and innovation team at Birmingham Community Healthcare NHS Foundation Trust, but the researchers analysing the data won't know who you are.

When we share the results of the study, we will use some quotes, but it won't say who said them. All electronic information will be encrypted and/or password protected. Any information kept on paper will be transported in the same secure way as health records, and will be kept in a locked filing cabinet that is only accessed by the researchers.

We may publish our raw data, or use it in other research, but this will be anonymous.

How many others are taking part?
Its hard to know how many people will sign up to the online workshop, we hope lots of people will! Please share this information and the website with any colleagues, service users friends or family you think would be interested in participating. Between 3 and 10 people will be in each focus group.

What happens when the study is finished?
You will be able to keep up with what's happening and the results of the study via our website (do-more.org.uk). The programme will be produced and there will be a small study to see if it can be used in the NHS and what the young people think of it. The results will be used to write presentations and to publish in research journals so we can share what we find out with other young people with disabilities and other professionals.

Who is organising and funding the research?
Birmingham Community Healthcare NHS Foundation Trusts are responsible for running the study in accordance with existing research legislation and guidelines. The study is funded by the National Institute for Health Research and Sport Inspired charity.

Who is reviewing the research?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee (REC), to protect your interests. This study has been reviewed and given a favourable ethical opinion by a REC. It has also been reviewed by the National Institute for Health Research, the study steering group and an expert fellowship collaborator who holds a highly regarded academic post in childhood disability and has considerable clinical and research experience.

How have patients and the public been involved in this study?
Members of the West Midlands Young Persons Steering Group (YPSG), public and patient involvement (PPI) representatives who are non-ambulant young people, parents of young people with disabilities and adults attending a day centre for people with cerebral palsy have been involved in developing the research. The YPSG and PPI representatives have lived experience of long-term disability. A lay member sits on the study steering committee.

The PPI representatives have been involved in developing the participant information sheets and adverts for the online workshops, and have contributed to production of the website. They will assist with disseminating the adverts via relevant networks they are members of, opportunities in their local communities and face to face activities where possible.

Will my data be kept confidential?

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You can find out more about how Birmingham Community Healthcare NHS Foundation Trust will use your information, or raise a complaint about how your personal data has been handled by contacting their Data Protection Officer:

- **Tel:** 0121 466 7033
- **Email:** bchc.dpo@nhs.net
- **Address:** Data Protection Officer, Corporate Affairs, Birmingham Community Healthcare NHS Foundation Trust, 3 Priestley Wharf, Holt St, Birmingham. B7 4BN

If you are not satisfied with their response or believe they are processing personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). Tel: 0303 123 1113, www.ico.org.uk)

We will use your name, email address, NHS number and your contact details to contact you about the research study, and to oversee the quality of the study. This information will only be used for the DoMore study. It will not be used for any other purpose. Clever Together will have access to all information you enter online via the study website. They have a strict privacy policy for handling this information, that you can access via the study website. Two weeks after the study ends Clever Together will delete all the data they hold relating to this study. Your consent form will be transferred to a representative at Birmingham Community Healthcare NHS Foundation Trust. Your anonymised responses will be retained by the researcher team.

Individuals from Birmingham Community Healthcare NHS Foundation Trust, Clever Together (who are hosting the online workshop) and regulatory organisations may look at your research records to check the accuracy of the research study. The only people in Birmingham Community Healthcare NHS Foundation Trust who will have access to information that identifies you will be people who need to contact you to audit the data collection process or the research and innovation team who are archiving the study information when the study has finished. The people who analyse the information will not be able to identify you and will not be able to find out your name, your NHS number or your

contact details. However, if you attend a focus group, the researchers running the group will be aware of your name and appearance, and may later analyse the data.

Birmingham community Healthcare NHS Foundation Trust Research and Innovation Team will securely store identifiable information about you from this study for 5 years after the study has finished. Clever Together will only keep the information they have for 14 days after the end of the workshop.

Under the General Data Protection Regulation (GDPR), some of the personal data which will be collected from you is categorised as "sensitive data" (e.g. your name and contact details). The processing of this data is necessary for scientific research in accordance with safeguards. This means that study has gone through an ethical committee to ensure that the appropriate safeguards are put in place with respect to the use of your personal data. Personal data will be processed on the public task basis. Individuals' rights to erasure and data portability do not apply if you are processing on the basis of public task. However, individuals do have a right to object. If you withdraw from the study, we will keep the information we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Clever Together will pass data collected during the study to Birmingham Community Healthcare NHS Foundation Trust securely.

We would need to break confidentiality and share identifiable information with external agencies if we think there is a risk of harm to you or others at any point in the study, or disclosures of criminal activity are made. In this case we will follow the Trust's Safeguarding Policies and inform appropriate staff or agencies.

What is said in the recordings of the focus groups will be typed up by the researchers. They will remove anything that might identify you.

If you would like further information about how your data is managed in health research, please follow the link below:
https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/

What if there are any problems?
It is very unlikely, but if during the study any concerns about clinical care, criminal activities or safeguarding concerns are highlighted, the researchers have to share this information with the relevant authorities.

Some people may feel anxious about taking part in the online workshops or focus groups. Participants will be signposted to appropriate local support services on the study website and at focus groups if required.

What if I want to complain?
Please speak to the research team initially if you are worried about the study (tel: 07701371838 email: domore.study@nhs.net). If you wish to formally complain, you can contact customer services (formerly the patient advice and liaison service) at Birmingham Community Healthcare NHS Foundation Trust using the details below:

Anne Pemberton (Patient Experience Manager) or Zarina Mansuri (Advise and liaison officer), Birmingham Community Healthcare NHS Trust Customer Services
Moseley Hall Hospital, Alcester Road, Moseley, Birmingham, B13 8JL
Tel:
e-mail: contact.bchc@nhs.net

What if I want to find out more about the study?
If you have questions about any aspect of the study that are not answered by this information sheet, please contact Marilyn Bradbury, HEE/NIHR Clinical Doctoral Research Fellow, Medical Directorate, Research and Innovation, Birmingham Community Healthcare NHS Foundation Trust, Trust Headquarters, 3 Priestley Wharf, 20 Holt Street, Birmingham, B7 4BN. Tel: . E-mail: domore.study@nhs.net

Thank you for taking time to read this information.

Parent / Guardian / Family Member Participant Information Sheet

Version 4 (23/07/2020) IRAS Project ID: 271259

Research Title:	**Developing an intervention to reduce sedentary behaviour in non-ambulant young people with long-term disabilities (DoMore).**
Chief Investigator:	**Mrs Marilyn Bradbury, HEE/NIHR Clinical Doctoral Research Fellow, Birmingham Community Healthcare NHS Foundation Trust**

I'm Marilyn Bradbury. I would like to invite your family to be involved in my research project. To help you to decide whether to take part, this form explains what you would need to do. Please take time to read the information and contact me if you have any questions. It can be helpful to talk to your friends and family about the research project when you are deciding whether to participate.

What is the study about?
Previous research has shown that young people with disabilities do less physical activity than able-bodied young people. Supporting them to increase their physical activity has, therefore, been identified as a high priority for research.

I want to help young people who use a wheelchair and are unable to walk due to their disability, to spend less time being sedentary. Being sedentary means you're awake, but using very little energy. This includes:

- Time on your phone
- Watching TV
- Playing video games
- Reading

Spending long periods of time being sedentary reduces fitness, and can increase the risk of obesity, heart disease and mental health issues.

Aim of the study
The aim of this study is to develop a programme to encourage young people who are unable to walk due to their disability to be active more regularly through their day. The programme will include an app on a tablet.

Different groups of people will be getting involved with developing the programme. The groups are: young people who are unable to walk as a result of their disability, family members of young people with disabilities, professionals who work with young people with disabilities, experts / academics who are interested in disability, physical activity or using technology in health care and other interested parties. You and your child/family member may be able to take part.

Why do you want my family to take part?
Young people who use a wheelchair most of the time and are unable to walk, or only walk short distances with the help of a body support walker are being invited to take part. They need to be 12 - 25 years old, have a long term disability, live in the UK, be able to communicate using English language online or in a virtual focus group (video conference) and have sufficient understanding to be able to answer the questions asked.

All family members or carers (aged 16 and above) of children and young people who are unable to walk due to a long term disability can also take part.

What will we need to do?
There are two ways you and/or your child/family member can help with developing the programme. You can choose which one works best for you.

You and/or your child/family member can contribute to an anonymous workshop online which you can access at any time, or you can come to a virtual focus group which will be held online at a specific time.

If you are participating, you will be asked to complete a consent form and questionnaire online. If your child is under 16 and would like to take part, please read through the participant information sheet for 12-15 year olds with them. If you have doubts about your child's understanding of the study or ability to answer the questions, please don't take any further action. You can still take part as a family member. If you and your child are happy for them to participate, click the link to participate and select "I am a:

- Young person aged 12-15 and I am unable to walk, or I use a walker similar to those pictured below."

When prompted, enter your contact details and we will arrange a virtual online consent meeting with both of you (using video) to discuss their participation. Following this we will email you a link and password that allows you to provide consent for them to participate online. . They will not able to access the online workshop or virtual focus groups until you have completed a consent form for them. They will also be asked to agree that they want to take part. request If you are participating and think your child / another family member / friend would also like to please encourage them to visit the website with you and read about the study or share this link with them: https://do-more.org.uk/welcome. The link can be shared via social media.

You will be emailed a copy of the consent form and your child's agreement form if they are also taking part.

After consenting to take part, you/your child/family member will be asked to:

- provide some basic information about yourselves, including your diagnosis if you have a disability

- complete a short survey before you contribute to the workshop or focus group (you can't contribute to both).

You and/or your child will need to agree to accept the ground rules about how people participating should speak to each other both in the workshop and the focus groups, to make sure everyone taking part respects each others opinions.

There will be 3 steps you can contribute to that help me to:
1) understand the problem
2) decide how the app can best support young people to move regularly
3) decide how the support should be delivered.

I would like you to participate in all 3 if you can. Each step will happen at different times. The online workshop will open for approximately 2 weeks at each step. There will be several questions you can respond to at each step. You don't have to respond to them all. You can spend as much or a little time as you choose to on the online workshop.

There will be 2 focus groups held at each step; one for 12-15 year olds, and a second for all participants over 16. Focus groups will last for 45 – 90 minutes. Between 3 and 10 people will be in each focus group.

In the online workshop, you will be able to read other people's responses to the questions, and there is a button to agree or disagree with what they have written. You can write a reply about what they have written too. You will not be able to tell who has written responses. There is a ground rule that asks you not to use your name, or give too many details about yourself that could allow someone to know who you are. If someone writes something that upsets or offends you, or you feel would allow you to know who that person is, you can flag what they have written, and it will be removed either permanently, or until the platform administrators have reviewed what was said and edited it if needed. There will only be young people aged 12-15 contributing to the online platform your child/family member will take part in. Young people aged 16-25 and family members / carers, professionals and experts will each have their own separate platform to write on.

Once you have participated in one step, I will email to invite you to the next step, unless you ask me not to.

If you attend a focus group, you will receive a £10 shopping voucher as a thank you.

Do we have to take part?
No. It is up to you and your child. Your child's healthcare will not change whether you decide to take part or not.

What if we change our minds about taking part?
You can pull out at any stage and it won't change the care your child receives. We will still use any information we have already collected, but this will remain anonymous.

When will it be and how long will it last?
This part of the study (developing the app) will take place in October or November 2020 and last for 6-8 months.

What are the benefits of taking part?
- The programme will be designed using the information everyone who participates has given us. This means its much more likely to work well, and you will have helped us to achieve that.
- You will have contributed to a new digital treatment, that 20 young people with disabilities will use in our small study to test it.
- I hope that lots of young people will use the programme in the future, helping them to live healthy lifestyles and you/your child will heave helped with this.

What are the disadvantages of taking part?

There is a small risk of participants becoming upset, distressed or offended by the content of discussions in the online workshop or in the virtual focus groups. The ground rules and ability to flag any content you feel should be removed will help to reduce the risk of this happening.

Families participating need to find time for contributing to the online workshop or attending a virtual focus group. Groups may be held in school or working hours.

Will anyone else know we are taking part?
If you take part in a focus group, confidentiality cannot be assured, because the other participants will know your first name and see you on the video. Participants are asked in the ground rules to avoid making comments that could identify them. No one other than your family, the researchers and the other people at any focus groups you attend will know you have participated unless you want to tell them about it. Everything you say in the online workshop will be anonymous.

When we share the results of the study, we will use some quotes, but it won't say who said them. All electronic information will be encrypted and/or password protected (which means it won't be readable by anyone who shouldn't see it). Any information kept on paper will be transported in the same secure way as health records, and will be kept in a locked filing cabinet that is only accessed by the researchers.

We may publish our data, or use it in other research, but this will be anonymous.

How many others are taking part?
Its hard to know how many people will sign up to the online workshop, we hope lots of people will! Please share this information and the website with any friends or family you think would be interested in participating.

Will it affect my child's normal healthcare?
The study is not related to your child's/family members routine healthcare. This will not change as a result of their participation.

What happens when the study is finished?
You will be able to keep up with what's happening and the results of the study via our website (**do-more.org.uk**). The programme we designed together will be produced and there will be a small study to see if it can be used in the NHS and what the young people think of it. The results will be used to write presentations and to publish in a medical magazine so we can share what we find out with other families who have children with disabilities and other professionals.

Who is organising and funding the research?
Birmingham Community Healthcare NHS Foundation Trusts are responsible for running the study in accordance with existing research legislation and guidelines. The study is funded by the National Institute for Health Research and Sport Inspired charity.

Who is reviewing the research?
All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable ethical opinion by a research ethics committee. It has also been reviewed by the National Institute for Health Research, the study steering group and an expert fellowship collaborator who holds a highly regarded academic post in childhood disability and has considerable clinical and research experience.

How have patients and the public been involved in this study?
Members of the West Midlands Young Persons Steering Group, public and patient involvement representatives who are non-ambulant young people, parents of young people with disabilities and adults attending a day centre for people with cerebral palsy have been involved in developing this research. The Young Persons Steering Group and patient and public involvement representatives have lived experience of long-term disability. A lay member sits on the study steering committee.

The patient and public involvement representatives have been involved in developing the participant information sheets and adverts for the crowdsourcing platforms, and have contributed to production of the website. They will assist with disseminating the adverts via relevant networks they are members of, opportunities in their local communities and face to face activities where possible.

Will my data be kept confidential?

Birmingham Community Healthcare NHS Foundation Trust is the sponsor for this study based in the United Kingdom. They will be using information about you/your child/family member obtained from you/your family member in order to undertake this study. Birmingham Community Healthcare NHS Foundation Trust will act as the data controller for this study. This means that they are responsible for looking after this information and using it properly. Birmingham Community Healthcare NHS Foundation Trust will keep the identifiable information collected for 5 years after the study has finished.

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- **Email:** bchc.dpo@nhs.net
- **Address:** Data Protection Officer, Corporate Affairs, Birmingham Community Healthcare NHS Foundation Trust, 3 Priestley Wharf, Holt St, Birmingham. B7 4BN

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We will use your/ your family member's name, email address, NHS number and your/your family member's contact details to contact you/them about the research study, and to oversee the quality of the study. This information will only be used for the DoMore study. It will not be used for any other purpose. Clever Together will have access to all information you enter online via the study website. They have a strict privacy policy for handling this information, that you can access via the study website. Two weeks after the study ends Clever Together will delete all the data they hold relating to this study. Your consent form will be transferred to a representative at Birmingham Community Healthcare NHS Foundation Trust. Your anonymised responses will be retained by the researcher team.

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Birmingham community Healthcare NHS Foundation Trust Research and Innovation Team will securely store identifiable information about you/your family member from this study for 5 years after the study has finished. Clever Together will only keep the information they have for 14 days after the end of the workshop.

Under the General Data Protection Regulation (GDPR), some of the personal data which will be collected from you/your family member is categorised as "sensitive data" (e.g. your name and contact details). The processing of this data is necessary for scientific research in accordance with safeguards. This means that study has gone through an ethical committee to ensure that the appropriate safeguards are put in place with respect to the use of your/your family member's personal data. Personal data will be processed on the public

task basis. Individuals' rights to erasure and data portability do not apply if you are processing on the basis of public task. However, individuals do have a right to object. If you/your family member withdraw from the study, we will keep the information we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Clever Together will pass data collected during the study to Birmingham Community Healthcare NHS Foundation Trust securely.

We would need to break confidentiality and share identifiable information with external agencies if we think there is a risk of harm to you or others at any point in the study, or disclosures of criminal activity are made. In this case we will follow the Trust's Safeguarding Policies and inform appropriate staff or agencies.

What is said in the recordings of the focus groups will be typed up by the researchers. They will remove anything that might identify you.

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https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document/

What if there are any problems?
It is very unlikely, but if during the study any concerns about clinical care, criminal activities or safeguarding concerns are highlighted, the researchers have to share this information with the relevant authorities.

Some people may feel anxious about taking part in the online workshops or focus groups. Participants will be signposted to appropriate local support services on the study website and at focus groups if required.

What if I want to complain?
Please speak to the research team initially if you are worried about the study (tel: [redacted] email: domore.study@nhs.net). If you wish to formally complain, you can contact customer services (formerly the patient advice and liaison service) at Birmingham Community Healthcare NHS Foundation Trust using the details below:

Anne Pemberton (Patient Experience Manager) or Zarina Mansuri (Advise and liaison officer), Birmingham Community Healthcare NHS Trust Customer Services
Moseley Hall Hospital, Alcester Road, Moseley, Birmingham, B13 8JL
Tel: [redacted]
e-mail: contact.bchc@nhs.net

What if I want to find out more about the study?
If you have questions about any aspect of the study that are not answered by this information sheet, please contact Marilyn Bradbury, HEE/NIHR Clinical Doctoral Research Fellow, Medical Directorate, Research and Innovation, Birmingham Community Healthcare NHS Foundation Trust, Trust Headquarters, 3 Priestley Wharf, 20 Holt Street, Birmingham, B7 4BN. Tel: [redacted]. E-mail: domore.study@nhs.net

Thank you for taking time to read this information.

Appendix 3 Organisations / roles of individuals contacted during recruitment to the DoMore Study

Organisations

AbleThrive (Social media: x)

Acorns (charity)

Activity Alliance

Association of Paediatric Chartered Physiotherapists

Birmingham Phoenix Wheelchair Basketball Club

Bourneville Rugby

Brainwave (charity)

Burnley Football Club community

Calvert Trust, Exmoor

Caudwell Children (charity)

Cerebral Palsy Midlands (charity)

Cerebral Palsy Plus

Children Today (charity)

Disability Social Club

CP Sport

Dusk till Dawn Charity (charity)

Go Kids Go (charity)

JCM (rehabilitation equipment company)

Jiraffe (rehabilitation equipment company)

Kidsphysiotherapy

Leckey (rehabilitation equipment company)

Made for Movement

Parasport (was parasport.org.uk, website now inactive)

Peninsula Childhood Disability Research Unit

Physio4kids

R82 (rehabilitation equipment company)

Scope (charity)

Shine Charity

Smirthwaite (rehabilitation equipment company)

Sportsable

The Nihal Armstrong Trust

The Sequal Trust

Together for short lives (charity)

Variety (charity)

Whizz-kidz (charity)

Clinical teams (within Birmingham Community Healthcare NHS Foundation Trust (BCHC) unless stated otherwise)

Acute orthopaedic inpatient services (external to BCHC)

BCHC divisional leads

BCHC staff bulletin

Birmingham Wheelchair Services

Regional neuromuscular centre of expertise (external to BCHC)

Local acute paediatric services (external to BCHC)

Paediatricians

Paediatric Physiotherapy

Young adults clinic (transition service from children's therapy)

Specialist clinics at West Midlands Rehabilitation Centre (including spasticity clinic)

Schools

Calthorpe Academy, Birmingham

Hallmoor School, Birmingham

Mayfield School

Springwood School

Timberley School

Victoria School, Birmingham

Wilson Stuart School

Individuals

Disability speaker, Dr, writer, EDI consultant

Disability blogger, traveller, campaigner, community builder and keynote speaker

Academic paediatric physiotherapist interested in physical activity (International)

Academic (paediatric physiotherapist) x2

Research active paediatrician

Research active SEN educator

Young adults previously involved in Public and Patient Involvement

Wheelchair dance instructor

Magazines

Able Magazine

Disability Horizon

SEN Magazine

Networks

CHILD research group (Newcastle)

Cerebral Palsy Parents Information Group

Cerebral Palsy UK Facebook group

Contact for families with disabled children Facebook group

CP Teens UK Parent/Carer Voice Facebook group

Life and Other stories Facebook group

Parent carer networks

Parent Carer wellbeing-Affinity Hub UK Facebook group

Sedentary behaviour network

West Midlands Clinical Research Network

Media

BBC Birmingham and Black Country news online

BBC radio WM

Midlands Today

Solihull radio

Targeted paid social media advertising, Facebook and Instragram

The Last Leg

University of Birmingham Press Office

Individuals / organisations who contacted the study via email having seen adverts.

Acute orthopaedic inpatient services (external to BCHC)

Clinical research facilitator (outside Midlands area)

Community paediatrician (outside Midlands area)

Disability sport leader

Made for movement manager

MOVE Programme

Paeditric dietician (external to BCHC)

Paediatric physio (NHS - external to BCHC)

Paeditric physio (private) x2

Physical Disability Support Service (Birmingham)

Professor of Movement Science

SEN teacher

Speech and Language Therapist from Augment Communication Team (BCHC)

This protocol has regard for the HRA guidance and order of content

FULL/LONG TITLE OF THE STUDY

Developing an intervention to reduce sedentary behaviour in non-ambulant young people with long-term disabilities.

SHORT STUDY TITLE / ACRONYM

DoMore

PROTOCOL VERSION NUMBER AND DATE

Version 4. 19/05/2021

RESEARCH REFERENCE NUMBERS

IRAS Number:	271259
SPONSORS Number:	BCHCTrustwide271259.Portfolio
FUNDERS Number:	ICA-CDRF-2018-04-ST2-021

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature: Date:

.....
.....

Name (please print): Christine Burt

Position: Research and Innovation Director

Chief Investigator:

Date: .....

Signature:
.....
.....

Name: (please print): Marilyn Bradbury

KEY STUDY CONTACTS

Chief Investigator and Study Co-ordinator	Marilyn Bradbury, Tel: , Email:
Sponsor	Birmingham Community Healthcare NHS Foundation Trust Tel: 0121 466 7065 Email: Research.Innovation@bhamcommunity.nhs.uk
Funders	HEE/ NIHR ICA Programme (Clinical Doctoral Research Fellowship) NIHR Academy , 21 Queen Street, Leeds, LS1 2TW Tel: 0113 532 8401 , Fax: 020 8843 8001, Email: academy@nihr.ac.uk Sport Inspired Limited, in WeWork, Aldgate Tower, 2 Leman Street, London, E1 8FA Tel: , Email: contactus@sportinspired.org
Key Protocol Contributors	**Professor Joan Duda,** Professor of Sport and Exercise Psychology, School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham, Edgbaston, Birmingham, B15 2TT, UK, Email: **Dr. Sally Fenton,** Lecturer in Lifestyle Behaviour Change, School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham, Edgbaston, Birmingham, B15 2TT, Email: **Dr. Susan Neilson,** Lecturer, School of Nursing, School of Nursing, Institute of Clinical Sciences, University of Birmingham, Edgbaston, Birmingham, B15 2TT, UK Email: **Dr. Elizabeth Croot,** Senior Research Fellow, School of Health and Related Research (ScHARR), University of Sheffield, Room 3004, Regent Court, 30 Regent Street, Sheffield, S1 4DA Tel: E-mail: **West Midlands Young Persons Steering Group (YPSG) and Patient and Public Involvement (PPI) representatives.**
Committees	DoMore Study Steering Committee. Chair – Prof Joan Duda (see above for contact details)

STUDY SUMMARY

Study Title	Developing an intervention to reduce sedentary behaviour in non-ambulant young people with long-term disabilities.
Internal ref. no. (or short title)	DoMore
Study Design	Complex intervention development following the "Six Steps in Quality Intervention Development" method. **Steps 1-4** • Co-designing a digitally -enabled intervention via an online crowdsourcing platform and focus groups / 1:1 interviews enabling triangulation of data. Wherever interviews are referred to throughout this protocol they will be 1:1. • The crowdsourcing platform has been designed and is managed by a company called Clever Together **Step 5** • A single armed, mixed methods feasibility study • This will be dealt with as a separate protocol for which subsequent HRA approval will be sought. **Step 6** • An evaluation of whether optimisation and more rigorous evaluation is justified based on the findings of step 5.
Study Participants	**Participants:** • Children and young people aged 12-25 years, who are unable to walk due to a lifelong disability • Family members of children and young people who are unable to walk due to a lifelong disability • Education and healthcare professionals who work with these children and young

	people. Experts in sedentary behaviour, paediatric disability, behaviour change, or digital health interventions. • Other interested members of the public Participants will choose to participate in the crowdsourcing discussion or take part in a virtual focus group / 1:1 interview.
Planned Size of Sample (if applicable)	**Crowdsourcing:** The minimum number of participants on any platform is 1. There is no maximum number of participants. **Virtual focus groups or 1:1 interviews:** The minimum number of people participating in a focus group will be 2. Individual interviews can also be undertaken. There will be a maximum of 10 participants in focus groups. The number of focus groups held will depend upon demand to participate in this way; therefore there is not an absolute maximum. We predict that fewer than 70 people will participate. . It is hoped the same participants will attend several groups as the co-design progresses. See Table 1.
Follow up duration (if applicable)	NA
Planned Study Period	Recruitment and data collection - 9 months
Research Aims	1) To co-create a digitally-enabled health intervention, in partnership with: young people who are non-ambulant, family members of and professionals who work with young wheelchair users and academic and industry experts, to reduce and break up sedentary behaviour by promoting light physical activity.

LAY SUMMARY

What are the aims?

• Develop a digitally-enabled intervention (using software) to help young people with long-term disabilities, who are unable to walk, spend less time being sedentary. Being sedentary means sitting or lying down whilst awake, and not using much energy.

• Develop the intervention in partnership with young people, their families, professionals and experts.

Why is this research being done?

• Long periods of sedentary time can lead to poor health, for example obesity, heart diseases, type II diabetes or mental health problems. Reducing and breaking up sedentary time can help to prevent poor health.

• Research shows that children with disabilities spend more time being sedentary than other children. Older children who are unable to walk are more sedentary than other children with disabilities.

• There are no evidence based interventions to help young people with disabilities to reduce their sedentary time.

What are we going to do?

• We will follow a method based on previous research to develop the intervention, using models, theories and behaviour change techniques.

• Young people with disabilities, their families, professionals, and experts will contribute to the development of the intervention via an online platform (crowdsourcing) and virtual focus groups or 1:1 interviews.

• The intervention:

- might include advice, information, links to resources, monitoring of sedentary time, goal setting, rewards and/or interaction with others.

- could encourage use of standing frames or supportive walkers, active floor time and/or exercise whilst sitting.

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON** **FINANCIALSUPPORT GIVEN**
HEE/ NIHR ICA Programme (Clinical Doctoral Research Fellowship) NIHR Academy , 21 Queen Street, Leeds, LS1 2TW Tel: 0113 532 8401 , Fax: 020 8843 8001, Email: academy@nihr.ac.uk	Main funder of study Fellowship grant total is £349, 512 This includes funding for a feasibility study, training and development for the CI and PI and travel/subsistence in addition to research costs.
Sport Inspired Limited, in WeWork, Aldgate Tower, 2 Leman Street, London, E1 8FA Tel: , Email: contactus@sportinspired.org	Payment for use of the Clever Together crowdsourcing platform £45,000.

ROLE OF STUDY SPONSOR AND FUNDER

As sponsors, Birmingham Community Healthcare NHS Foundation Trust (BCHCFT) are key members of the study steering committee, providing oversight of the conduct of the study. BCHCFT will review and approve study documentation produced by the research team, and administer the grant for the research. BCHC have not contributed to the design of this research and will not be involved in data analysis and interpretation, manuscript writing, or decision making in relation to the choice of journal the work will be submitted to. BCHC may offer support with dissemination of the results and provide support with the next steps for continuing with this work; i.e. the feasibility study to test the intervention and any further work following this. BCHCFT will be the owners of any Intellectual Property (IP) generated by the research, and are responsible for data protection in relation to all aspects of the research.

The NIHR are funding the majority of this research, and Sport Inspired are kindly funding use of the Clever Together crowdsourcing platform. Neither organisation will

be involved in study design, conduct, data analysis and interpretation, manuscript writing, or final decision making in relation to dissemination of results. Sport Inspired have requested that they are acknowledged as a supporter of the research in all dissemination activities, and that the research is publicised with their key stakeholders as is appropriate, taking into consideration any IP implications.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

Study Steering Committee

The DoMore Study Steering Committee (SSC) is chaired by Professor Joan Duda and comprised of the supervision team, the CI, a representative from collaborators Clever Together and Dignio (who will build and support the intervention), a lay member and a sponsor representative. It will meet biannually, and at appropriate key points as the research progresses. The role of this group is outlined in the Committee's Terms of Reference Document.

Patient & Public Involvement (PPI)

Members of the West Midlands Young Persons Steering Group (YPSG), and public and patient involvement (PPI) representatives who are non-ambulant young people are involved this research. They have reviewed this protocol, helped to produce advertisements and write the participant information sheets (PISs) and assisted with designing the crowd sourcing platform adverts. They will help with advertising (via relevant networks they are members of, social media and distributing posters), design of the crowdsourcing platforms and assist with designing patient facing elements of the software. A young man with disabilities is sitting on the SSC as a lay member.

<u>Clever Together</u>

Clever together are a collaborating industry partner whose crowdsourcing platform will be used. Clever Together have had involvement in many successful healthcare related projects. They will:

- Provide support with gaining a favourable opinion from the NHS Research ethics committee (REC) and HRA approvals in relation to using crowdsourcing to undertake data collection
- Assist with developing 4 crowdsourcing platforms, relating to four steps of the Six Steps of Quality Intervention Development Model (6SQuID), to undertake a complex intervention development process online.

  Clever Together will host 13 online discussions in total, that will take place via the 4 platforms (see Table 1).

- Host the four crowdsourcing platforms described above and the study website, ensuring requirements stipulated in the ethics application in relation to consent, data management and security and confidentiality are upheld

- Contribute to decisions relating to data analysis methods, and assist with data analysis, including data collected online and via the focus groups / 1:1 interviews.
- Be involved in the design of the digital intervention to reduce sedentary behaviour in young people with long term disabilities who are non-ambulant
- Be involved in further iterations of the software based on early feedback and Public and Patient Involvement (PPI) activities

Provide coaching and mentoring in relation to leadership and career development across the course of the fellowship, including, but not limited to 12 days of face to face support to develop, host and analyse the crowdsourcing platforms whilst undertaking the Clever Together Academy Course. Dr. Peter Thomond is Co-founder and Chief executive of Clever Together and a trustee of funders in kind Sport Inspired.

PROTOCOL CONTRIBUTORS

Supervision team

Professor Joan Duda: Primary doctoral supervisor. Joan will have overall oversight of the research, supporting the CI with protocol development, application for ethical and HRA approvals, conduct of the research, data analysis, interpretation and dissemination.

Dr. Sally Fenton and Dr. Sue Neilson: Doctoral Supervisors. They will contribute to supporting protocol development, application for ethical and HRA approvals, application for ethical and HRA approvals, conduct of the research, data analysis, interpretation and dissemination.

The supervision team are employed by the University of Birmingham and are independent of BCHCFT and the NIHR.

Expert advisor

Dr. Elizabeth Croot is an expert advisor employed by The University of Sheffield. She will support protocol development, conduct of the research, data analysis, interpretation and dissemination in relation to complex intervention development.

Elizabeth is independent of BCHCFT and the NIHR.

Clever Together

Clever Together are a collaborating industry partner. Their contribution is described in detail in the “roles and responsibilities of study management committees /groups & individuals” section.

Clever Together are independent of BCHCFT and the NIHR.

BCHFT (Sponsors)

BCHCFT will review and approve study documentation produced by the research team. They will not be involved in data analysis and interpretation, manuscript writing, or decision making in relation to dissemination of results. BCHCFT are responsible for data protection in relation to all aspects of the research.

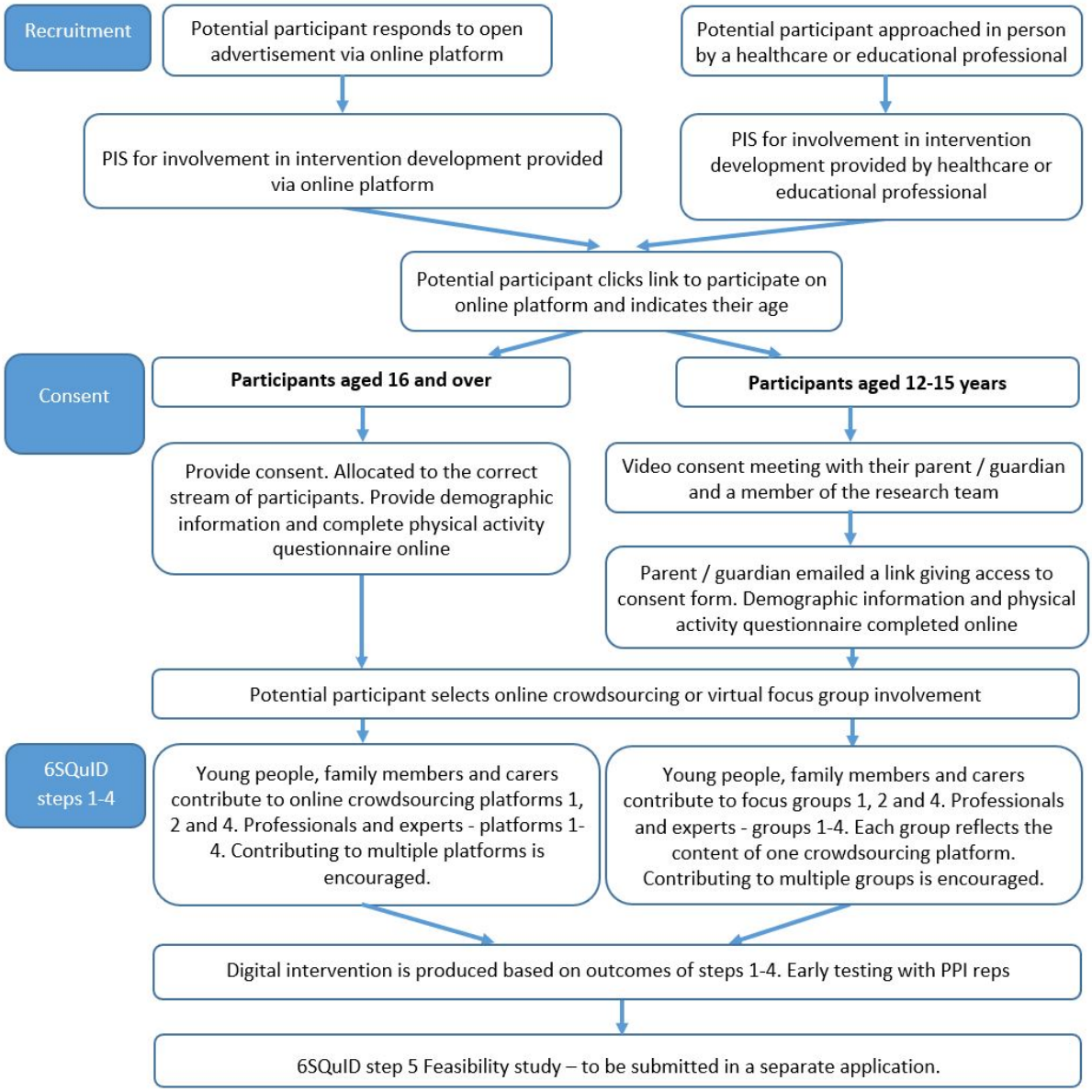
PPI representatives

West Midlands YPSG, public and patient involvement (PPI) representatives who are non-ambulant young people and parents of young people with disabilities have been involved in developing the application to undertake this research and have reviewed this protocol. Their feedback has supported the application itself and resulted in editing of the plain English summary and a change to the inclusion criteria to include a wider age range. They have assisted with developing the recruitment strategy for the crowdsourcing platforms and will be involved in it. We have discussed how participants with negative opinions could influence the rest of the group, people’s cultural backgrounds may discourage them from participating, and the point that it may be difficult to reach a consensus with a large number of participants. The crowdsourcing platforms and focus groups will be designed, facilitated and monitored with these potential difficulties in mind, to minimise the risk of them becoming

problematic. The public engagement video for the DoMore study includes a diverse group of parents and young people to encourage those from varying cultural backgrounds to participate. If there is lack of consensus in the crowdsourcing platforms, this can be discussed in the focus groups / 1:1 interviews to reach a conclusion.

KEY WORDS: Sedentary behaviour, disability, children and young people, complex intervention development, crowdsourcing, digital interventions.

Figure 1 STUDY FLOW CHART



PIS = Participant information Sheet 6SQuID = Six Steps of Quality Intervention Development

STUDY PROTOCOL

Developing an intervention to reduce sedentary behaviour in non-ambulant young people with long-term disabilities.

GLOSSARY OF ACRONYMS

BCHCFT Birmingham Community Healthcare NHS Foundation Trust

BSW Body support walker

CP Cerebral palsy

GMFCS Gross Motor Function Classification System

LPA Light physical activity

METS Metabolic equivalents

MRC Medical research council

MVPA Moderate to vigorous physical activity

NHS National Health Service

NICE National Institute for Health and Care Excellence

PIS Participant Information Sheet

PPI Public and patient involvement

REC Research Ethics Committee

R&I Research and Innovation

SDT Self determination theory

6SQuID Six steps of quality intervention development

SSC Study steering committee

SMG Study management group

YPSG Young Persons Steering Group

1 BACKGROUND

Sedentary behaviour is defined as any waking behaviour characterized by an energy expenditure ≤1.5 metabolic equivalents (METs) and a sitting or reclining posture [1]. Evidence suggests sedentary behaviour increases risk of all-cause mortality, cardio-metabolic disease and mental health problems. In children, a causal link between sedentary time and increased body mass index, reduced physical fitness, low self-esteem and reduced academic achievement has been established [2]. Importantly, these adverse health risks occur irrespective of the levels of moderate to vigorous physical activity (MVPA) engaged in [2]. Consequently, national guidelines for children recommend minimising sitting time [3]. Children with disabilities are more sedentary than their able-bodied peers [4-6]. Lower levels of gross motor function [7-9] and increasing age [10-12] lead to increased sedentary behaviours in children with disabilities. Young people who are non-ambulant (i.e do not walk or walk short distances as part of their physiotherapy programme, with support of a body support walker [BSW]) are therefore at greatest risk of experiencing negative health outcomes associated with sedentary time. These young people face barriers to undertaking MVPA [12-14], so intervening to help them reach the recommended levels [3] is challenging. A more achievable approach to increasing this population's physical activity is reducing sedentary time by displacing it with light, rather than MVPA [15, 16]. Adult studies suggest interventions promoting physical activity in general do not reduce sedentary time as effectively as interventions specifically targeting this behaviour [17, 18]. No evidence-based interventions to reduce and break up sedentary time, by encouraging light physical activity (LPA), have been developed for non-ambulant young people with long-term physical disabilities. Examples of how this can be achieved include using equipment such as BSW's or standing frames, encouraging young people to be active whilst on the floor and whilst sitting, or using active computer games [19, 20].To address this, this research will develop an intervention to resolve this unmet need, and a feasibility study will be undertaken to evaluate the intervention.

A systematic review of evidence related to sedentary behaviour in non-ambulant children (aged 0-18 years) with long-term disabilities has been undertaken, but is unpublished at present. This review will be updated to include research conducted since September 2017 and expanded to include 18-25 year olds prior to publication. No existing published reviews summarising this evidence, and very few interventional studies were identified. Therefore, both observational and interventional studies of any design and grey literature was included. Studies published before 2007, studies regarding reliability/validity of physical activity assessments, commentaries, narrative reviews and studies which didn't state the proportion of non-ambulant participants were excluded. Databases were searched using the terms sedentary, disabled children and cerebral palsy (CP). Relevant articles were critically appraised using established quality assessment tools [21, 22].

Eighteen relevant articles were identified: 12 journal articles, 1 evidence based clinical guideline, 3 theses and 2 conference abstracts. One of the journal articles and 1 thesis evaluated interventions. The remainder explored patterns of sedentary behaviour utilising quantitative, qualitative and mixed methods designs, including one systematic review, cross sectional and cohort studies. The conference abstracts and clinical guideline could not be appraised because there was insufficient information regarding methodology. The authors will be contacted to request any reports which

describe the methodology prior to publication of the systematic review. Seven articles were good quality [6, 7, 10, 12, 23-25], 4 fair quality [8, 16, 26, 27] and 4 poor quality [11, 28-30]. Poor quality articles and the systematic review [6] were excluded. The studies measuring sedentary time in the review did not include non-ambulant children.

The limited number of interventional studies provided questionable evidence of effectiveness and highlighted the need for development of new interventions.

The thesis evaluating an intervention was excluded due to poor quality. The remaining interventional study used indirect calorimetry to estimate METS. It concluded that therapeutic horseback riding raised participants out of sedentary and into LPA for 56.7% of riding time, but highlighted how the low frequency and short duration of this activity meant it was unlikely to improve cardiopulmonary fitness [27]. Delivery of this intervention in the NHS would be costly.

Verschuren et al. [16], found participants with CP (aged 4-20 years) had elevated energy expenditure (measured using indirect calorimetry) during standing that exceeded the sedentary threshold of 1.5 METs across all Gross Motor Function Classification System (GMFCS) levels, including participants using a standing frame. These findings suggest standing successfully contributed to the accumulation of LPA and interrupted periods of sedentary time in the population our intervention targets.

Shkedy et al. [8], investigated sedentary behaviour in participants with CP (13-22 years, GMFCS levels II-IV). Children in GMFCS level II walk with limitations. Those in level IV use manual or powered wheelchairs for mobility, and may use a BSW. Sedentary time (measured using the ActivPAL posture sensor) was significantly longer, and durations of standing and walking were significantly shorter for participants in higher GMFCS levels. The number of steps per day, transitions from standing to walking, and sedentary, standing, and walking events were reduced as GMFCS level increased. This study supports targeting our intervention towards non-ambulant young people.

Only qualitative data describing sedentary behaviour of adolescents with CP in GMFCS level V (who are pushed in a manual wheelchair) has been collected previously [11]. Inclusion of participants in GMFCS level V in our research would provide new information about sedentary behaviour in this group.

Luther et al. [12], interviewed parents and carers of 7-12 year olds with spina bifida. They believed children became more sedentary and gained weight approaching puberty, wheelchair use increased, walking with aids was less frequent, and motivation and physical ability to be active reduced. Parents described children’s growing resistance to physical activity, and a preference for sedentary activities parents hadn’t predicted, and healthcare workers hadn’t prepared them for. Developing an intervention to support young people and their parents with reducing sedentary behaviour would be beneficial. The crowdsourcing platform will raise awareness of this issue amongst healthcare professionals.

Five observational studies have measured sedentary time in non-ambulant children under 5 years with CP, using ActiGraph accelerometers and employing cut points validated for this population [7, 10, 24-26]. Keawutan et al., found the proportion of

participants who were sedentary for ≤ 60 minutes at a time, was significantly higher in an ambulant group of children than in the non-ambulant group [26]. Percentage of sedentary time was significantly and negatively associated with GMFCS level [26]. In a longitudinal study, children in GMFCS levels I (independently ambulant) -II had significantly lower sedentary time than those in level III (who need a hand-held device to walk) or levels IV-V [10]. Oftedal et al. [7], and Oftedal et al. [24], reported children in GMFCS levels IV-V were sedentary 74% of the time, had the largest number and longest mean duration of sedentary bouts lasting >10 minutes, and were more likely to have sedentary bouts of >60 minutes than children in other GMFCS levels and those with typical development [7]. Sedentary time significantly increased annually; the increase was larger in GMFCS levels III-V [10].

These papers showing children are more sedentary at higher GMFCS levels, support targeting our intervention towards non-ambulant young people. Oftedal and Boyd [24] recommended examining interventions to increase physical activity (of any intensity) in GMFCS levels III – V.

McPherson et al [31] carried out a retrospective medical records review of children with spina bifida (2-18 years) and found patient reported sedentary behaviour was only documented in 16.7% of records. No objective measures of sedentary time were recorded. No advice or recommendations about reducing sedentary behaviour, or appropriate levels of it was documented. Lack of awareness of this issue amongst health professionals will be reduced via participation in crowdsourcing and dissemination of results.

2 RATIONALE

Research related to improving engagement in physical activity for children with disabilities has been prioritised by the James Lind Alliance [32]. In the population targeted, a realistic method of achieving this is replacing sedentary time with LPA (>1.5 METS), and interrupting prolonged periods of sedentary time. These aims can be achieved using equipment such as BSW's or standing frames, encouraging young people to be active whilst on the floor and whilst sitting, or using active computer games [19, 20].

For those engaging in high volumes of sedentary behaviour, small increases in activity could lead to profound health gains [15, 33]. A targeted intervention is needed to interrupt sedentary time and increase LPA in non-ambulant young people.

Public and patient involvement (PPI) representatives advised an intervention utilising technology would be effective, as young people enjoy using technology. Interventions utilising computer, mobile and wearable technology have reduced sedentary time in other populations [34]. Utilising established intervention development methodology to co-create a digital intervention, in partnership with non-ambulant young people and key stakeholders, will enhance effectiveness and ensure the intervention meets their needs [35].

This research will include non-ambulant young people with a range of diagnoses, to maximise impact of the intervention, by ensuring the results are generalisable to a wide population.

Working with industry partner (Clever Together), to use crowdsourcing to undertake intervention development will contribute to the evidence base for digital health interventions and innovative research methods, achieving goals 4 and 5 of the NIHR CRN Allied Health Professionals Strategy [36], and priority 4 of the Allied Health Professionals into Action strategy [37].

3 THEORETICAL FRAMEWORK

This complex intervention development will follow the 6SQuID model [38]. This model was developed to improve effectiveness of public health interventions but has wider applicability. It draws on strengths of frameworks such as intervention mapping [39], and the MRC guidance for the development and evaluation of complex health interventions [40]. It aims to simplify intervention mapping, and assists with the early development of interventions, rather than their evaluation, making 6SQuID ideal for the scope and timescales of this research.

The first step of the 6SQuID model is to define and understand the problem and its causes. The factors influencing sedentary behaviour, including barriers to and facilitators of undertaking LPA will be identified in the first crowdsourcing platform. These factors will be classified according to the COM-B model [41] (Figure 2) and the Systems of Sedentary Behaviour Framework [42], which captures a system-based map of determinants of sedentary behaviour, grouped into 6 clusters: Physical Health and Wellbeing, Psychology and Behaviour, Built and Natural Environment, Social and Cultural Context, Institutional Settings and Politics and Economics) (Figure 3). Using the word “sedentary” will be avoided in the crowdsourcing and focus group / 1:1 interview questions, as there is potential for it to be interpreted in many differing ways by the differing groups of participants. Language such as moving more or less during daily routines will be used to avoid this issue.
In step two (identifying which causal or contextual factors are malleable and have greatest scope for change), the category / cluster in which the modifiable factors sit within the COM-B and Systems of Sedentary Behaviour Framework will be considered. Targeting factors in multiple levels within the intervention would increase its potential for effectiveness [43].
Step three (identifying how to bring about change: the change mechanism) involves formulating the theoretical basis for the intervention. A range of theories, will be discussed to identify which are most relevant, compatible and appropriate to use as a basis for this intervention. The selected theories/theory will be used to identify the theoretical determinants and processes to be targeted by the intervention. Models such as the behaviour change wheel [41] and the taxonomy of behaviour change techniques [47] will be used to identify the strategies that will be used to target these determinants, maximising the impact the intervention has on reducing sedentary time. Reference will also be made to the NICE behaviour change guidance [48].

The fourth step involves identifying how to deliver the change mechanisms and should be informed by the underlying theories and models described above.

The fifth step is the feasibility study that will be undertaken to test the intervention. This study will be submitted in a separate application. Step 6 will also be described in this separate application.

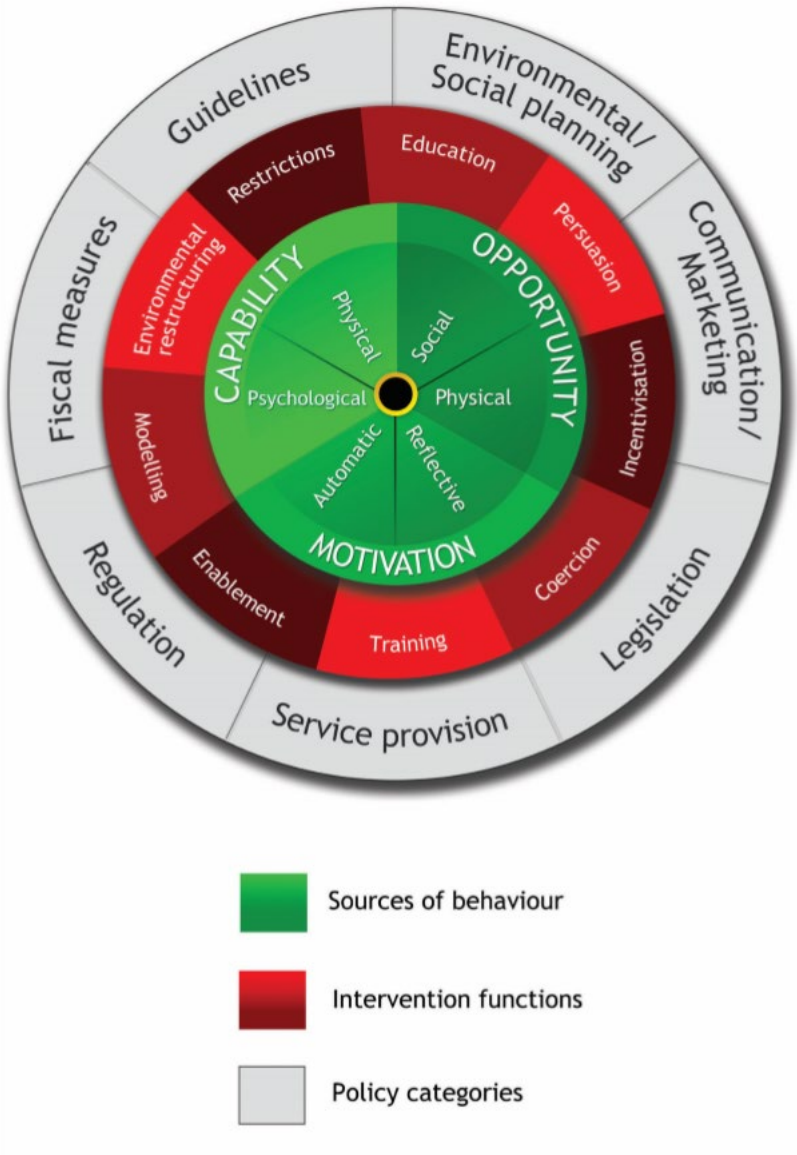


Figure 2. The Behaviour Change Wheel. Michie, van Stralen [41]. Reproduced without amendment under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/2.0).

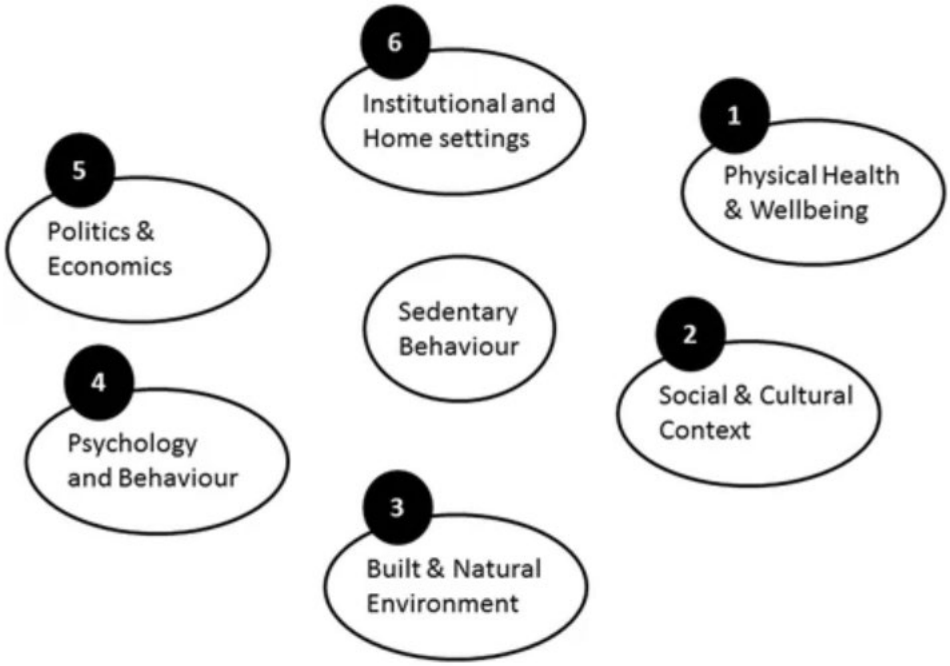


Figure 3 The SOS-Framework (Systems of Sedentary Behaviours) Chastin, De Craemer [42]

4 RESEARCH OBJECTIVES

4.1 Objectives

1. To co-create a digitally-enabled health intervention, in partnership with young people who are non-ambulant and key stakeholders, to reduce and break up sedentary behaviour by promoting LPA.

4.2 Outcome

Intervention development

Production of a digitally-enabled intervention to reduce and break up sedentary behaviour by promoting LPA.

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

STUDY DESIGN:

This research protocol describes a complex intervention development following the 6SQuID model.

Steps 1-4 involve co-designing a digital intervention via an online crowdsourcing platform, virtual focus groups and 1:1 interviews. Focus groups and 1:1 interviews will follow a topic guide similar to that used in the crowdsourcing platform. Once these discussions have ended, any data collected via the crowdsourcing platforms will be summarised for the focus group / 1:1 interview participants, and they will have an opportunity to discuss whether their conversations reflected the crowdsourcing results, or if not, where they differed, and why that might be.

Step 5 includes a single armed, mixed methods feasibility study. This study will be descried in a separate application to the Health Research Authority with its own protocol.

Step 6 evaluates whether optimisation and more rigorous evaluation is justified based on the findings of the feasibility study carried out in step 5. This step will be described within the analysis section of the feasibility study protocol.

STEPS 1-4 of 6SQuID VIA CROWDSOURCING:

Involvement of key stakeholders is integral to co-developing an intervention and increasing likelihood of effectiveness (15). Five groups of key stakeholders have been identified in this research and will be invited to join the “crowd”. They are:

Children and young people aged 12-25 years, who are unable to walk due to a lifelong disability and live in the United Kingdom (UK)
Family members or carers (aged 16 and above) of children and young people who are unable to walk due to a lifelong disability and live in the UK
Education and healthcare professionals who work with these children and young people and live in the UK
Experts in sedentary behaviour, paediatric disability, behaviour change, and/or digital health interventions (Worldwide)
Other interested members of the public (aged 16 and above) who live in the UK

Engaging these individuals, and arranging meetings in an environment where they can
contribute freely is challenging. They will have varying physical, communication and learning abilities,
experience barriers to travelling, be spread over a wide geographical area and/or have limited spare time. To overcome these challenges, crowdsourcing, an innovative method of data collection, will be utilised to facilitate intervention development.

Crowdsourcing involves inviting a defined group of volunteers “the crowd”, via an open advertisement, to undertake a task with a clear goal via a participative online process [49]. Members of the crowd log in to one or more of the 4 online platforms. It is hoped as many participants as possible will begin at step 1 and continue to contribute to all the steps they are eligible for as the intervention development progresses. As all contributors are assigned a Unique Identifying Number (UIN) it will be possible to identify dropout rates, and contributors who join for the first time in platforms 2-4. On the platform, members of the crowd respond anonymously to a list

of specific questions posed by the researchers. They can choose which questions they respond to. It is not compulsory to respond to every question. The crowd can read the responses of others and comment on them, they can also like or dislike responses and comments from other members of the crowd. These features of crowdsourcing create an interactive dialogue between the contributors.

Participants who are unable to type can contribute using voice recognition software, or with support from friends, family members or carers who can type on their behalf. Alternatively, they can select to attend a virtual focus group instead of contributing via crowdsourcing. Where a participant's ability to attend a focus group is limited, 1:1 interviews may also be offered. These groups will be conducted via videoconferencing to avoid unnecessary face to face contacts during the COVID-19 pandemic. Regardless of which step in the 6SQuID they first contribute to, members of the crowd will be encouraged to remain engaged with the intervention development process throughout the remaining steps via the participant information sheets, the study website and email reminders sent to previous contributors via Clever Together. Engaging individuals who wish to follow the journey of the intervention development, allowing them to develop a deeper understanding of it, is likely to provide richer qualitative data. The size of the crowd is unlimited. Utilising this method to engage young people in research has been advocated [50] and the "AHPs into action" document [37] demonstrates clinician engagement. Clever Together's crowdsourcing platform will be used. Clever Together are NHS digital partners and have had involvement in many successful healthcare related projects. For details relating to recruitment of the crowd and consent see section 7.3 and 7.4.

CROWDSOURCING PLATFORMS

The demographic information provided by online participants will allow them to be added to the correct platform. There will be separate platforms for some of the groups of key stake holders outlined above (see Table1). There will not be a mixed platform where all of these groups of stakeholders interact with each other. The young peoples group will be divided by age into 12-15 year olds and 16-25 year olds to safeguard contributors who are under 16. The 5th group of key stakeholders (Other interested members of the public [aged 16 and above]) has been included to reduce the likelihood of participants answering the demographic questions incorrectly in order to be able to participate. Those in group 5 will be asked to describe the reason for their interest in this topic.

A new platform will open and close for each of the first 4 steps of the 6SQuID. Young people and family members/carers will not participate in step 3, as some prior knowledge of relevant theories and models is needed, and the YPSG fed back that young people were more likely to remain engaged throughout the process if there were fewer steps to contribute to. There will therefore be 13 live platforms in total (see Table 1 below for platform codes). Each platform will remain open until sufficient data has been collected to continue to the next step of the co-design. The previous platform will close when a new platform opens. The final platform will close when there is adequate representation from each participant group. If this proves to be unachievable in an appropriate timescale data collection may need to close in order

to complete the co-design. Platforms will be hosted in English language only. Data from each step will be analysed prior to the opening of the subsequent step.

6SQuID step	**Key Stakeholder Group**			
	Young people aged 12-16	Young people aged 17-25	Family members and carers	Health and education professionals, Experts and other interested parties (including adults aged 26 and over with disabilities).
1	1_YP12-16	1_YP17-25	1_F+C	1_PExO
2	2_YP12-16	2_YP17-25	2_F+C	2_PExO
3				3_PExO
4	4_YP12-16	4_YP17-25	4_F+C	4_PExO

Table 1

The content of steps 1-4 is described briefly below. The exact questions to be posed on the platforms will be developed in partnership with PPI representatives and the study management group (SMG) (see SSC terms of reference for membership of the SMG).

(1) Defining and understanding the problem and its causes

The literature review summarised above will be updated and expanded to include those aged 18-25. The "crowd" will contribute their views via the online platform about:

- the extent to which the target population are sedentary,
- positive or negative experiences related to these sedentary behaviours,
- positive and negative factors influencing sedentary behaviour and
- barriers and facilitators to undertaking LPA and interrupting sedentary periods.

(2) Identifying which causal or contextual factors are malleable and have greatest scope for change

Present to the "crowd" the facilitators and barriers to reducing sedentary time. Select which modifiable factors to target with them by requesting comments and opinions on which are modifiable, and using the number of like/dislike ratings allocated to each factor to prioritise them. The category / cluster in which the modifiable factors sit within the COM-B [41] and Systems of Sedentary Behaviour Framework [42] and any evidence base for changing these modifiable factors will be considered.

(3) Identify how to bring about change: the change mechanism

Formulate the theoretical basis for the intervention in partnership with the professionals and experts and other interested parties' streams. The young people and family members/carers groups have been excluded from this step, as the PPI group felt reducing the number of platforms the crowdsourcing participants needed to contribute to would increase the likelihood of them remaining engaged with it until the end of the process. The requirement for some prior knowledge of the theories and models involved in this step made it the most logical to remove.

A range of theories will be discussed to identify which are most relevant, compatible and appropriate to use as a basis for this intervention. The selected theories/theory will be used to identify the theoretical determinants and processes to be targeted by the intervention. Models such as the behaviour change wheel [41] and the taxonomy of behaviour change techniques [47] will be used to identify the strategies that will be used to target these determinants and processes, maximising the impact the intervention has on reducing sedentary time. Reference will also be made to the NICE behaviour change guidance [48].

Appropriate behaviour change techniques will be selected from the taxonomy [47] to address the modifiable factors chosen in step 2. Ideas for practical application of the selected behaviour change techniques will be generated. The strategies that will be used to achieve a reduction in sedentary time and the evidence base behind them will be identified.

(4) Identify how to deliver the change mechanisms

Determine methods of delivering the intervention strategies with the "crowd" by designing programme materials and resources with input from PPI representatives and reviewing them with the "crowd". The crowd will be involved in reviewing all programme materials and resources related to the intervention, which may or may not be delivered via a digital format.

The data analysis techniques chosen for each step will be dependent upon the volume of data collected. As data is already in a digital text format, transcription will not be required.
All contributions made to the crowdsourcing platforms are anonymous, however care will be taken to ensure there is no potential for indirect identification via comments made on the crowdsourcing platform, (especially if there are a small number of contributors), and that quotes published in dissemination of the results do not allow the contributor to be identified by their context or content. Administrators will remove any content posted by participants which directly identifies them within a maximum of 24 hours. Incidences of risk of indirect identification will be identified and assessed by the research team within 24 hours, and be removed if required.

STEPS 1-4 of 6SQuID VIA VIRTUAL FOCUS GROUPS / 1:1 INTERVIEWS

All participants will be invited to choose whether they participate in a virtual focus group, or participate in the crowdsourcing online, regardless of how they were

recruited. They will not be able to take part in the online platform and a virtual focus group or 1:1 interview. If participants who wish to participate via a focus group have limited availability and cannot be accommodated in a group, they will be offered a 1:1 interview, or asked if they would like to participate via the crowdsourcing workshop as an alternative. This will ensure they still have the opportunity to participate. It is not possible to complete these focus groups / 1:1 interviews face to face as originally planned due to the current COVID 19 pandemic.

The purpose of the virtual focus groups /1:1 interviews is to provide an additional source of rich data that can be used to triangulate the crowdsourcing data, because it is collected via an alternative method. Crowdsourcing is relatively new data collection method in the field of clinical research. Apart from the 12-15 year olds (who have a consent meeting via video conference prior to participating),there is no way of ensuring that those who participate in the crowdsourcing are being truthful about their identity. The inclusion of the virtual focus groups / 1:1interviews not only provides additional data, collected via an alternative method, it also contributes to verification of data collected via crowdsourcing, using a more conventional methodology.

It is not feasible within the scope of this project to carry out focus groups to align with each of the crowdsourcing platforms shown in Table 1. For steps 1,2 and 4 of the 6 SQuID, there will be separate groups or 1:1 interviews for children aged 12-15. This is because existing literature relating to conducting focus groups with children recommends participants are from within a narrow age range [51, 52]. All other participants over 16 will be in mixed groups with representation from a mixture of non-ambulant young people aged 16-25, family member, professionals, experts and other interested members of the public or will be interviewed. ,. For step 3, focus group / 1:1 interview attendance will be limited to the professionals, experts and others group, as it is in the crowdsourcing. Sufficient groups will be arranged to allow all participants who select to contribute via a focus group or 1:1 interview to do so where feasible, with a maximum of 10 participants in each group.

The questions asked on the crowdsourcing platform will be used as a topic guide for the focus groups and 1:1 interviews. The virtual groups / 1:1 interviews will be led by the CI. They will be recorded and transcribed verbatim. For focus groups, a second facilitator will be present to make field notes and assist with smooth running of the group. Groups will be conducted in English language only. Methods used for analysis will be dependent upon the volume of data collection.

STEP 5 of 6SQuID – FEASIBILITY STUDY

> As the precise nature of the digital intervention is yet to be decided, this study will be submitted to the HRA as a separate application

6 STUDY SETTING

CROWDSOURCING

Undertaking crowdsourcing online helps to overcome the challenges of varying physical, communication and learning abilities, barriers to travel, accessibility of environments and limited time, facilitating inclusion of a more diverse group of participants. A data protection impact assessment has been undertaken to ensure this online environment is secure and data is handled according to GDPR regulations. The impact assessment is included in the supporting documentation.

Members of the crowd (participants) will visit the study website after seeing the open advertisement. Participants will give consent digitally. The processes for this are described below in section 7.4. Participants will create a log in to participate in one or more of the 4 online platforms (one for each step of the 6SQuID). Basic demographic information will be provided by participants including: name, age, email address, participant group, high level location (first 3 characters of postcode or town/country if outside the UK), gender, ethnicity, employment status and diagnosis if they have a disability. Based on this information they will be added to the correct platform. The 5th group of participants (other interested members of the public [aged 16 and above]) will be asked to describe the reason for their interest in this topic.

It is hoped as many participants as possible will begin at step 1 and continue to contribute to all the steps they are eligible for as the intervention development progresses. On the platform members of the crowd complete a physical activity questionnaire, then comment anonymously on a list of specific topics posed by the researchers. They can choose which topics they respond to. It is not compulsory to respond to every topic. The crowd can read the responses of others and comment on them, they can also like or dislike responses and comments from other members of the crowd. These features of crowdsourcing create an interactive dialogue between the contributors, as it is possible to log into the platform multiple times, and to have simultaneous discussions if other members of the crowd are logged in at the same time as you.

Regardless of which step in the 6SQuID they first contribute to, members of the crowd will be encouraged to remain engaged with the intervention development process throughout the remaining steps.

Crowdsourcing allows collection of data inclusively, globally, quickly and efficiently, removing the need for transcription prior to analysis. The anonymity it provides reduces the potential for power imbalances between researchers and participants to bias the data collected.

FOCUS GROUPS

All participants will be offered the opportunity to participate in a virtual focus group 1:1 or interview (if they do not have availability to attend a group). Participant's needs in relation to communication will need to be established, so appropriate support can be provided

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

7.1.1 Inclusion criteria

CROWDSOURCING AND FOCUS GROUPS / 1:1 INTERVIEWS

1. Children and young people aged 12-25 years, who are unable to walk due to a lifelong disability and live in the UK

   or

2. Family members or carers (aged 16 and above) of children and young people who are unable to walk due to a lifelong disability and live in the UK

   or

3. Education and healthcare professionals who work with these children and young people and live in the UK
   or

4. Experts in sedentary behaviour, paediatric disability, behaviour change, or digital health interventions (Worldwide)

   or

5. Other interested members of the public (aged 16 and above) who live in the UK

   and

   1. Participants can communicate using English language online or in a focus group
   2. Participants can sufficiently understand and communicate their assent or consent and answer the questions asked.

The 12-25 years age range was chosen to include those entering puberty and experiencing transition into adulthood, who are more likely to be sedentary than younger children (12).

7.1.2 Exclusion criteria

CROWDSOURCING AND FOCUS GROUPS / 1:1 INTERVIEWS

Children and young people who are under 16 and do not have a lifelong disability that prevents them from walking are unfortunately unable to participate.
Children and young people, family members, education and healthcare professionals and other interested members of the public (aged 16 and above) who live outside of the UK are also unable to participate.

7.2 Sampling

7.2.1 Size of sample

CROWDSOURCING
There is no minimum or maximum sample size.

VIRTUAL FOCUS GROUP

A minimum of 2 and maximum of 10 participants will be invited to each focus group. This small minimum number reflects that participants are being engaged as experts in this topic area. If only one participant attends, data collection will continue as a 1:1 interview. It is inappropriate to cancel groups when participants have made commitment to attending.

7.2.2 Sampling technique

CROWDSOURCING

Anyone who responds to the open advertisement or is approached face to face by a professional and lives in the UK can participate, to allow a broad and inclusive exploration of the topic. Members of the experts group (point 4 of the inclusion criteria), can be recruited from outside the UK. Ideally the samples will be as diverse as possible, including young people with a wide range of diagnoses, health professionals from differing disciplines and participants a wide range of ethnicities, cultures and socioeconomic backgrounds.

VIRTUAL FOCUS GROUPS

Purposive sampling will be employed to ensure as many of the 5 groups of key stake holders are included as possible and that there is diversity amongst the group, as described for the crowdsourcing exercise above.

7.3 Recruitment

A variety of adverts and a video have been designed that are appropriate to all of the key stakeholder groups, with input from PPI representatives. The research team and YPSG/ PPI representatives will attend relevant events where possible to promote the opening of the study.

The West Midlands Clinical Research Network YPSG, and other PPI representatives who have lived experiences that are relevant to the intervention being developed will assist with advertising the study.

The advertisements will be disseminated via social media, posters in public buildings and at conferences, emails to existing networks and be disseminated via organisations and professionals who work with young people with disabilities such as charities and professional bodies.

Staff at BCHCFT and local schools will also distribute advertisements and discuss the research with service users in their appointments, providing the CI's contact details or gaining consent for the CI to contact them.

The video will be disseminated via digital methods only.

Dissemination of the adverts and video will be targeted to UK audiences for all but the experts group.

When participants consent they will be asked to verify that they live in the UK.

The same recruitment procedures will be used to recruit to the crowdsourcing and virtual focus groups / 1:1 interviews. Individuals will be invited to visit the study website. On the home page there will be links to all PISs. After giving consent, providing demographic information and completing the physical activity questionnaire (this process is described below) there will be an option to participate in a virtual focus group or via crowdsourcing. Those who choose to attend a virtual focus group will provide contact details and the CI will get in touch with them to explain what's involved. £10 payments will be offered to virtual focus group / 1:1 interview participants only to thank them for their contributions.

7.4 Consent

Informed consent will be obtained before any research activities commence.

The advertisements and promotional activities described above will invite individuals to visit the website for this research project on the Clever Together platform. On the home page there will be links to all PISs and a link for those who wish to participate to follow. Four PISs have been produced: one for young people aged 12- 15, a second for young people aged 16 -25, a third for parents/carers and a fourth for professionals, experts and other interested parties. PISs will be downloadable. When a potential participants click the link to say they wish to participate, they will select from the following options.

I am a:

- **Young person aged 12-15** and I am unable to walk, or I use a walker similar to those pictured below.
- **Young person aged 16-25** and I am unable to walk, or I use a walker similar to those pictured below.
- **Family member** of a child/young person of any age, who is unable to walk, or uses a walker similar to those pictured below.
- **Professional** who works with children/young people who are unable to walk or use walkers similar to those pictured below.
- **Expert** in childhood disability, physical activity, sedentary behaviour, digital health, complex intervention development, behaviour change.
- **Adult aged 26 or more with disabilities** who is unable to walk, or uses a walker similar to those pictured below.
- **Interested member of the public** who would like to participate.

Family members, professionals, experts, and interested members of the public will be asked to confirm that they are aged 16 or above.

All participants apart from the experts will be asked to confirm that they live in the UK.

For participants aged 12-15 years, a consent meeting with the participant and their parent / guardian will be arranged with a member of the study team via video conferencing. They will provide their contact details via the study website for this to be arranged. This will be shared with the CI via an encrypted email. The parent / guardian will be emailed a link following this meeting that allows them to provide their digital consent and then the 12-15 year old can assent. Only once this has been completed will the young person be able to access the gateway questionnaire and the crowdsourcing platform.
Everyone 16 years and over will be directed immediately to the digital consent form once they have indicated that they wish to participate, and they will not need an individual link to access this.

Online consent will follow best practice guidelines [62]. All participants will provide consent digitally via the same platform, and will need to click to agree that they accept the ground rules (see appendix 2) prior to entering a crowdsourcing platform or virtual focus group.

Parents/guardians who consent to participate will have the option to enter the email address of young people they care for to invite them to participate also if they wish to. If this is done, an invite to participate will be emailed to the young person containing

a link to the study website, and if they are aged 12-15 a video consent meeting will be arranged as described above..

A copy of the completed consent form will be emailed to the parent and / or participant.

The date and time at which consent was provided will be recorded.

VIRTUAL FOCUS GROUPS / 1:1 INTERVIEWS

The consent procedure is the same as that described above for the crowdsourcing. Only after consent has been provided and the demographic information and physical activity questionnaire has been completed will participants be offered the option of joining a virtual focus group instead of participating in the crowdsourcing. If they are unable to attend a group, an interview will be offered.

8 ETHICAL AND REGULATORY CONSIDERATIONS

8.1 Assessment and management of risk

Risks associated with trial interventions ☐ A ≡ Comparable to the risk of standard medical care ☒ B ≡ Somewhat higher than the risk of standard medical care ☐ C ≡ Markedly higher than the risk of standard medical care				
Justification: Young people with disabilities are a vulnerable population. Their risk of experiencing physical and emotional abuse is elevated in comparison to children and young people without disabilities. Openly advertising an online platform including young people with disabilities creates a risk of this platform being targeted to communicate with them with the intention of causing harm.				
What are the key risks related to therapeutic intervention you plan to monitor in this trial?		How will these risks be minimised?		
Intervention/ Activity	Hazard	Activity	Frequency	Comments
Participation in Crowdsourcing platforms and focus groups / 1:1 interviews	Participants providing false information to join the platforms with the intention of causing harm/distress to other participants.	Video consent meeting with parent / guardian to verify identity of 12-15 year old participants. Clear ground rules for participating outlined after consent is given. Participants check a box to agree to the ground rules prior to entering the platform / virtual focus group. (see appendix 2) Close monitoring and moderation of platform content by the CI, following Clever Together's	On-going throughout data collection via crowdsourcing	Young people with disabilities are a vulnerable population in relation to safeguarding, however the consent and monitoring systems described and previous safely conducted examples of crowdsourc

		policies and procedures. Reporting of abusive content system that all users can access. Anything flagged by another user because it is inappropriate, or due to potential for the contributor to be identified will be removed immediately and automatically for review by the research team. A list of key words will be written and entries including those words will be removed automatically and immediately for review by the research team.		ing with young people result in likeliness of harm being low.
	Participants becoming upset, distressed or offended by content of discussions	Inclusion of a link to signpost participants to voluntary support organisations on study website. Clear ground rules for participating outlined after consent is given. Participants check a box to agree to the ground rules prior to entering the platform. Ground rules discussed at beginning of focus groups. (See appendix 2)	On-going throughout data collection via crowdsourcing and virtual focus groups	Low risk – not an emotive subject area to explore.

		Reporting of abusive content system that all users can access. Second facilitator available in focus groups to be able to leave the conversation to support participants over the telephone / in a second online meeting and offer support and signposting to other services if required. Questions for the first platform have been reviewed by a group of 7 adults with disabilities who did not have any concerns about their content.		
	Participants identifying themselves on the online platform, directly or indirectly	No identifiable information shared on the platform. Close monitoring and administration of platform content Other users can flag if a participant is potentially identifiable Prompt removal of any identifying information.	On-going throughout data collection via crowdsourcing and virtual focus groups	
Outline any other processes that have been put in place to mitigate risks to participant safety (e.g. DMC, independent data review, etc.) Safeguarding: The PIS will state that any disclosure that raises concerns in relation to the safety and wellbeing of participants or criminal activity will be				

shared with relevant services. Any concerns will be managed in line with BCHCFTs Safeguarding Children and Safeguarding vulnerable Adults policies.
Outline any processes that have been simplified based on the risk adapted approach.

Adverse events will be defined as; any untoward medical occurrence, unintended distress, disease or injury or any untoward clinical signs whether or not considered to be causally related to the intervention.

Serious adverse events will be defined as an adverse event that:

○ Led to death

○ Led to a serious deterioration in the health of the participant that either:

○ Resulted in a life-threatening* illness or injury

○ Resulted in a permanent impairment of a body structure or a body function

○ Required in-patient hospitalization or prolongation of existing hospitalization**

○ Resulted in medical or surgical intervention to prevent life threatening illness or injury, or permanent impairment to a body structure or a body function

○ Other important medical events***

* the term life threatening here refers to an event in which the patient is at risk of death at the time of the event; it does not refer to an event that might hypothetically cause death if it was more severe (eg a silent myocardial infarction)

** Hospitalisation is defined as an in-patient admission, regardless of length of stay, even if the hospitalisation is a precautionary measure for continued observation. Hospitalisation for pre-existing conditions (including elective procedures that have not worsened) do not constitute an SAE

*** Medical judgement should be exercised in deciding whether an AE is serious in other situations. Important AEs that may not be immediately life threatening or result in death or hospitalisation, but may seriously jeopardise the participant by requiring intervention to prevent other undesirable outcomes.

A detailed digital record of any adverse events or serious adverse events which occur as a result of this study will be made according to guidelines for adverse event reporting. A serious adverse events report form will be used for serious events. This will be saved on the BCHCFT's study folder on the common drive. The date, time, nature and people involved in any adverse events will be logged on a table to identify any recurring issues.

The study will stop if:

There is one incident of a serious advert adverse event - it may resume if appropriate once the event has been fully investigated if the study steering committee consider it to be safe to do so.

There are 3 or more similar adverse events. The Study steering committee would meet to discuss the events in this case and decide on the actions to be taken.

8.2 Research Ethics Committee (REC) and other Regulatory review & reports

Before the research commences, a favourable opinion will be sought from an NHS Research Ethics Committee for the study protocol, informed consent processes and other relevant documents e.g. advertisements.

Any substantial amendments that require review by NHS REC will not be implemented until that review is in place and other mechanisms are in place to implement the amendments at each site.

An annual progress report will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended.

The Chief Investigator will notify the REC of the end of the study.

If the study ends prematurely, the Chief Investigator will notify the REC, including the reasons for the premature termination.

Within one year after the end of the study, the Chief Investigator will submit a final report with the results, including any publications/abstracts, to the REC.

Regulatory Review & Compliance

Before any site can enrol patients into the study, the CI/PI will ensure that appropriate approvals from participating organisations are in place and comply with the relevant guidance.

For any amendment to the study, the CI or designee, in agreement with the sponsor will submit information to the appropriate REC in order for them to issue approval for the amendment. The CI or designee will work with sites (R&D departments at NHS sites as well as the study delivery team) so they can put the necessary arrangements in place to implement the amendment to confirm their support for the study as amended.

Amendments

If the sponsor or CI wish to make an amendment to the REC application or the supporting documents, they willuse the amendment tool to determine what action is required to make the amendment. The sponsor will decide whether any amendments are substantial or non-substantial for the purposes of submission to the REC.

If applicable, other specialist review bodies will be notified about substantial amendments in case the amendment affects their opinion of the study.

Amendments will be notified to the HRA where the lead NHS R&D office is based (England) and communicated to the participating organisations (R&D office and local research team) and departments of participating sites to assess whether the amendment affects the NHS permission for that site.

Substantive changes will be communicated to relevant stakeholders (e.g., REC, R&D, regulatory agencies) via email.

Version control in the sponsors R&I folders on the common drive will ensure the amendment history is tracked to identify the most recent protocol version.

8.3 Peer review

The proposed methods were reviewed extensively as part of a competitive NIHR Fellowship application. This protocol has been peer reviewed by members of the SSC, as outlined in the SSC terms of reference document and an expert fellowship collaborator who is not involved or named in this protocol, holds a highly regarded academic posts in paediatric disability and has considerable clinical/research experience.

8.4 Patient & Public Involvement

Patient & Public Involvement (PPI)

Members of the West Midlands YPSG, four public and patient involvement (PPI) representatives who are non-ambulant young people and two parents of young people with disabilities have been involved in developing the application to undertake this research. The YPSG and PPI representatives with lived experience of long-term disability have reviewed this protocol. Hannah Dines, a Paralympian, understands the study and its aims, and is acting as a champion for it. Adults with disabilities at the Cerebral Palsy Midlands day centre helped to develop the adverts for the study and been involved in piloting the questions for the first workshop. Three young adults with disabilities at an educational facility for 19-25 year olds have also piloted the workshop 1 questions. A lay member sits on the SSC.

The PPI representatives have been involved in developing the PISs and adverts for the crowdsourcing platforms, have contributed to production of the website, and have been involved in piloting the platform 1 questions. They will assist with disseminating the adverts via relevant networks they are members of, opportunities in their local communities and face to face activities. They will assist with the patient facing elements of the software, carrying out early testing prior to the feasibility study commencing. Some of the PPI representatives offered to be involved with analysis of data and writing and reviewing dissemination materials such as journal articles and reports, presentations and posters, and this will be arranged.

PPI representatives will have an opportunity to produce a short video to disseminate the findings of the feasibility study and contribute to presenting the findings at conferences.

The population of Birmingham is very diverse. Ensuring this diversity is reflected in research carried out in this area is challenging due to cultural differences and language barriers. Encouraging more people and groups often overlooked or ignored by mainstream society to become involved in research as PPI representatives or participants is important. Funding has been allocated for working alongside

Birmingham Community Healthcare NHS Foundation Trust's dedicated Equality, Diversity and Human Rights Manager, to reach out to local communities to improve understanding of and trust in health research.

8.5 Protocol compliance

Any accidental protocol deviations will be documented on the relevant forms and

reported to the Chief Investigator and Sponsor immediately.

Deviations from the protocol which are found to frequently recur are not acceptable, and immediate action will be taken to prevent any further incidences. An emergency meeting of the TSC may be required if this situation arises.

8.6 Data protection and patient confidentiality

All investigators and study site staff must comply with the requirements of the Data Protection Act 2018 with regards to the collection, storage, processing and disclosure of personal information and will uphold the Act's core principles. A data protection impact assessment (DPIA) is being undertaken to ensure the intervention development section of the study (steps 1-4) is compliant with GDPR, and is included in the supporting documents.

CROWDSOURCING

All contributions made to the crowdsourcing platforms are anonymous, and participants will be able to flag entries that include identifiable information. These entries will be removed until the researcher can review them. Care will be taken to ensure quotes used in dissemination of the results do not allow the contributor to be identified by their context or content. Administrators will remove any content posted by participants which directly identifies them within a maximum of 24 hours if it is not flagged by another user. Incidences of risk of indirect identification will be identified and assessed by the research team within 24 hours, and removed if required.

Minimal personal information will necessarily be collected online by Clever Together. All identifiable data will be stored and transferred in accordance with Clever Together's Information Security Policy, BCHCFT's Information Governance Policy and the data processing agreement between Clever Together and BCHCFT (see the supporting documentation for the study). Identifiable data will only be accessed by BCHC R&I team and individuals employed by or on the behalf of Clever Together. Each participant will be allocated a UIN when they consent to participate. Whilst the crowdsourcing platforms are underway, Clever Together will collate and store the linking code, in accordance with their Information Security Policy. Members of the research team who are undertaking data analysis should not require access to identifiable information or the linking code. In the case of an adverse event/protocol

deviation/complaint there is a facility that allows the researcher to contact the participant without their identity being shared with the researcher. If this is insufficient to resolve the issue, Clever Together can directly contact the participant. Clever Together only store identifiable information for 14 days once a project is completed or terminated, so personal identifiable information re: participants will be transferred to the sponsor at BCHCFT for archiving when the crowdsourcing platforms have closed, as research consent forms need to be stored for 5 years. Anonymised data may be stored on lap tops which require a password/biometric identification to access or at the University of Birmingham. Personal devices held by University of Birmingham staff will be encrypted. Identifiable and anonymised data will be archived by BCHCFT for a maximum of 5 years.

VIRTUAL FOCUS GROUPS / 1:1 INTERVIEWS
Identifiable data will be stored and transferred in accordance with BCHCFT's Information Governance Policy and the DPIA. Identifiable data (contact details, consent form), the UIN and responses to the demographic and physical activity questionnaires will be transferred to BCHCFT from Clever Together via encrypted email / file sharing. The latter will only include the UIN, not any identifiable data. Contact details and documents linking contact details to the UIN will only be accessed by the CI and members of BCHCFT's Research and Innovation (R&I) team. The linking code will be saved in the R&I folders on BCHC's intranet. Access will be limited to two sponsor representatives. Participants will be encouraged to use and display first names only during the focus groups, which will be recorded. Initials will be used on transcripts. Anonymised data may be stored on personal devices which require a password/biometric identification to access or at the University of Birmingham, to allow access to analysis software. Personal devices held by University of Birmingham staff will be encrypted. Identifiable and anonymised data will be archived by BCHCFT for a maximum of 5 years.

Auditors may require access to any of the data collected in line with study. BCHCFT's Caldicott guardian is medical director Dr. Doug Simkiss.

8.7 Indemnity

The sites included in this study will be covered by the NHS indemnity scheme to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research, design of the research and conduct of the research.

The collaborators from outside the NHS will be responsible for their own indemnity insurance arrangements. This will be specified in the collaboration agreement with BCHCFT

8.8 Access to the final study dataset

The CI and members of the SSC will have access to the full anonymous data set. Data collected by BCHCFT will not be shared with any other parties prior to

publication. It is included in the consent forms and PISs that anonymised data may be used for secondary analysis.

9 DISSEMINIATION POLICY

Dissemination policy

The sponsors (BCHCFT) own the data arising from the study. On completion of the study, the data will be analysed and tabulated and a final study report will be prepared to share with the REC and funders (NIHR). Sections of this report will be published on the NIHR website, and the full report may be accessible via the NIHR on request.

A final report will be submitted to the REC within 12 months of the study ending, and to the NIHR by 02/12/2022. Funding for open access publication will need to be utilised by 31/03/2023 to avoid funds held by BCHCFT Research and Innovation team needing to be carried over into a new financial year. The study participants and PPI representatives will be informed of the findings via the study website. Some PPI representatives and participants may be involved in producing a video and/or attending conferences to disseminate the findings.

Following the main publication of study findings, participating investigators can request permission from the SSC to publish further papers.

Participants will receive feedback about their progress throughout the intervention. They will not be able to specifically request personal data once the study has closed.

9.2 Authorship eligibility guidelines and any intended use of professional writers

Authorship eligibility will follow the International Committee of Medical Journal Editors authorship criteria for manuscripts submitted for publication [64]. Professional writers will not be used.

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11. APPENDICIES

11.1 Appendix 1- Required documentation

CVs of the research team,

Advertisements – 4 versions as for PIS

Patient Information Sheets for intervention development– 4 versions:. young people aged 12- 15, young people aged 16 -25, parents/carers, professionals, experts and other interested parties

Consent/assent forms for intervention development – 6 versions (3 e-consent, 3 face to face)

Data Processing Agreement between BCHCFT and Clever Together

Data Protection Impact Assessment for intervention development– in preparation to include amendments

IRAS form

Clever Together's information Security Policy

Serious Adverse events report form

11.3 Appendix 2 Ground rules for crowdsourcing workshops and focus groups

When sharing your views in the crowdsourcing workshops or at our focus groups, we ask you to abide by these guidelines:

Be considerate - Your input will be read/heard by other people, who will reflect on it. You in turn will reflect on the input of others. Any choice we make will affect other participants, we should therefore consider them when doing so.

Be respectful - Disagreement is no excuse for poor manners. Assume good intentions, do your best to act in an empathic fashion, work together to resolve any conflict. A community where people feel uncomfortable or threatened is not productive.

Do not write names or content that could allow you to be identified in the online workshop. Avoid discussions that could allow you to be identified in the focus groups. If you feel someone has written something online that would allow them to be identified, or if you read anything you feel is offensive or inappropriate, please put a red flag against the comment and it will be automatically removed until it can be reviewed by the research team.

Take responsibility for your words and actions - We can all make mistakes; when we do, we take responsibility for them. If someone has been harmed or offended, we listen carefully and respectfully, and work to right the wrong.

Be collaborative - Collaboration between people with different experiences is essential. Collaborating openly improves the quality of our work.

Value decisiveness, clarity and consensus - Disagreements are normal, but we do not allow them to persist and fester leaving others uncertain of the agreed direction. We expect participants in the workshops and focus groups to resolve any disagreements constructively.

Ask for help when unsure - Asking questions early avoids any problems later, so you're encouraged to ask questions, though do make sure to direct them to appropriate ideas and comments shared by colleagues. If you are asked, try to be responsive and helpful.

Don't try this at home! We ask that you do not try any new activities other have suggested in the discussions held in the workshops or focus groups / interviews without consulting a health professional who knows you well first. Everyone has different abilities, and new activities that are fine for someone else, could be harmful to you.

We commit to preserving the integrity of the conversation, by never revealing your identity publically and by seriously considering all ideas which are prioritised through your likes and dislikes.

11.4 Amendment History

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made

List details of all protocol amendments here whenever a new version of the protocol is produced.

Protocol amendments must be submitted to the Sponsor for approval prior to submission to the REC.

Appendix 5 Additional questions for specific stakeholder groups from the gateway survey.

Stakeholder Group				
1) NAYP	**2) Family members of NAYP**	**3) Professionals**	**4) Experts**	**5) Other**
Diagnosis	Family member's diagnosis	Job role	Job role	Please tell us why you are interested in this topic
Number of people in household (including participant)*	Relationship to family member with disabilities*	Frequency of working with NAYP*	How does your work relate to this study?	
Other members of household	Do you live with your family member with disabilities?*	Number of years working with young people with physical disabilities*	Number of years working in this field*	
Proportion of a typical day spent lying / sitting*	Age of family member with disabilities	Do you measure / monitor the amount of time NAYP spend sitting or lying still?*	Do you measure / monitor the amount of time NAYP spend sitting or lying still?*	
Activities involving movement	Does your family member have learning difficulties?*	How do you measure / monitor amount of time NAYP spend sitting or lying still?	How do you measure / monitor amount of time NAYP spend sitting or lying still?	
Duration of activities involving movement	Can your family member tell you what they want?*			

Activities done in sitting and lying	Do you help your family member to spend time moving?			
Duration of activities done in sitting and lying	Activities your family member does that involve movement			
	Activities your family member does that involve movement			
	Activities your family member does when sitting and lying			

*Note: Questions marked * had multiple choice responses. NAYP: non-ambulant young people.*

Appendix 6 Stationary Study protocol

Protocol for the Stationary study.

Full/ Long title: Objective measurement of **s**edentary **t**ime and physical **a**c**t**ivity in n**on-a**mbulant young people with long-term disabilities: protocol for an accele**r**ometer and activPAL^{TM} validation stud**y**

Short title: Stationary

Protocol version number and date: Version 0.5 24/03/2020

IRAS: Not submitted to ethics committee due to COVID-19 pandemic.

Funders number: ICA-CDRF-2018-04-ST2-021

Chief investigator: Marilyn Bradbury

Funder: HEE/ NIHR ICA Programme (Clinical Doctoral Research Fellowship)
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Sponsor: Birmingham Community Healthcare NHS Foundation Trust (BCHCFT)

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PROTOCOL CONTRIBUTERS

Supervision team

Professor Joan Duda: Primary doctoral supervisor. Joan will have overall oversight of the research, supporting the CI with protocol development, application for ethical and HRA approvals, conduct of the research, data analysis, interpretation and dissemination.
Dr. Sally Fenton: Doctoral Supervisor. Sally will contribute to supporting protocol development, application for ethical and HRA approvals, application for ethical and HRA approvals, conduct of the research, data analysis, interpretation and dissemination.

BCHCFT (Sponsors)

BCHCFT will review and approve study documentation produced by the research team. They will not be involved in data analysis and interpretation, manuscript

writing, or decision making in relation to dissemination of results. BCHCFT are responsible for data protection in relation to all aspects of the research.

PPI representatives
West Midlands YPSG and public and patient involvement (PPI) representatives who are non-ambulant have reviewed this protocol. Their feedback has supported writing of the plain English summary and information sheets.

SCIENTIFIC ABSTRACT

Background: No previous studies have validated wearable devices to measure sedentary time or physical activity in young people (aged 12-25) who have long-term disabilities that prevent them walking. This study aims to establish a valid method of objectively measuring time spent sedentary in this population; that is applicable in a free-living environment. The method selected will be used in a digital intervention to reduce sedentary time.

Method: The validity of the following devices will be assessed by comparing them with indirect calorimetry and direct observation, whilst participants complete activities requiring a range of physical activity intensities. 1) a wrist-worn accelerometer (GENEActive), 2) a thigh worn accelerometer and inclinometer (the activPAL4) and 3) the ActivInsights Health Band (wrist-worn).

Analyis: The triaxial accelerometer signals for the 3 axes will be analysed by calculating a Euclidean Norm Minus One (ENMO) metric for each 5 second epoch in which a steady state VO_2 was achieved. For the GENEActiv data, the averages will be used to carry out a receiver operating characteristic (ROC) curve analysis using SPSS to determine triaxial accelerometer thresholds for sedentary time, light PA and (if possible) moderate to vigorous PA that are appropriate to this population. The value corresponding to the area under the curve (AUC) will represent the sensitivity and specificity of the thresholds identified.

The ActivInsights band provides summary level data only. The classification accuracy of this device will be evaluated using the indirect calorimetry data and videos.

Outcome: The validity of the wearable devices for measurement of physical activity and sedentary time in this population, and the best combination of devices to use in the development and evaluation of the subsequent intervention, will be established.

LAY SUMMARY

Background: No previous studies have tested whether wearable devices can accurately measure sedentary time or physical activity in young people (aged 12-25) who have long-term disabilities that prevent them walking. This study aims to establish a way of measuring time spent sedentary in this population; that can work in day to day life, not just in a laboratory. The method chosen will be used in a health improvement programme being developed to reduce sedentary time.

Method and analysis: The accuracy of different wearable devices will be assessed by comparing them with a measurement of how much oxygen participants are using and direct observation of what participants are doing (by making a video recording), whilst participants complete activities that range from very low to higher intensity. The different devices are worn on the wrist, thigh and upper arm.

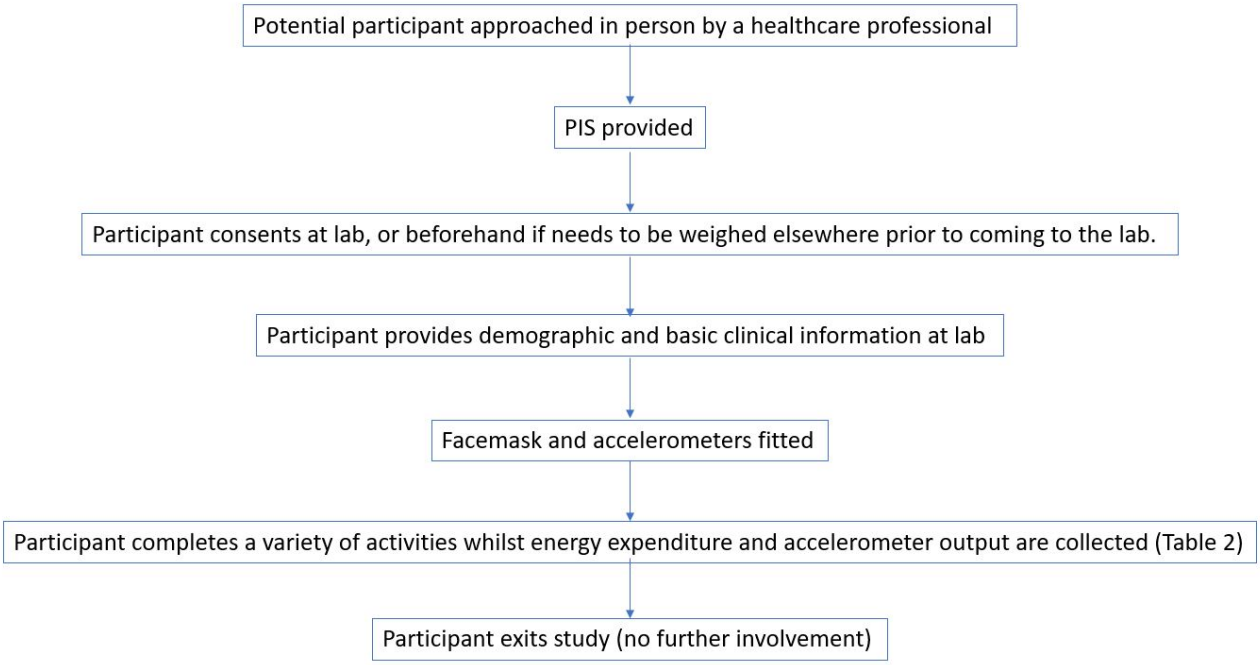
Outcome: The accuracy with which the wearable devices measure sedentary time and physical activity in this population, and the best combination of devices to use in the health improvement programme being developed and tested, will be established.

ABBREVIATIONS

BCHCFT	Birmingham Community Healthcare NHS Foundation Trust
HRA	Health Research Authority
METS	Metabolic equivalents
PA	Physical activity
PIS	Participants Information Sheet
PPI	Public and patient involvement
UIN	Unique Identifying Number
VM	Vector Magnitude
YPSG	Young persons steering group

Table 1. Abbreviations.

STUDY FLOW CHART



INTRODUCTION

Sedentary behaviour is defined as any waking behaviour, requiring low energy expenditure (□1.5 METs), undertaken in a sitting/reclining/lying posture [1]. Evidence suggests sedentary behaviour is linked to poor health outcomes among the general population, and interventions to reduce sedentary behaviour may help to improve health outcomes [2]. However, no interventions to date have sought to examine the feasibility and efficacy of interventions to reduce sedentary behaviour among non-ambulant young people living with long-term disabilities. This heterogeneous population are characterised by unique and varied movement patterns, including altered muscle tone and involuntary movements. These young people have a range of diagnoses and physical impairments. The distribution of physical impairments across the body varies widely. Methods to assess sedentary behaviour have not been validated among this specific population [3]. Establishing a validated method to measure sedentary behaviour, which may also be used as part of an intervention (e.g., to provide feedback on behaviour), is therefore of critical importance in evaluating the value and effectiveness of interventions to reduce sedentary behaviour in this specific population.

The aim of this study is therefore to establish an accurate and valid device-based method of measuring free-living time spent sedentary in young people who are unable to walk due to long-term disabilities. The study is linked to a larger programme of work, which involves co-designing a digital intervention to reduce

sedentary time with non-ambulant young people aged 12-25 and other key stakeholders.

A recent systematic review of device-based measures of physical activity used in studies involving adults who use manual wheelchairs recommended employing the Actigraph GT3X+, GENEActiv, Physical Activity Monitoring System [4], or Actiheart to quantify the frequency, intensity and duration of physical activity [3]. Placing the devices at the wrist or upper arm was reported to provide the most valid estimates of physical activity, as was combining heart rate and accelerometer data. However, all participants included in these studies were able to self-propel their wheelchair, which is not the case with all young people who are non-ambulant.

The objective of this study is therefore to validate device-based measures of physical activity and sedentary time, to enable accurate measurement of these behaviours among non-ambulant young people with long-term disabilities. Specifically, this study aims to validate; 1) a wrist-worn accelerometer (GENEActive), 2) a thigh worn accelerometer and inclinometer (the activPAL), and 3) the ActivInsights Health Band (wrist-worn).

The devices to be validated are described below.

Accelerometers

Accelerometers are small, lightweight devices which enable continuous monitoring of free-living sedentary time and physical activity [5]. They can be worn on various parts of the body, for example the wrist, upper arm or thigh [5]. To validate accelerometers for the measurement of sedentary time and physical activity, they must be calibrated against a criterion standard. Indirect calorimetry is the most commonly employed criterion standard in this context. Using this method, typically, raw data collected via accelerometry is compared to that collected concurrently by indirect caolimetry, and analytical approaches are employed to determine thresholds or “cut-points” that are able to accurately distinguish between sedentary time (≤1.5 METS), and physical activities of light (ie., 1.6 – 2.9 METS) moderate (i.e., 3-5.9 METS) and vigorous (≥6 METS) intensities.

Most accelerometer cut-points that have been calibrated against indirect calorimetry have been developed in studies of healthy adults and children. No accelerometers have been validated in this way for young people who are non-ambulant. Research in this area is critical prior to the application of such devices to measure sedentary time and PA, as for this patient population, movements can be more effortful, and require greater energy expenditure than in the general population [6]. Therefore, analytical approaches that have been validated based on the relative energy costs of behaviours for non-ambulant young people are required. Indeed, there are many alternative ways in which raw accelerometer data can be processed and analysed. Whatever method is chosen, it is important that the algorithm selected has been validated in the population being studied.
Devices to be validated:

This study will validate the GENEActiv original (Activinsights), Activinsights Band (Activinsights) and ActivPAL4 (PAL Technologies Ltd). These devices have been selected because of either their potential application as; 1) an outcome measure (i.e., GENEActiv and ActivPAL4, to measure changes in free-living sedentary time as part of the intervention), or 2) an intervention tool (i.e., Activinsights Band and Lynck 2 (wrist worn heart rate monitor), to deliver feedback on behaviour to participants). In regards to the latter, it is feasible that both the Activinsights or Lynck 2 could be used in interventions subsequently commissioned by the NHS, as they operate using wireless communication systems and data is stored within the EEA. However, the Activinsights Band does not offer the option of extracting raw acceleration data and requires proprietary algorithms developed by the manufacturer to establish time spent sedentary and engaged in different intensities of physical activity (PA). Thus, for our population of interest, they may not offer the most valid estimates of sedentary time when employed to establish the efficacy of an intervention (i.e., for outcome assessment).

The GENEActiv and ActivPAL sensors do not have wireless communication (and thus cannot be used as an intervention tool), but provide raw accelerometer data without any filtering to the accelerometer output. The availability of raw data offers several options in regards to the analytical approaches that can be applied to these data (e.g., can be calibrated against indirect calorimetry to provide population specific cut-points for estimating sedentary time and physical activity). The GENEActiv and ActivPAL will therefore be validated in this study, with the intention of using these devices as a method to establish the effectiveness of our intervention (in development), for reducing sedentary behaviour in non-ambulant young people.

Device information:

The GENEActiv device is a wrist-worn, research-grade accelerometer, and is able to accurately record acceleration in 3 axes at a sample rate of to 100Hz. It is waterproof, so can be worn for continuous 24-hour periods if necessary. All movements are measured and raw data represented in the data output. A near-body temperature sensor helps to confirm wear time. It has been used in over 300 peer-reviewed papers, but has not been validated in non-ambulant young people.

The Activinsights Band is a wrist-worn accelerometer, and is used as a diagnostic and intervention tool. It runs for a year without needing to charge the battery. The device embodies techniques based on established research with able bodied adults to measure physical activity, and features of the device can be used to encourage behaviour change (e.g., feedback on behaviour). Application Processing Interfaces are available to integrate data into existing platforms and apps. The Activinsights Band data can be regularly uploaded in the field by participants via an Android mobile app when they press a button. This data can then be integrated via a .csv or .json format to provide direct participant feedback, as is required for the intervention in question. This band is also waterproof. Activity events are recorded by the band and a daily summary of the participant's approximate total energy expenditure and steps taken is available in the participants overview.

ActivPal Posture Sensor

The ActivPAL is an accelerometer with inclinometer function, allowing it to differentiate between lying, sitting, standing and stepping, using proprietary algorithms. It also counts transitions between sitting, lying and being upright and cadence when stepping. The activPAL is worn on the anterior midline of the thigh, (attached via a waterproof tegaderm dressing) which assists with detecting postural changes, a key feature of the definition of sedentary behaviour (i.e., sitting/lying). None of the accelerometers described above offer this feature, which infer sedentary behaviour based on lack of movement (i.e., low accelerations).
Due to these strengths, it is considered to be the 'gold standard' to measure sedentary time in field-based research, and may offer a more valid assessment of sedentary behaviour in non-ambulant young people that the GENEactiv, due to its placement (thigh-worn).

Validation studies of the activPAL typically compare the accuracy of this device for quantifying sitting/lying time, standing and stepping against direct observation. In healthy populations, validity studies demonstrate the activPAL provides excellent agreement with direct observation for sitting/lying time, time spent upright and transitions between sitting/lying and upright postures [7]. However, the validity of the activPAL for detecting slow walking speeds (when compared to direct video observation), is reduced, with zero steps detected at or below 0.1 m/s or below 24 steps/min [8], which may be relevant when non-ambulant young people use a body support walker.

The ActivPAL has been used previously in studies of children with cerebral palsy [9, 10]. However, its validity in this specific age group for non-ambulant young people has not previously been studied.

AIMS

The specific aims of this study, are therefore to;

1) Validate the GENEActiv, Activinsights Band and ActivPAL devices for measurement of sedentary time and physical activity in non-ambulant young people aged 12- 25 years, via comparison with indirect calorimetry and direct observation.
2) In evaluating validity, establish whether the devices should be worn on the dominant, non-dominant, or both sides of the body to measure sedentary time as accurately as possible.
3) Determine what combination of devices is most valid and appropriate to evaluate the efficacy of a behaviour change intervention to reduce sedentary time and provide feedback to participants about their behaviour during the intervention in this population.

METHODOLOGY

This study will be submitted to a National Health Service Research Ethics Committee for approval.

Study design

This is an observational study, with the aim of determining the validity of several wearable devices for measurement of sedentary time and physical activity in a specific population.

Participants and recruitment

Inclusion Criteria

Participants will:
1) be aged 12-25 years
2) have a lifelong disability
3) be non-ambulant, or only able to walk using a body support walker
4) have sufficient understanding to engage in the activities outlined in the protocol
5) be able to safely and comfortably wear the face mask required for indirect calorimetry and the wearable devices

Equipment and staff that allow the participant to undertake the activities required safely are available on site.

Exclusion Criteria:

Participants who:
1) are under 12 year of age or 26 years or above.
2) do not have sufficient understanding to engage in the activities outlined in the procotol
3) have had orthopaedic surgery (excluding botulium toxin injections) in the 3 months prior to invitation to take part in the study.
4) are not able to tolerate the calorimeter face mask or wearable devices due to discomfort, anxiety, respiratory difficulties or having a tracheostomy.

Equipment and staff needed for the participant to undertake the activities required safely are not available onsite.

Sample Size:

No previous studies have been conducted with the aim of validating device-based measures of physical activity and sedentary time in non-ambulant young people. However, similar studies in the review of adult wheelchair users described above [3]

included between 10 and 45 participants to validate accelerometers for the measurement of sedentary time and physical activity.
Considering that it is difficult for young people who are wheelchair users to travel and that they are often reliant on family members and carers for transport, it is expected that recruitment will be challenging. Using the adult studies as a guide, we will therefore aim to recruit n = 20 participants to his study. As participants will need to travel to the University of Birmingham, recruitment will be from 2-3 local NHS Trusts within the West Midlands, to reduce participant burden.

Sampling Strategy: A convenience sample will be recruited locally as access to individually prescribed equipment such as standing frames, and/or walkers is needed. Some participants may be invited specifically to ensure there is representation of a wide range of diagnoses and varying physical impairments.

Recruitment

Participants will be recruited via healthcare professionals in their direct clinical care teams at Birmingham Community Healthcare NHS Foundation Trust (BCHCFT) and 1-2 other patient identification sites. Participant information packs including consent forms will be distributed to potential participants by post, email or face to face at appointments. Where possible, a follow up phone call from the research team will confirm receipt of information and answer queries prior to willing participants being recruited to the study and providing their consent. Travel expenses will be limited to a maximum of £25 per participant. Parking at the University is free for research.

CONSENT

Participants will have been provided with a Patient Information Sheet (PIS), and given sufficient time to read study information and ask any questions (a minimum of 24 hours, prior to providing their consent). Four PISs will be produced; one for young people with learning difficulties, a second for those aged 12-15 without learning disabilities, a third for young people aged 16 -25, and a fourth for parents/carers. If they have capacity to do so, participants aged 12-15 will give verbal assent to participate. A written consent form will be completed by the parent/guardian of all participants under 16. Participants and/or their parents/guardians will have the opportunity to ask questions prior to the consent form being completed. Participants aged 16 and above will complete their own consent form, with assistance if required. If participants are unable to write a signature, verbal consent will be documented by a witness, following HRA guidance [11]. For participants aged 16 – 25 who do not have capacity to consent, a consultee will complete a declaration form on their behalf.

Parents/ consultees will be present at all times, so will be able to withdraw consent freely during the study. Participants who lack capacity to consent or assent will be monitored throughout data collection. If they appear distressed, they will be withdrawn. It will be clear that declining to participate will not affect future care.

Consent will be obtained by the Chief Investigator, who has recent Good Clinical Practice training.

METHODS

The indirect calorimeter (Vintus CPX: vyaire) will be calibrated according to the manufacturers instructions. A video camera will be set up on a tripod overlooking the area where the activities will be carried out.

Participants will first be asked to provide demographic and basic clinical information including gender, age, ethnicity, diagnosis, equipment routinely used and a brief assessment of gross motor function on a paper form. This will also include hand and leg left/right dominance if known, and details of any asymmetry in the body, or functional differences between the left and right side. Participants will select a pseudonym, which will be recorded on this paper form, and will be used to set up an anonymous account on the MyDignio app on a tablet. This will allow data from the Lynck 2 device, which gives an indication of heart rate, to be viewed in real time via the Dignio Prevent platform on a lap top.

All transfers will be carried out according to the moving and handling risk assessment for each participant, which will be provided by the referring clinician. Participants will be weighed in a hoist sling or with wheelchair scales in their wheelchairs, then the empty chair will be weighed and subtracted from the initial measure to calculate the participants weight. Shoes and orthotics will be removed prior to weighing. Participants height will be measured by lying them on their backs on a plinth to achieve the most symmetrical and extended posture possible and measuring their length from the top of their head to their heels. Participants' height, weight and sex will be recorded in the database which collects the indirect calorimetry data (on the PC on the metabolic cart).

GENEActiv accelerometers (wrists) and ActivInsights bands (wrists) will be placed on the left and right arms (so two of each device are worn). An ActivPAL will be placed on the left and right mid thigh, and will be secured with a tegaderm dressing. Finally, a face mask attached to the indirect calorimeter will be fitted to the participant with elasticated straps. The face mask will be worn for the duration of the data collection. Participants will be asked to minimise the amount of speaking they do once the mask has been fitted, but will be reassured that they should inform the researchers if they feel uncomfortable or want a break, need to share something with them or don't understand what they are needed to do/what is happening. Participants can use hand signals to indicate yes and no (thumbs up, thumbs down) if they are able to do this. If participants are distressed due to wearing the mask, data collection will discontinue.

All devices and equipment will be time synchronised to a master device (the indirect calorimeter), to ensure time stamping is aligned for all measurement methods.

Whilst wearing this equipment, participants will carry out the activities described in Table 1 below. All participants will carry out these activities in the same order (omitting any that are not possible due the participants abilities/lack of access to equipment/fatigue or pain), to minimise the number of transfers between the plinth,

floor and specialised seating being carried out, and the length of time taken to collect the data.

The activities selected (Table 1), represent a range of intensities of physical activity (i.e., sedentary, light and moderate), and cover the types of activities participants are likely to be able to access in their daily routines. However, not all participants will be able to do all the activities. Any that cannot be completed will be omitted from the data collection for that participant, and a record of completed activities kept for each participant.

Each activity will be undertaken for a minimum of 3 minutes and a maximum of 6 minutes, apart from the transfers, which will be of varying durations, depending on the participants transfer method and level of ability. Participants' baseline resting heart rate (beats per minute) and VO_2 (ml/kg/min) will be measured during the static supported sitting activity. A 5 minute rest period will separate each of the activities to allow the participant to return to these baseline levels. If the values do not return to resting levels after 5 minutes, additional 1 minute rest periods will be added until baseline heart rate and VO_2 are reached. Heart rate will be visible in real time via the Dignio Prevent software and VO_2 is displayed on the screen of the indirect calorimeter.

The time displayed on indirect calorimeter (the master device) will be used to record the start and finish time of the data collection, and the time at which each activity or rest period began and ended. It is anticipated that participants will be in the lab for approximately 3 hours in total.

Activity	**Description**	**Expected activity intensity**
1. Supine lying on a plinth.	In a comfortable position (document any supports used, and any postural asymmetry)	Sedentary
2. Sitting static with full support in specialised seating	e.g. wheelchair/class chair.	Sedentary
3. Sitting static with full support on egde of plinth	clinician/parent supporting.	Sedentary
4. Sitting static with minimal support on edge of plinth	Sitting with the least support that can be offered to maintain sitting balance (document position and support provided)	Sedentary/light
5. Transfer plinth to specialised seating	Document method e.g. hoist, slide board etc and body position	Sedentary/light

6. Using a tablet or moving small objects such as doing a puzzle/playing a musical instrument, rolling small balls) in sitting (plinth or specialised seating)	Description of movements made	Sedentary
7. Play involving large movement of arms (throwing a large ball/ banging drum, hitting a ball with a bat etc)	Description of activity done and movements made	Light
8. Transfer specialised seating to floor	Describe method, hoist, or active assisted and body position	Sedentary/light
9. Floor mobility	Describe whether attempting lying to side lying, rolling, creeping, crawling and level of success (i.e. can data be used)	Moderate - vigorous
10. Floor sitting static – minimal support	Aim for crossed legged sitting, if not possible describe sitting posture. Describe level of success	Light
11. Floor sitting - active	Playing whilst in floor sitting with arms. Describe activity and level of success.	Moderate
12. Standing in standing frame - static	In standing frame, but not attempting any additional movements	Light
13. Standing in standing frame - dynamic	Self propelling standing frame, or doing upper limb activities such as playing on tray, throwing a ball, Banging/pushing on a gym ball, playing a musical instrument, playing a racquet sport	Moderate - vigorous
14. . Using body support walker	Specify walker type, describe gait in it, speed, pattern.	Vigorous

Table 1 Validity study activities.

OUTCOME MEASURES

- VO_2 (ml/kg/min): measured by breath by breath gas analysis of the concentration of oxygen inspired and carbon dioxide expired, using the Vintus CPX: vyaire indirect calorimeter (criterion standard)
- Metabolic equvalents (METS: by converting the VO_2 measure to identify sedentary (<1.5 METS), light (1.6 -2.9 METS) and moderate-to-vigorous (≥3 METS) physical activity. One MET is defined as oxygen consumption whilst sitting at rest (ml/kg/min), i.e. the basline VO_2.for each participant. The standard figure (3.5 ml/kg/min) will be used to calculate METS in this study.
- Heart rate via Lynck 2 device
- Posture i.e. Sitting/standing/lying/stepping differentiation (via ActivPAL comparison with video)
- Physical activity intensity recorded by ActivInsights band and GENEActiv accelerometers.
- ActivInsights band activity classifications

DATA MANAGEMENT AND ANALYSIS

All participants will choose a pseudonym which will be used to anonymise all data collected. The anonymised data will be downloaded to and stored on a password protected lap top and will be uploaded to the University of Birmingham Bear Research Data Store for subsequent analysis. The anonymous data will be stored indefinitely by the University of Birmingham to enable it to be accessed for secondary analysis in future research.

The data stored on the indirect calorimeter will be deleted when data collection for the study is completed.

Data from the Lynck 2 devices will be transferred to the My Dignio patient application on a mobile tablet via Bluetooth, then uploaded in real time from the tablet to the Dignio Prevent software platform. The heart rate indicator data will be visible to the researchers during data collection via the Dignio Prevent dashboard. Dignio software is a cloud based solution, and the software is accessed over an encrypted internet connection. Dignio's systems comply with the applicable EU laws and regulations for processing of personal and health data, including General Data Protection Regulation. Please see the supporting data protection impact assessment / documentation supplied by Dignio for further information. The raw data from the Dignio cloud will be downloaded as a CSV file.

Once the protocol has been completed, data from all the remaining devices (ActivInsights band, GENEActiv, activPAL) will be downloaded via manufacturers software (Activinsights, GENEActiv and PAL Connect, respectively) onto a password protected lap top with blue tooth capability or a university PC prior to upload to the research data store.

Statistical analysis:

GENEactiv (outcome assessment)

For the GENEActiv data, raw triaxial accelerometer signals for the 3 axes (vertical (Y), horizontal right-left (X) and horizontal front-back (Z)) will be analysed by calculating a Euclidean Norm Minus One (ENMO) metric in milligravitational units for each 5 second epoch (for method see Bakrania, Yates [12]). The time period over which a steady state VO2 was achieved will be identified for each activity undertaken by each individual participant, using indirect calorimetry data. The ENMO metric and the METS from the indirect calorimetry during these steady state periods will be extracted for analysis.

ENMO metric data from the GENEActiv accelerometers (on the dominant and non-dominant side of the body) and METS for each participant, and each activity, will be averaged across the steady state time period identified. For the GENE Activ data, the averages will be used to carry out a receiver operating characteristic (ROC) curve analysis using SPSS for each accelerometer. This analysis will be used to determine triaxial accelerometer ENMO thresholds for sedentary time, light PA and (if possible) moderate to vigorous PA that are appropriate to this population using a leave-one-out-cross-validation model.

ROC curves will then be generated for sedentary time, light physical activity and (if possible) moderate to vigorous activity. The value corresponding to the area under the curve (AUC) will represent the accuracy of the analysis for each accelerometer (0.90-1.00 = excellent, 0.80-0.89 = good, 0.70-0.79 = fair, 0.60-0.69 = poor, and <0.60 = failure).

ActivPAL (outcome assessment)

Analysis of the video recordings will involve recording whether participants were sitting, lying, standing, standing or stepping (as defined by the sedentary behaviour research network terminology consensus project [13]) in 15 second epochs, to determine the total amount of time participants were observed being in each of these states during data collection (minutes [mean ± standard deviation]). If the participant is able to do any steps (supported by a body support walker, or during transitions) or sit to stand transitions the number of these will be recorded. The ActivPAL data will also be organised into 15 second epochs (categorised as sitting, standing, lying or stepping) and number of steps and sit to stand transitions will be extracted via the PAL connect software. The means and standards deviations for amount of time spent in each state, number of steps and number of sit-stand transitions from direct observation and the ActivPAL data from the dominant and non-dominant leg will be calculated using SPSS. Bland -Altman plots will be generated using SPSS to compare direct observation with the ActivPAL data from the either the dominant and non-dominant sides if the data differs, or one side only, if the data is similar for both legs. Percentage difference between direct observation and ActivPAL data for time spent lying, sitting, standing, stepping, number of steps and number of transitions will be reported.

Activights band (intervention tool) and lynck 2 device.

The ActivInsights band and Lynck 2 provides summary level data only. The classification accuracy of this device will be evaluated using the indirect calorimetry data and videos.

RISK ASSESSMENT

Risks associated with trial interventions

☒ A ≡ Comparable to the risk of standard medical care

☐ B ≡ Somewhat higher than the risk of standard medical care

☐ C ≡ Markedly higher than the risk of standard medical care

Justification: These risks are no higher than those experienced during interventions in clinical environments. These activities are being carried out for the purpose of research, however there is no new intervention or unusual activity being carried out by the participants. Face masks would not usually worn in a community setting, but frequently are in acute care.

What are the key risks in this study?		How will these risks be minimised?		
Activity	Hazard	Activity	Frequency	Comments
Being in an unfamiliar laboratory environment	Fire	Each participant will have a personal emergency evacuation plan in place prior to coming to the lab. The buildings health and safety co-ordinator will be aware of when participants are visiting.	Prior to attending	
	Risk of injury to participant / parent / carer / siblings	All visitors will be advised via the PIS and verbally on arrival that equipment in the laboratory is potentially dangerous, and they should not touch any of the equipment unless the researcher asks them to. Parents/ carers will be asked to ensure they supervise any siblings in	Prior to attending and on arrival. Two researcher in the room or nearby in the building throughout data collection.	

		the lab closely due to this, and that they bring activities for them to do so they are occupied whilst in the lab. At least two researchers will be present during data collection due to the vulnerability and complex needs of this group of participants.		
	Medical emergency e.g. epileptic fit, asthma attack resp or cardiac arrest	The CI will always be present and has paediatric and adult CPR training. First aiders can be requested by dialing 44444 from an internal phone. This still applies at weekends. At least two researchers will be present during data collection due to the vulnerability and complex needs of this group of participants. The buildings health and safety co-ordinator will be aware of when participants are visiting.		
Moving and handling participants with limited mobility	Risk of injury to researchers and participants	Moving and handling risk assessments will be requested from the participants physiotherapist and will be followed Participants will not be moved unless the correct equipment to do so is not available.	As required	

		If the participant is hoisted, this will be carried out by two hoist trained members of staff.		
Face to face contact with young people with disabilities	Safeguarding concerns/disclosures	The CI (who will be present throughout data collection) has safeguarding children and vulnerable adults training. The PIS will state that any disclosure that raises concerns in relation to the safety and wellbeing of participants or their family members will be shared with relevant services. Any concerns will be managed in line with BCHCFTs Safeguarding Children and Safeguarding vulnerable Adults policies.	Prior to and throughout study	
Indirect calorimetry	Discomfort/marks due to mask	If participants inform the research team that their mask is uncomfortable and this cannot be resolved, or if they are distressed or anxious due to wearing the mask a mouthpiece will be trialled. If this is not successful data collection will cease.	During data collection	
	Infection control related to wearing mask and head straps	Masks are washed in soap and warm water between participants and dried in a drying cupboard.	During data collection.	

		Head straps will be washed at 40 degrees between participants.		

Adverse events will be defined as; any untoward medical occurrence, unintended distress, disease or injury or any untoward clinical signs whether or not considered to be causally related to the intervention.
Serious adverse events will be defined as an adverse event that:

- Led to death
- Led to a serious deterioration in the health of the participant that either:
- Resulted in a life-threatening* illness or injury
- Resulted in a permanent impairment of a body structure or a body function
- Required in-patient hospitalization or prolongation of existing hospitalization**
- Resulted in medical or surgical intervention to prevent life threatening illness or injury, or permanent impairment to a body structure or a body function
- Other important medical events***

* the term life threatening here refers to an event in which the patient is at risk of death at the time of the event; it does not refer to an event that might hypothetically cause death if it was more severe (eg a silent myocardial infarction)
** Hospitalisation is defined as an in-patient admission, regardless of length of stay, even if the hospitalisation is a precautionary measure for continued observation. Hospitalisation for pre-existing conditions (including elective procedures that have not worsened) do not constitute an SAE
*** Medical judgement should be exercised in deciding whether an AE is serious in other situations. Important AEs that may not be immediately life threatening or result in death or hospitalisation, but may seriously jeopardise the participant by requiring intervention to prevent other undesirable outcomes.
A detailed digital record of any adverse events or serious adverse events which occur as a result of this study will be made according to guidelines for adverse event reporting. A serious adverse events report form will be used for serious events. This will be saved on the BCHCFT's study folder on the common drive. The date, time, nature and people involved in any adverse events will be logged on a table to identify any recurring issues.
The study will stop if:
There is one incident of a serious advert adverse event - it may resume if appropriate once the event has been fully investigated if the study steering committee consider it to be safe to do so.
There are 3 or more similar adverse events. The Study steering committee would meet to discuss the events in this case and decide on the actions to be taken.

DATA PROTECTION AND CONFIDENTIALITY

The PIS will inform participants that any information they share in relation to the study is treated as confidential and any results or data shared and stored other than their consent form and manual handling risk assessment will be anonymous. Their rights in relation to GDPR will also be explained in the PIS.
All researchers will comply with the requirements of the Data Protection Act 1998 with regards to the collection, storage, processing and disclosure of personal

information and will uphold the Act's core principles. Paper records will be stored and transferred in accordance with BCHC's information governance policy. Paper records will be locked in a locker pod at BCHCFT's headquarters, in accordance with the locker pod management process.

A data protection impact assessment (DPIA)has been undertaken to ensure all aspects of electronic data collection, storage and transfer are compliant with GDPR, and is included in the supporting documents.

PUBLIC AND PATIENT INVOLVEMENT

YPSG and a PPI representative who is a non-ambulant young person will review the protocol, lay summary and information sheets.

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Appendix 7 Descriptions of barriers / facilitators of sedentary time for NAYP

Barrier/ Facilitators	Description
Barriers	
Category: Attitudes of others	
Cultural attitudes to movement	Some social groups, particularly those from non-Caucasian backgrounds may struggle to participate in physical activities because they do not have a role model. This is particularly true for girls and young women. Teenage girls may wish to avoid activities that involve physical contact with others. Weight gain viewed as a positive attribute in some cultures. Professionals should recommend activities that fit individual's cultures and lifestyles.
Family attitudes and routines in relation to movement	Prioritising academic learning. Parents don't encourage / support physical activity. Safety concerns if participating in sport. Believing children can't / shouldn't do PE. Feeling physio is the only appropriate physical activity. Being protective. Families finding it easier if child doesn't move. Family don't expect disabled children to become independently mobile. Families feel it's a battle fighting for services and equipment. Many factors of home situations influence engagement with movement. Lack of physically active role models in family.
Family, staff, carers not feeling moving is important	Lack of education / awareness about benefits and risks of not moving. Miscommunication / missed opportunities to share information from professionals. Physical aspects of healthcare not prioritised, focus on medical / equipment needs. School staff not engaging with training about movement opportunities. Parents don't get feedback from school about what movement child has done. Helping children to move needs to be compulsory for school staff, not done if it's optional. Lack of recognition that learning is influenced by physical comfort. “Move more not move less” ethos needed in schools. Not enough information in education and healthcare plans in movement / physical activity section.

Barrier/ Facilitators	Description
Professionals beliefs, attitudes, behaviour	Beliefs and perceptions of healthcare professionals. e.g. prognosis of individuals physical abilities, needing to diagnose / categorise individuals into boxes or groups for accessing services and support. Difficult if you don't fit a box. Impractical advice / solutions from professionals. Sugar coating information for parents / young people to protect them. Professionals hope parents will google to understand risks. A professional participant previously discouraged floor time without postural support but is re evaluating due to this study as this limits children's opportunities to move.
Social perceptions of disability	Lack of understanding of disability e.g. wheelchair users don't move / can't leave chair / organized club or group needed. Stigma. Can't do sport / PE. Low expectations from supporting adults. Society's barriers to movement for disabled people. Lack of friendliness / disgust from able-bodied people towards disabled people. Young people adopt the perspectives of those around them. Academic work more important than moving. Friends and family of parents who care for a disabled child don't understand what it's like to be a parent to a disabled child. Parents can feel isolated. Less media exposure for disability resources / restrictions on what is shown. Being "wheeled out" for ofsted inspections.
Category: Availability of resources	
Access to organised activities	Not knowing about local activities. Inability to accommodate young people with complex needs. Less activities in mainstream vs special school. Activities only accessible if you live in a specific area / have a specific condition. Public health interventions only appropriate to able-bodied people. Insufficient signposting from professionals. Withdrawal of public funding due to low uptake. Government policies, opportunities are not being successfully created. Less variety in activities available in comparison to those for able-bodied people. Not able to access residential trips. Challenges of doing sports alongside able-bodied people, differing ability levels / sharing equipment. Lack of Sport England funding and national lottery support.

Barrier/ Facilitators	Description
Access to therapy	Access to professionals and quality of therapy. Frequency of access. Appropriateness of teachers and parents carrying out physio programmes. How much training do they need to do this. Mismatch between the input and monitoring children with cerebral palsy need, and what is provided by the state. What is provided is not enough. Needing to fundraise for private physiotherapy.
Affordability and funding	Health and Wealth inequalities. Not having funding for organised activities. Families with low income have less access to fun activities. Only one parent able to work. The other cares for child. Navigating and negotiating funding streams is complex. No single point of access. Low income reduces space and equipment access at home. Local authority reluctant to fund non-essentials such as trikes or walkers. Disability sports activities cost more than opportunities for able-bodied people. Peers can't afford the same activities. Price increases for disability equipment. Not being signposted to grants. Self-funding a wheelchair - NHS vouchers don't cover costs. Fundraising for equipment / therapy. Funding equipment adjustments. School budgets to support inclusion. Schools need more funding. Schools can't afford to implement education healthcare plan. Limited funding to support movement in adult services. Families have less money for luxuries, e.g. pets. Expensive if you are self-funding and can't claim compensation for injury at birth. Procurement systems require purchase from mainstream suppliers. Doesn't have bath at home, dreams of a hot tub.
Inappropriate facilities or housing	Wheelchair accessibility, environment. Hoist only covers small floor area or limited rooms. Power chair too wide to use at home. Public pools too cold. No hydrotherapy pool. Can't help with activities of daily living as home environment not accessible. Inaccessible facilities on school / organisation's residential trips. No disabled changing rooms. Stairs with no lift or lift broken. Lack of dropped curbs. Inappropriate facilities limits sports participation.
Category and barrier: Becoming socially isolated	Poor inclusion. Comparison with able-bodied peers. Reduced participation. Loss of confidence. Staying at home after leaving school. Feeling "swept under the

Barrier/ Facilitators	Description
	carpet". Looked at with disgust. Lack of acceptance of disability. Doing less movement at school due to attitude of others. Vulnerability due to being reliant on mobility equipment to go out. Young person finds expectation of participation / social interaction in team sports challenging. Being an only child. Being excluded from activities.
Category: Being independent	
Moving less to achieve greater independence or participation	Choosing to use a wheelchair instead of walking. Choosing to use a power chair instead of self - propelling. Less independent in manual wheelchair than power wheelchair. Able to keep up with peers better in wheelchair. Can't use communication aid when moving. Balance to ensure you move enough to maintain physical abilities but not to be physically and mentally exhausted / unable to participate following physical effort / causing damage to body due to movement. More independent in a wheelchair than a standing or walking frame.
Category and barrier: Boring and / or repetitive activities	Exercises on physiotherapy programmes can be boring and repetitive. Often recommended to be done daily. Lack of motivation and lack of incentives to do physio.
Category: Covid-19	All barriers related to covid
Advise for maintaining physical activity not appropriate for non-ambulant young people	Can't walk outdoors for exercise as government recommended. Being outdoors in wheelchair is not being physically active. Many online resources weren't appropriate for those with disabilities. The online resources that were produced for wheelchair users were limited. "Where is the disabled Joe Wicks?"
Demands on parents	Increased social pressures. Less able to help child to move due to working from home or caring for siblings who weren't at school.

Barrier/ Facilitators	Description
Deterioration in physical health and wellbeing	Increased risk of common comorbidities. Increased pain, worsening scoliosis / contractures. Risk of increased surgery in the future. Increased anxiety. Hip dislocation. Irreversible physical changes. Decision to stop walking using a Knee Ankle Foot Orthosis during lockdown. Feeling trapped. Reduced fitness levels. Reduced strength and stamina. Not sleeping well leading to tiredness for individuals and parents / carers. Feeling unmotivated. Finding lockdown mentally challenging.
Disability events and activities closed or cancelled	No access to swimming. Clubs closed due to lack of funding. NAIDEX disability exhibition cancelled.
Increased screen time and virtual services	Including virtual learning / therapy. Difficulties engaging with virtual interactions. Prolonged periods of time sitting still using screens. Less variety in daily activities. Less movement in online activities such as drama than there would be face to face.
Inequality increased	Varied what families could access depending on the resources they had available. May not be able to access online resources. May be confined to a small space. No garden. When NHS services stopped or reduced, couldn't afford to have private physio instead. Stigma around not wearing a mask when you have a disability. People less accepting of wheelchair users since lockdown - concerned they have covid. Society moving backwards in relation to disability. Parents made redundant.
Not attending school or school resources limited	Less movement opportunities. Moved more at school. No PE. Teaching poor quality during the pandemic. Minimal contact from schools.
Prolonged reduced social interaction	Reduced contact with friends and teachers. Reduced contact with other families with children with disabilities. Bubbles in school. Young people have felt forgotten and sad. Separated from peers. Can't engage in movement with peers. Single parents felt isolated and trapped with disabled child.

Barrier/ Facilitators	Description
Reduced access to equipment	No access to wheelchair services so sitting in inappropriate wheelchairs. Not having power chair at home limited independence. Didn't have Innowalk at home, would have been really helpful. Not able to bring toys into school for therapy sessions. Insufficient space at home to store equipment normally accessed at school. School didn't offer for equipment to be sent home. Not able to get equipment reviewed or adjusted if outgrown. Inability to share equipment due to risks of cross infections.
Reduced access to healthcare services	Prolonged reduced access to face to face appointments as staff redeployed. Reduced access to therapy and medication (baclofen / botox). Reduced services affected ability to move. Increased strain on services. No communication from professionals. Delayed surgery. Uncertainty. Lost time. Provision specified in education healthcare plans not adhered to. Accessing private services as an alternative. Difficulty timetabling convenient online sessions. Difficult to manage healthcare for those transitioning during the pandemic. Coronavirus act 2020 removed legal obligations on responsible authorities to provide services. Local authority only needed to endeavour to provide services.
Reduced movement	More sitting and lying time. Risk of reduced motivation. Reduced walking distances. Reduced confidence to move. Step count of ambulant wheelchair user dropped.
Shielding or limited opportunities to go out	No 1 hour of outdoor exercise if shielding. Not being able to go out. Young person dislikes being at home, so doesn't engage / not motivated to do an exercise program. Results in doing less than normal. Being confined to a small space. If shielding and no garden can't go outdoors.
Category: Education and Healthcare Plans	Physical activity not prioritised / supported in plan. Plans being out of date or inappropriate is a longstanding issue. Physical activity section not enforceable by law. Only educational aspects can be appealed. Limited capacity and capability of professionals to keep plans up to date and appropriate. Not adhered to in COVID. Reluctance form professionals to state specifics e.g. hours of input in plans. Parents have to chase to get

Barrier/ Facilitators	Description
	anything done that isn't in the plan. Plans not individualised.
Category: Individual's characteristics, feelings and experiences	
Age	Older children have more pain and stiffness. Children's size and weight increases making it harder to get out of wheelchair and to be active. Spending longer sitting. Increased focus on academic work. Schools larger. Appearance of equipment not age appropriate e.g .trikes. More fearful of injury, more aware of consequences. More aware of differences to peers. Younger children reluctant to do physio. Making mobility choices when older e.g. choosing to stop walking or power chair over manual chair. Younger children don't understand why moving is important. Needing more help from adults when maturing is the opposite experience to able-bodied young people, who need less help.
Cognitive capability	Learning disability / difficulty. Too young to understand long term consequences of mobility decisions. Processing difficulties e.g. autism / brain injury. Appropriate resources and rewards needed for all cognitive levels in interventions. Tailoring conversations about movement to individual's level of understanding.
Dislike of being different	Wanting to be seen as normal. Being looked at because you are a wheelchair user. Not volunteering to take part in things to protect against negative reactions. Not liking needing to wear splints due to appearance. Not wanting to be seen using a trike. Becoming more aware of differences to peers with age. Loss of confidence due to reduced physical ability in comparison to peers in mainstream school.
Experiences of prolonged sitting and lying	Limited experience of moving. Habitual sitting e.g. for mobility in school. Some children are predominantly lying down prior to starting school. Capable of moving but not knowing how to. Not been helped to move by parents.

Barrier/ Facilitators	Description
Negative emotions in when unable to move	Frustration. Guilt. Feeling scared of consequences of not moving e.g. surgery / increased pain. Feeling should move despite pain. Pain is necessary. Children feeling they are to blame for not moving when they haven't had help to move.
Feeling trapped	Stuck indoors. Not feeling able to move or do things. Stuck in bed. Fear of getting stuck due to limitations of power chairs - battery life, not waterproof, punctures. Lightweight manual chairs not a good enough alternative when power chair is broken.
Not feeling able to express an opinion	Power difference between school staff / carers and child. Can't express if don't feel safe when moved / want to rest / want to move more. Afraid of consequences.
Reduced health and wellbeing	Poor health / wellbeing is a barrier to moving, not the result of not moving. e.g. pain prevents movement / fatigue or tiredness / poor sleep / feeling negative / poor mental health or being stuck in bed / limited ability to multitask due to diagnosis e.g. move whilst doing school work with brain injury. Unpleasant / disappointing / hurtful experiences in relation to moving. Sensory impairments e.g. autism / visual impairment. Breathlessness misunderstood due to limited experience.
Limited Physical Capability	Physical limitations, activities are too hard, progressive weakness / crouching, injury, illness, dislocated hips, not being able to do bimanual activities (one impaired hand). Botox not effective. Poor outcomes of surgery. Limited cardiovascular fitness. Fractures. Not able to sit or stand. Need to do activities in lying. Not able to compete with able-bodied people in mixed sports. Arthritis prevents self-propelling. Core strength deteriorates when not self-propelling.
Young person doesn’t want to move or chooses to sit or lye	Feels comfortable / safer in their chair. Fearful of moving out of chair. Moving not important to them. Preference for sedentary activities. Not understanding associated benefits and risks. Not confident / motivated. Challenging behaviour. Gender differences. Reducing handling. Wants help with activities of daily living. Moving effortful. Exercises boring. Not trusting staff moving them. Fearful of being moved by others. Feeling

Barrier/ Facilitators	Description
	lazy. Bad experiences. Not a goal for that young person. Will move at school but doesn't want to at home. Finds moving too tiring and effortful. Parents want child to move and child tries for them. Feeling self-conscious.
Not succeeding	Experiences of lack of success when moving. Comparison with able-bodied peers. Doing activities in mixed ability groups with able-bodied peers. Withdrawing from activities because you are always the least successful in a mixed ability group.
Category and barrier: Knowing how to facilitate more movement	Poor inclusion. Staff / family confidence, training, experience. Less support for moving at mainstream vs special school. Understanding individual's medical needs. Skill sets and confidence of coaches. Education about conditions. Conflict with professionals over nature of movement. Specifying how young person should move is unhelpful. Having expertise and resources to create appropriate interventions. Interventions for the general population not always beneficial for this group. Enabling good quality of movement. Required frequency of movement opportunities.
Category and barrier: Multiple demands on families	Siblings. Working. Not being able to work to care for child. Work involved in bringing up a disabled child is considerably more. Help needed for most tasks. Relentless chasing of services. Young people reliant on parents. Parents problem solving. Can something be done, if so, how? Parents feel isolated / lonely without support of others with disabled children.
Category and barrier: Not having support from others to move	Excluding family attitudes as covered above. Effort required by staff to achieve movement / follow professionals recommendations. Limited opportunities to move. Lack of encouragement / motivation from others. School staff not supportive. Providing movement opportunities in school shouldn't be optional. Less support for movement in mainstream schools in comparison to special school. Navigating and negotiating access to services and funding is complex. Difficulty accessing activities is demoralising. Negotiating and fighting for services. Feeling demoralised. Conflict with professionals. Feeling "swept under the carpet". Special school staff fear incorporating movement into sensory sessions clashes with

Barrier/ Facilitators	Description
	educational targets and teachers would not meet requirements if assessed on their performance. Independence removed if wheelchair is stored where an individual can't reach it or people are admitted to hospital urgently and can't take their wheelchair. Ageing parents not physically able to help.
Peer support	Peers not interested in physical activities / prefer doing seated activities. Peers choosing to do different physical activities you can't access (e.g. wrong area / affordability). Peers can't afford to access the activities you do, or you can't afford to access what they do. Difficulty making friends and being included in activities in mainstream school.
Category and barrier: Not knowing about appropriate local facilities	Lack of awareness about what facilities are available locally.
Category: Planning for movement	
Accessing appropriate equipment	Sharing with others. Supply delays. Outgrowing. Breakages / waiting for repairs. Knowing what's available. Availability of sports wheelchairs. Equipment doesn't meet needs e.g. power chairs unreliable for outdoors (electrics not waterproof/ get punctures) / doesn't fit properly / needs changing following surgery / needs adjusting. Limited access to / waiting for power chairs. Equipment stored too far away. Needing to self fund wheelchair via charity and NHS voucher to meet needs. Lack of home equipment or it doesn't allow independence in activities of daily living. Lack of accessible equipment in gyms. Sports wheelchair goes to able-bodied person in activities with mixed able bodied-people and wheelchair users. Hoist doesn't cover floor space. Not having access to bath / hot tub. Equipment breaks if used for sport when not designed for it. Wheelchair not taken to hospital in emergency admissions. Conditions applied by local authority to use of electric chair – no outdoor use including at school (can't go out at lunchtime / change buildings). Can use

Barrier/ Facilitators	Description
	electric chair outdoors to move between house and taxi to school only.
People needed	Availability of trained people needed to facilitate movement. Lack of help increases sitting time. Two people needed to hoist, maybe only one parent at home. Limited number of stands / week in school due to people needed. Parents working. Insufficient people is a barrier to going out.
Remembering	Not forgetting movement opportunities.
Safety	Risk of injury to parents / carers by moving and handling. Parents having back injuries / frozen shoulder. Risk of injury to young person whilst moving / being moved. Having the correct number of people to move safely. School staff have safety concerns. Spaces are safe and clean. Risk of glass / dog fouling on ground outdoors. Need to be in wheelchair outside of home environment. Ensuring sports participation is safe.
Space	Size of space is appropriate. Limited space at home. Room for a hoist. Hoist only covers small area. No garden. Flat spaces for trikes. Secondary school too large to self propel around.
Time	Young person / staff / family members all need time for moving. Timetabling around individual's needs. Young people have limited time. Many appointments / therapy time. School / homework / takes longer. Personal care / preparing to go out and coming home takes longer. Doing things for the child is faster. Not enough time to go out. School won't commit to a timetable. Lack of flexibility in staff / professionals availability. Waiting for equipment when sharing. Special school staff only have time for bare minimum. Can't manage a second stand. Insufficient time to meet request from child to move in school. Mainstream school staff having time to plan inclusive activities.
Transport	Needing to travel further to activities than able-bodied people do e.g. ferry to mainland to attend disability sport. Travelling long distances tiring at end of day. Distances between classroom and disabled toilets. Not having a wheelchair accessible car. Can't transport

Barrier/ Facilitators	Description
	power chair so have to use manual chair. Wheelchair accessibility on public transport / coaches. Reliant on parents for transport.
Category and barrier: Reasons to be in sitting or lying	Activities such as eating and drinking, mobility in wheelchair, communication, travel on bus, academic work. Postural support / care. Choosing to lie down or rest to reduce pain and improve concentration. Improved function sitting vs lying. Lying down to stretch. Getting good sleep / resting. Needing to rest after physical activity. Aiding digestion. Relaxing with family. Part of physiotherapy - gaitors / long sitting. Poor weather outdoors. Yoga.
Category and barrier: Screen time	Reducing screen time. Screens are easy entertainment. Gaming is a safe activity. Online gaming. TV. You tube. Solitary or playing with peers online. Gaming increased in COVID-19
Category and barrier: Transition Points	Children's to adult services. Primary to secondary. Secondary to college. College to university. Reduced services. Lack of continuity of provision. Sudden change in expectation on the individual. Sudden change in language used and information shared. Difficult for service users to understand. Paediatric services should be more blunt about risks with older children and empower them to take charge. Changes should begin in paediatric services so more gradual. Starting to attend appointments independently. Health packages focus on medical needs, not physical activity. Shock for parents. Sadness. Fighting to protect services. Staying at home after leaving school.
Facilitators	
Category: Attitudes of others	
Family attitudes and routines in relation to movement	Quality time, gives hope, doing activities together. Fighting for services and equipment. Parents are advocates for promoting movement. Resilience. Parents are positive and encouraging about movement. Parents want child to walk. Parents asking for movement tasks to be done at school and requesting feedback.

Barrier/ Facilitators	Description
Professionals beliefs, attitudes, behaviours	Child feeling respected and understood by teachers. Willing helpers. Can do attitude. Motivated adults / carers.
Understanding benefits of moving and risks associated with prolonged sitting	Moving important as affects all areas of life. Educating staff about importance of movement and promoting movement. Young person understanding early is better, this nurtures good behaviours. Discuss risks sensitively with child, use peers experiences. Awareness of evidence. People with disabilities leading training and education around physical activity for disabled people. Being aware children need opportunities to move. Being aware children may be uncomfortable if not moved.
Category: Availability of resources	
Access to activities and resources that suit the individual's needs	Including knowledge of what's available locally, disability sport, activities organised through school, ensuring activity meets child's specific needs, therapists identifying activities that are achievable for families and appropriate for child, structured activities, ensuring young person is successful in the activity, activity suits lifestyle, young person feels comfortable with activity, individualised activities, access to conductive education / MOVE program. Resources and rewards for all intellectual levels. Professionals supporting school staff to find activities for children with limited movement.
Therapies	e.g. rebound / hydrotherapy / music therapy / massage. Virtual access to therapy. Availability of therapy e.g. home and school, private therapy.
Facilities for wheelchair users	Wheelchair accessibility, knowledge of local facilities, indoor and outdoor facilities, soft play facilities, appropriate swimming facilities. Swimming pool / hot tub at home.
Funding	Charities. Being able to afford home equipment. Being signposted to grants.

Barrier/ Facilitators	Description
Category and facilitator: Being independent	Less reliance on support of others. Ability to transfer out of chair independently. Self-management of condition. Being independent raises self-esteem. Moving more opens doors. Freedom and independent control of movement e.g. in water / power chair. Choice. Using equipment to exercise independently e.g. motomed, innowalk. Dressing and showering independently. Non-essential straps being unfastened on equipment when safe to do so. Aspirations to be independent at university. Sense of achievement.
Category and facilitator: Being outdoors	Providing opportunities to access outdoor space. Fresh air, nature. Not being stuck inside. Good weather.
Category and facilitator: Competition and individual challenge	Motivating. Appropriate level of competition. Winning / being successful. Disabled people tend to be competitive with themselves in order to recover e.g. from surgery.
Category: Covid	
Being at home during lockdown	Moving more at home. Parents available to help. Had suitable equipment at home. Reduced time on travelling to and from school allowed more exercise.
Virtual health appointments	Convenience.
Category and facilitator: Having support from others to move	School staff / parents / carers are motivated. Physical aspect of healthcare is prioritised. Encouragement. Teamwork between families and professionals. Exercising with family. Promoting participation. Individual approach. Avoiding negativity. Being reminded and supported to move. Professionals' role is to support movement. Sensitive, careful conversations. Staff having the understanding, confidence, skills, experience needed to facilitate movement. Helping young people to be confident to move. Specialised help increases frequency of movement and position change. Seeing children move more creates new ideas for inclusion and games.

Barrier/ Facilitators	Description
Peer support	Belonging. Having peers with similar abilities / challenges / diagnosis. Exercising with friends. Shared experiences. Talking (applies for some, not all individuals). Motivating to do things with others. Social experiences. Meeting friends in walker. Peers learn child can move and play with them. Learning from each other. Fun with other children.
Category and facilitator: Improvements to health and wellbeing	Confidence. Increased appetite. Increased range of movement. Reduced muscle tightness. Building muscles. Reduced hospital visits / admissions. Reduced pain or increased comfort. Weight management. Pressure relief. Postural management (reduce contractures). Position change. Improved breathing. Aids digestion. Improves menstrual cycles (regularity and pain). Good for heart, lungs, bone density. Experience of being upright in standing frame. Preventing DVT. Quality of life. Sensory regulation. Different viewpoints e.g. being upright, side lying not lying on your back. Promotes growth. Internal organs have space to work properly.
Improving mental health	Making people happy, getting rid of frustration, feeling more positive, improved self-esteem.
Improving motor skills through movement	Spatial awareness, learning about body, motor control, building muscle, enabling good quality of movement.
Category: Individual's characteristics, feelings and experiences	
Age	Easier for young children to be out of chair. Better understanding of body with maturity. Older children request to walk / stand / be on the floor for comfort more often.
Physical abilities	Good legs.

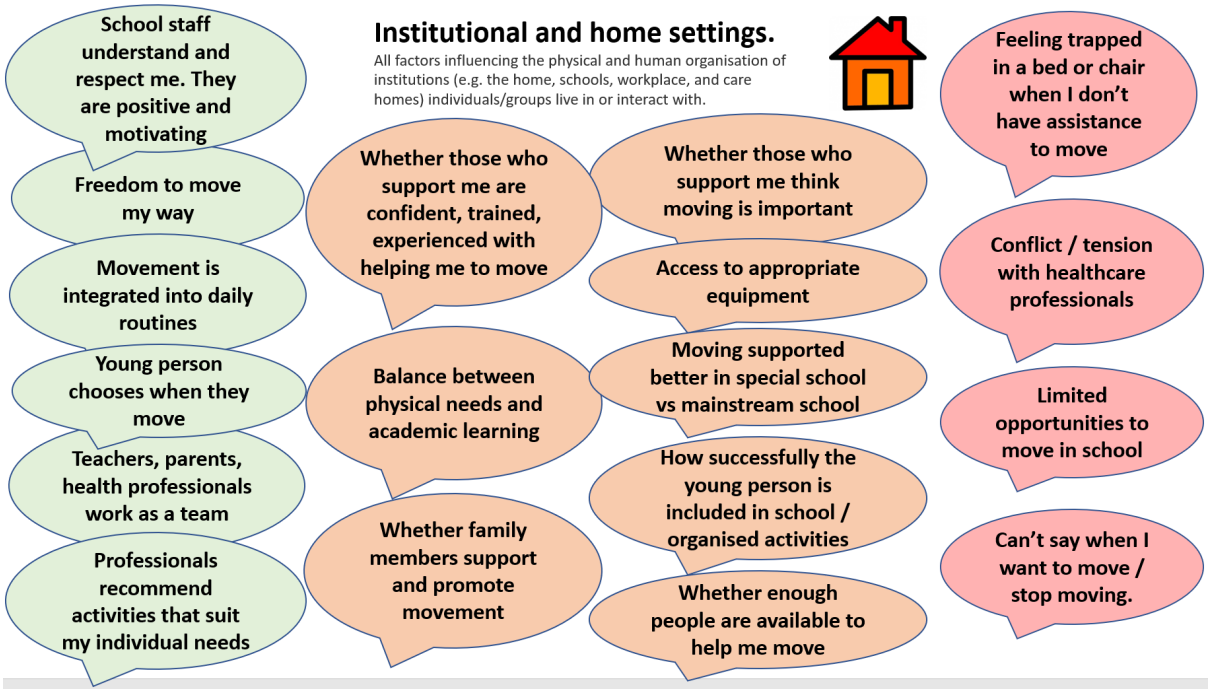
Barrier/ Facilitators	Description
Good medical management of condition	e.g. baclofen pump to control pain and spasticity. Changing anti dystonic medications to CBD due to side affects of previous medication. Complementary medicine e.g. Ayurveda
Involuntary movements	Involuntary movements increase movement, but aren't purposeful. Young person indifferent towards them (doesn't see them as problematic) as this is all they have experienced.
Resilience	Having resilience to pursue access to resources. Determination to recover and improve physical abilities / quality of life.
Young person wants to move	Having goals relating to movement. Moving for a reward. Feeling confident. Feeling inspired to move. Feeling motivated. Feeling positive. Enjoys the sensation. Likes to exercise. Feeling of freedom when moving. Sport gives a sense of purpose. Exercising is rewarding. Feels lazy if doesn't move. Having energy to move. Preventing boredom and isolation. Understanding of why they need to move more. Learning better in standing frame / when comfortable. Young person requests repositioning for comfort. Learns better when standing up.
Category: Making movement enjoyable	
Participating in fun, exciting, motivating activities	Including promoting participation, joining in, playing games, sport, being creative, swimming, cycling, yoga, chair yoga, pilates, boxing, forest school, using walker, work outs, team activities, boccia, rebound, frame football, sensology, switch activities. arts and crafts. Spending time with family. Visiting Ikea in walker.
Music	Music therapy, dance, wheelchair dance.
Pets	Assistance dog. Playing with pets on the floor. Hold the lead on walks. Taking dog to school.
Screen time that	Seated exercise. Therapy groups. Individual therapy. Exergaming. Active screen time is emerging through

Barrier/ Facilitators	Description
promotes activity	COVID-19. TV / gaming in standing frame. You tube channels for wheelchair exercise and dance.
Category: Planning for movement	
Accessing equipment	Appropriate wheelchair e.g. motorised / active user chair. MotoMed bike, standing frame, walker, hoist at home, school equipment. Power chair that allows reaching / standing position. Equipment available at home. School offer equipment at home in the holidays. Access to own suitable equipment. Trikes and bikes. Hydro pools, hot tubs, bath. Standing hoist slings. Equipment comfortable e.g. Ankle Foot Orthoses. Outdoor equipment e.g. gym equipment, play areas. Equipment stored in one close location. Trampoline. Manual handling equipment protects carers from injury. Comfortable alternative seating to wheelchair at home and school.
Having time to move	Young person / staff / family members all need time. Individual wanting to protect the small amount of time when they can choose the activity they do. Schedule movement breaks in schools. Feed child in standing frame to save time. Reframing thoughts that there isn't time to move.
Movement integrated into daily routines	Prompts to remember to move e.g. timetables / wearables / diary. Movement needs to be routine and habit. Housework / self-propelling / typing on a device / moving around the house to get things / dressing and showering / steering power chair. Frequently changing position, transferring or moving to a different room. Essential when living independently e.g. at university. MOVE program. Feeding child whilst in standing frame. Integrate movement into academic work. Unfasten non-essential straps on equipment.
People needed	Help to do facilitated stands. Carers helping young person to use pieces of equipment to move when the young person chooses to do it.
Safety	Clean, safe spaces. Ensuring sports participation is safe. Sufficient people.

Barrier/ Facilitators	Description
Space	Size of space is appropriate. Exercise away from clinical areas. Community gym / pool. Breakout spaces for movement in schools.
Transport	Being able to get to and from facilities.
Category: Transition	Maintaining some consistency through transition points, e.g. staying at same residential college for sixth form.

Appendix 8 Power point presentation summarising barriers / facilitators of sedentary behaviour which had potential for change

PowerPoint slides shared with participants for each SOS determinant: barriers / facilitators which are changeable via a digital intervention (shared prior to step 2 co-design workshops / interviews).



Psychology and Behaviour

Individual's/group's psychological and behavioural traits such as motivations and attitudes



Moving is enjoyable / fun / rewarding / inspiring

Moving stops me feeling isolated and being bored

Movement resulting in success and achievement

Having resilience and determination to improve

Minimising my reliance on others to help me move

Moving results in increased freedom, choice and independence

Learning is easier when I'm comfortable from moving regularly

Moving and being independent improves my confidence and self esteem

The right level of competition and competitiveness for me

Remembering to move when there is an opportunity to

Dislike of feeling different / comparison with able bodied peers

I'm not confident / I feel scared when moving

Guilt / fear of consequences if not moving regularly

Not having support to move is demoralising and independence is lost

I prefer doing other things

Not succeeding in physical activities in mixed ability groups.

Built and natural environment

The physical environment that individuals/groups live in and interact with. This includes the natural environment factors such as weather or built environment such as the physical layout of towns.



Being outdoors in the fresh air and with nature

Access to clean and safe spaces indoors and outdoors where I can be on the floor

Physical Health and Wellbeing

Everything related to an individual/group's health and wellbeing, including (but not limited) to their personal health status. For example, including systems for provision of health care or health enhancing facilities.



- Knowledge that moving more has lots of physical benefits
- Feeling better because I move regularly
- Experiencing improved control / quality of movement
- When my condition / symptoms are well controlled I can move more
- Fewer medical appointments / operations because I move regularly
- Poor mental health reduces motivation to move
- Moving is painful / tiring
- Recommended exercises can be boring / repetitive
- Needing to sit or lie for postural care / eating / drinking / transport / rest / work / communication
- Choosing increased independence over movement opportunities
- Limited experience of moving / sitting up

Society and Culture

The social environment that individuals/groups live in, the culture they were educated in and interact with.



- Having active role models (including role models with disabilities) and learning with friends
- Feeling accepted and like I belong to this community
- Active screentime: virtual exercise opportunities / active video gaming
- Activities that involve music
- Pet ownership
- Access to organised activities
- Whether friends encourage me to move more, or not
- Knowledge of local facilities
- Opportunities to move reduce at transition points between educational settings or childhood to adulthood
- People have been disgusted by my disability or are unfriendly, so I avoid getting involved in things, which limits my movement
- Society creates barriers to moving. Negative perceptions, low expectations, stigma
- Navigating / negotiating / fighting for services
- Concern from other people that it isn't safe for me to move
- Exercise isn't encouraged or weight gain is encouraged in some cultures
- Girls can be less active than boys and may avoid physical contact with others
- Being excluded from activities
- Reduced participation in society
- Being stuck at home after leaving school
- Inactive screen time: easy entertainment, safe, provides peer interaction

Politics and economics

Political and economic factors that influence the civic life of individuals/groups at international, national, regional and individual scales.



Good signposting to grants

Charity funding

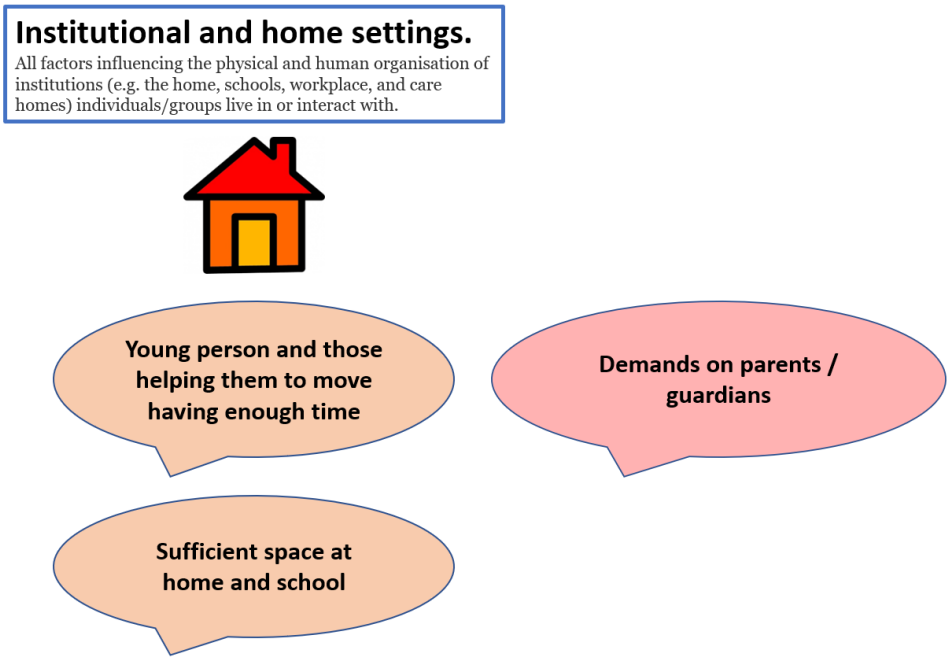
Able to purchase home equipment

Public funding for activities is withdrawn if uptake is low

Identifying and accessing funding opportunities is complex

Appendix 9 Power point presentation summarising barriers / facilitators of sedentary behaviour which were not amenable to change

PowerPoint slides shared with participants for each SOS determinant: barriers / facilitators which are not changeable via a digital intervention (shared prior to step 2 co-design workshops / interviews).



Psychology and Behaviour

Individual's/group's psychological and behavioural traits such as motivations and attitudes



How I process information from the world around me

Older children more: aware of differences, fearful of injury, aware of benefits

Built and natural environment

The physical environment that individuals/groups live in and interact with. This includes the natural environment factors such as weather or built environment such as the physical layout of towns.



Exercise facilities in community not clinical settings

Accessible swimming soft play, outdoor playground facilities

Access to a hoist, and the areas the hoist reaches

Wheelchair accessibility

Inappropriate facilities limits sports participation

Access to flat spaces for trikes

Weather

Distance you need to travel to reach organised activities

Access to accessible changing places / toilets

Power chair too wide for home use

Public pools too cold / no hydrotherapy pool

No bath at home

Vulnerable outdoors due to risk of power chair failing

Secondary school buildings too large to self propel around

Physical Health and Wellbeing

Everything related to an individual/group's health and wellbeing, including (but not limited) to their personal health status. For example, including systems for provision of health care or health enhancing facilities.



Risk of carers getting injured whilst moving me

Risk of injury when moving

Opportunities to participate in sport safely

Weak muscles / joint problems / altered muscle tone / injuries stop me moving

Access to therapy

Cognitive difficulties e.g. learning difficulty / disability

Society and Culture

The social environment that individuals/groups live in, the culture they were educated in and interact with.



Older children want to move to relieve pain / stiffness, but need more support due to size / weight

Only child = less play

Reliance on parents / guardians for transport

Politics and economics

Political and economic factors that influence the civic life of individuals/groups at international, national, regional and individual scales.



Low income = less space / home equipment / reduced access to private therapy/ organised activities

Inequalities in health and wealth

Participating in disability sports more expensive than able bodied sports

Fun / motivating activities usually cost more

Government policies don't support creation of accessible organised activities

Disability equipment expensive

Funding from medical negligence compensation can pay for resources to support movement

Access to an accessible vehicle

Physical activity not prioritised in Education and healthcare plans

Parents can't work as caring for their child

Local authority impose restrictive rules about power chair use

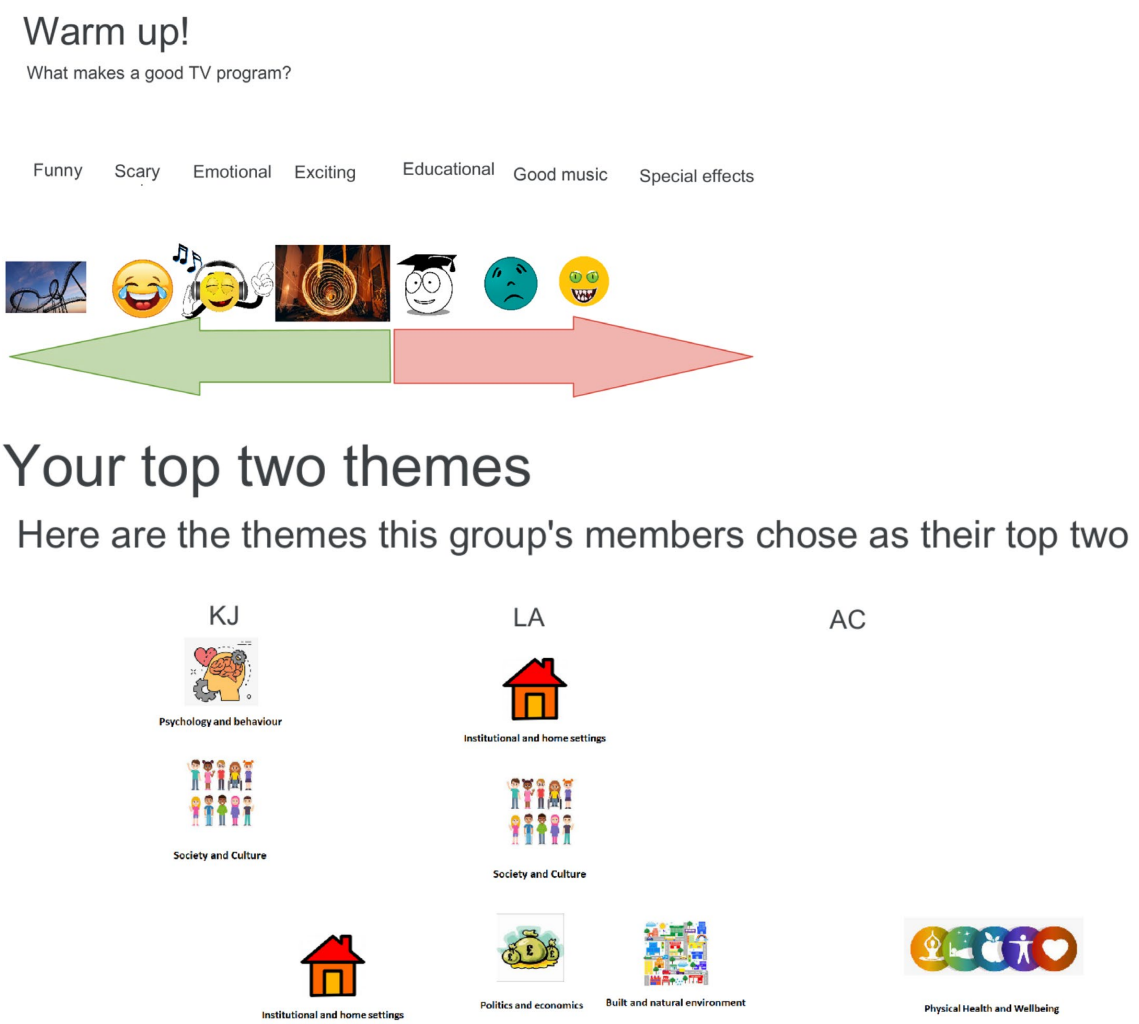
Schools have insufficient funds to deliver education and healthcare plans

Lack of funding for accessible organised activities

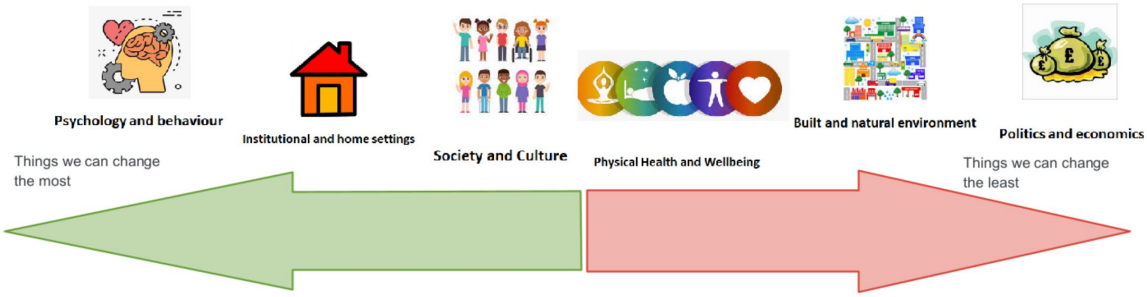
Local authority don't fund trikes or walkers

Appendix 10 Jamboard template for step two

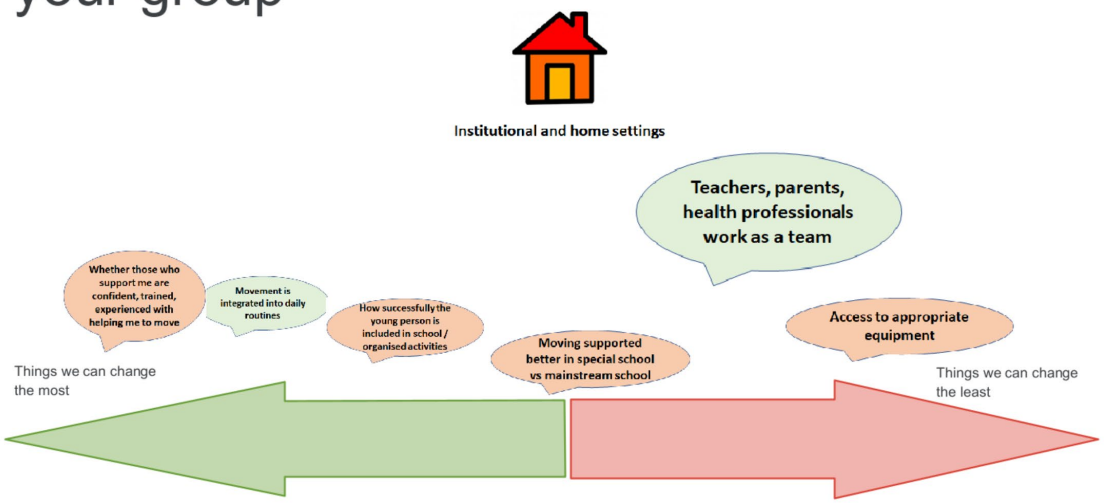
Example of a completed Jamboard from step 2 virtual co-design workshop.



What can we change with our intervention? Ordering the themes.



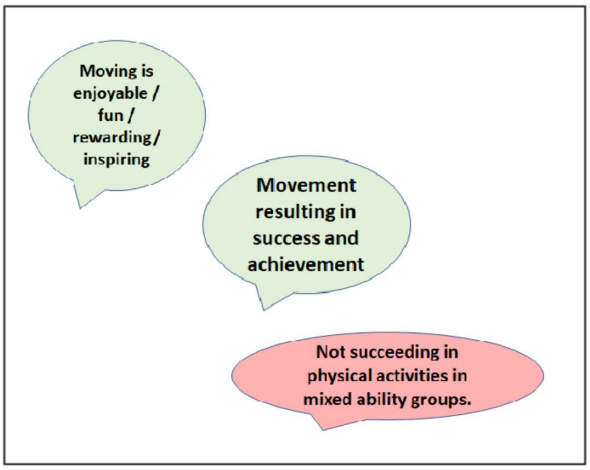
Speech bubbles previously chosen by your group



Speech bubbles for the group's top 2 themes

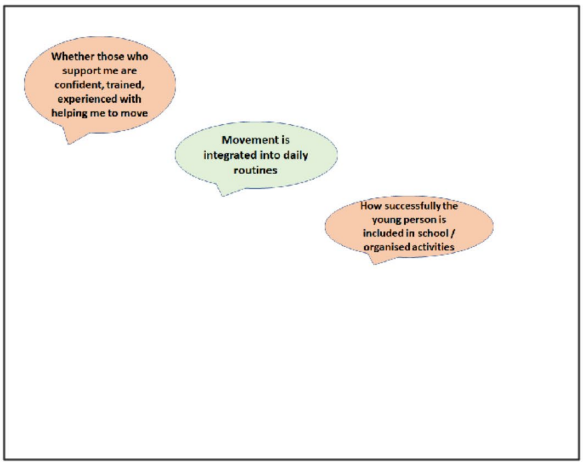
Theme 1= Psychology and behaviour

Speech bubbles



Theme 2 = Institutional and home settings

Speech bubbles



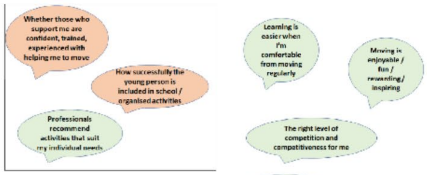
Feedback: What other groups have said

Workshop 1



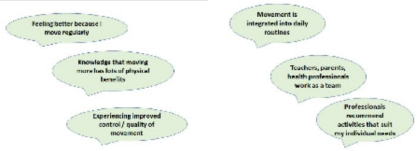
Interview 1



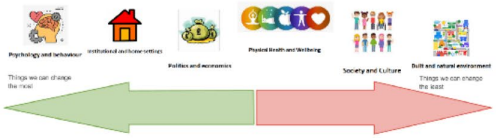


Workshop 2





Interview 2





Any changes?

Speech bubbles for the group's top 2 themes

Theme 1=

Speech bubbles

No changes

Theme 2 =

Speech bubbles

No changes

Appendix 11 APEASE criteria for selected behaviour change techniques from the Behaviour Change Taxonomy (v1) (Michie et al., 2013)

Behaviour change technique (MoveMore goal number)	**APEASE for Behaviour change techniques. APEASE: Affordability, practicability, effectiveness/cost effectiveness, acceptability, side-effects/ safety, equity**
For all the Behaviour change techniques:	**Affordability** – NAYP and AS need internet access and devices to access the app. The large majority of the UK population have this. **Equity for all of the BCT's –** When internet and device access is not possible this creates inequality as the intervention digitally delivered. Other accepted digital interventions are delivered this way despite this inequity. When AS / NAYP cannot speak English this creates inequity for accessing this intervention at present. It is planned that this will be addressed following evaluation of effectiveness.
1.1 Goal setting (behaviour) (4)	**Affordability –** time implications for AS resulting in an indirect cost to organisations **Practicability** and **acceptability** will be dependent on culture, attitudes, capacity and capability (including in relation to digital skills to enter information in app) of the young person and their AS in the specific context. There is an evidence base for **effectiveness** of using this BCT in rehab with this population**.** **Equity** - variable contexts will have a negative effect on the **equity** of using this technique. **Side effect / safety** – No concerns
1.2 Problem solving (2, 3, 5)	**Affordability –** time implications for AS resulting in an indirect cost to organisations **Practicability** and **acceptability** will be dependent on culture, attitudes and capacity of the young person and their AS in the specific context. **Effectiveness** is reliant on local resource and culture so whether problems can be addressed will vary depending on context and the problem in question. **Side-effects / safety** unlikely to be issues provided safety / side effects taken into account during problem solving. **Equity** - variable contexts will have a negative effect on the **equity** of using this technique. Using problem solving will be more successful where there is greater resource and an existing culture of prioritising movement, so it has potential to exacerbate health inequalities.
1.4 Action planning (2, 3, 5)	**Affordability, practicability** – only plans that are affordable and practical in the local context should be made. Time

	implications for AS resulting in an indirect cost to organisations. Will be dependent on culture, attitudes, capacity and capability (including in relation to digital skills to enter information in app) of the young person and their AS in the specific context. **Effectiveness, acceptability** - reliant on local resource (what can be planned that is affordable and practical) and culture. **Cost effectiveness, side-effects / safety** - unlikely to be issues provided safety / side effects / cost considered when plans are made. **Equity** - variable contexts will have a negative effect on the **equity** of using this technique. It has potential to exacerbate health inequalities.
1.5 Review Behaviour goals (4)	**Affordability** – time implications for AS resulting in an indirect cost to organisations **Practicability** and **acceptability** will be dependent on culture, attitudes and capacity of the young person and their AS in the specific context. There is an evidence base for **effectiveness** of using this BCT in rehab with this population**.** **Equity** - variable contexts will have a negative effect on the **equity** of using this technique. **Side effect-** NAYP / team demotivated by lack of progress against goals **Affordability / safety** – No concerns
2.3 Self-monitoring of behaviour (2, 4)	**Affordability –** additional cost of wearable devices is within budget **Practicability –** NAYP may need assistance from AS to enter and review information. Regularity of reporting required will influence practicability. **Effectiveness –** effectiveness may be influenced by what AS learn from the self-monitoring in addition to the NAYP. NAYP likely to be reliant on AS to achieve the desired change highlighted by the self-monitoring. **Acceptability –** Appearance / comfort of wearable device important. Fit bit has been more acceptable to NAYP than other devices in previous studies involving NAYP. Regularity of reporting required will influence acceptability. **Side-effects/ safety –** NAYP requests more support with movement than there is capacity to offer **Equity –** Some NAYP may need assistance from AS to enter and review information, others will be able to do it independently
2.4 Self-monitoring of outcomes of behaviour (5)	**Practicability -** NAYP may need assistance from AS to enter and review information. Regularity of reporting required will influence practicability. **Effectiveness -** effectiveness may be influenced by what AS learn from the self-monitoring in addition to the NAYP. NAYP

	likely to be reliant on AS to achieve the desired change highlighted by the self-monitoring. **Acceptability -** Reporting of comfort was identified as sensitive and complex in the co design, but too important to remove. Local flexibility in reporting will be offered to increase acceptability to overcome this. **Side-effects/ safety -** Communication about discomfort exacerbates chronic pain. NAYP reports discomfort to switch focus away from things they don't wish to do (e.g. school work) **Equity -** Some NAYP may need assistance from AS to enter and review information, others will be able to do it independently
3.1 Social support (unspecified) (2,3,4,5)	**Affordability –** time implications for AS resulting in an indirect cost to organisations **Practicability** – No concerns **Effectiveness -** Likely to be integral and essential to intervention change mechanism of promoting autonomy, competence, relatedness. **Acceptability** will be dependent on culture, attitudes and capacity of the young person and their AS in the specific context. **Side-effects/ safety** – no concerns **Equity** – reduced resource available for other individuals in the setting
12.2 Restructuring the social environment (2, 3, 4, 5)	**Affordability –** a consequence of other BCTS's in the intervention so no cost. **Practicability** – No concerns **Effectiveness** Will need to test to establish if communication and actions triggered by the app is powerful enough to elicit social change **Acceptability** will be dependent on culture, attitudes and capacity of the young person and their AS in the specific context. **Side-effects/ safety,** **Equity** – variable contexts will have a negative effect on the **equity** of using this technique.
13.2 Framing / reframing (5)	**Affordability** – time implications for AS resulting in an indirect cost to organisations **Practicability-** no concerns, deliver material via app / guidebook with input by AS **Effectiveness -** Will need to test to establish if communication and actions triggered by the app is powerful enough to reframe how movement can help with comfort / learning for NAYP and AS **Acceptability** - engagement will be dependent on culture, attitudes and capacity of the young person and their AS in the specific context. **Side-effects / safety –** no concerns

	Equity – variable contexts will have a negative effect on the **equity** of using this technique.
16.3 Vicarious consequences (5)	**Affordability** – no concerns **Practicability** – no concerns **Effectiveness** - will be dependent on culture and attitudes the AS in the specific context. May foster healthy competition between settings to be doing a good job. **Acceptability** dependent on culture and attitudes the AS in the specific context. **Side-effects/ safety** - No concerns **Equity** - variable contexts will have a negative effect on the **equity** of using this technique.
5.1 Information about health consequences (1)	**Affordability** – Is affordable but some of the available budget will be required to produce high quality content. **Practicability –** careful consideration of accessibility of information and AS having the time / skills to look at it with young people. **Effectiveness** – will be dependent on motivation of NAYP and AS to access the information and getting modes of delivery right so information is accessible as possible. Will vary across contexts. **Acceptability –** presentation of information needs to be positive where possible and use non-controlling informational language in order to fit with SDT theoretical basis and be sufficiently inclusive to be acceptable. **Side-effects/ safety** - negative reaction to information e.g. fear / guilt / feeling of needing to change but not having capability to do so. NAYP feels they should tolerate discomfort for health benefits of moving. **Equity**- Will be inequitable for non-English speaking families / those where English is not their first language at present (to address once intervention effectiveness demonstrated) variable contexts and sensory / cognitive impairments will have a negative effect on the **equity** of using this technique.
5.3 Information about social and environmental consequences (1)	**Affordability** – Is affordable but some of the available budget will be required to produce high quality content. **Practicability –** careful consideration of accessibility of information and AS having the time / skills to look at it with young people. **Effectiveness** – will be dependent on motivation of NAYP and AS to access the information and getting modes of delivery right so information is accessible as possible. Will vary across contexts. **Acceptability –** presentation of information needs to be positive where possible and use non-controlling informational language in order to fit with SDT theoretical basis and be sufficiently inclusive to be acceptable.

	Side-effects/ safety - negative reaction to information e.g. fear / guilt / feeling of needing to change but not having capability to do so. NAYP feels they should tolerate discomfort for social / environmental benefits of moving. **Equity**- Will be inequitable for non-English speaking families / those where English is not their first language at present (to address once intervention effectiveness demonstrated) variable contexts and sensory / cognitive impairments will have a negative effect on the **equity** of using this technique.
5.6 Information about emotional consequences (1)	**Affordability** – Is affordable but some of the available budget will be required to produce high quality content. **Practicability –** careful consideration of accessibility of information and AS having the time / skills to look at it with young people. **Effectiveness** – will be dependent on motivation of NAYP and AS to access the information and getting modes of delivery right so information is accessible as possible. Will vary across contexts. **Acceptability –** presentation of information needs to be positive where possible and use non-controlling informational language in order to fit with SDT theoretical basis and be sufficiently inclusive to be acceptable. **Side-effects/ safety** - negative reaction to information e.g. fear / guilt / feeling of needing to change but not having capability to do so. NAYP feels they should tolerate discomfort to experience emotional benefits of moving. **Equity**- Will be inequitable for non-English speaking families / those where English is not their first language at present (to address once intervention effectiveness demonstrated) variable contexts and sensory / cognitive impairments will have a negative effect on the **equity** of using this technique.
7.1 Prompts / cues (2)	**Affordability** – yes within budget **Practicability** – technique suited to delivery via app **Effectiveness** - will be dependent on culture, attitudes and capacity of the young person and their AS in the specific context. Digital prompts / ques could easily be ignored if NAYP and AS not engaged. **Acceptability-** unlikely to not be negatively received, but may be ignored. **Side-effects/ safety:** Conflict between AS / NAYP in relation to adherence to the prompts / cues. **Equity -** Will be inequitable for non-English speaking families / those where English is not their first language at present (to address once intervention effectiveness demonstrated)

	variable contexts and sensory / cognitive impairments will have a negative effect on the **equity** of using this technique. Could be mitigated to some extent by using pictures / symbols
(9.1 Credible source) (doesn't match to education, intervention function, is persuasion) (1)	**Affordability** - is affordable for initial set up but some of the available budget will be required to produce a variety of high quality content. Ongoing resource implications to continue this long term and keep it up to date need to be considered. **Practicability** – will require ongoing resource as above and management / updating of app regularly **Effectiveness** – supported by co-design workshop data **Acceptability** – supported by co-design workshop data **Side-effects/ safety** – some individuals may reject voice of authority more than receiving info from AS. Could include flexibility to adapt intervention locally in handbook to mitigate. **Equity -** Will be inequitable for non-English speaking families / those where English is not their first language at present (to address once intervention effectiveness demonstrated) variable contexts and sensory / cognitive impairments will have a negative effect on the **equity** of using this technique.
4.1 Instruction on how to perform a behaviour (3)	**Affordability** – no concerns, content locally produced. Time implications for AS resulting in an indirect cost to organisations **Practicality, effectiveness, acceptability** will be dependent on culture, attitudes, capacity and capability (including in relation to digital skills to enter information in app and to access it) of the young person and their AS in the specific context. AS need skills to produce the information. **Side-effects/ safety** -risk of out-of-date instructions followed leading to an incident or near miss. **Equity -** variable contexts, digital abilities of NAYP and AS and sensory / cognitive impairments will have a negative effect on the **equity** of using this technique. Encouraging use of pictures / symbols / audio to mitigate re: sensory and cognitive abilities.
8.1 Behavioural practice / rehearsal (3)	**Affordability** – time implications for AS resulting in an indirect cost to organisations **Practicability** - will be dependent on capacity and capability (including skills to facilitate movement, space, equipment, sufficient people available etc) of the AS in the specific context. **Effectiveness -** highly effective as directly involves NAYP moving. **Acceptability** – part of current practice in therapy / PE so is acceptable. Increasing regularity of this technique is the aim. **Side-effects/ safety** – AS need competence in facilitation skills**.** Activities attempted need to be safe. **Equity** - variable contexts will have a negative effect on the **equity** of using this technique (skills / confidence / motivation of AS, equipment, capacity, space etc)
2.2 Feedback on behaviour (4)	**Affordability** – no concerns

	Practicability- will be dependent on capacity and of the AS in the specific context. **Effectiveness** – unknown. Will need to be assessed in piloting. **Acceptability** – no concerns. NAYP are given feedback about other topics as part of education / therapy as part of standard practice. **Side-effects/ safety** – NAYP demotivated by the feedback if doesn't meet goals / expectations. Need to be autonomy supportive approach to mitigate this (SDT) **Equity** – ability to feedback to NAYP in an meaningful way taking into account cognitive / sensory impairments.
2.6 Biofeedback (4)	**Affordability –** additional cost of wearable devices is within budget **Practicability –** NAYP may need assistance from AS to put on wearable device and review information. NAYP / AS need digital skills to access information. **Effectiveness –** effectiveness may be influenced by what AS learn from the biofeedback in addition to the NAYP. NAYP likely to be reliant on AS to achieve the desired change highlighted by the biofeedback. **Acceptability –** Appearance / comfort of wearable device important. Fit bit has been more acceptable to NAYP than other devices in previous studies involving NAYP. **Side-effects/ safety –** NAYP requests more support with movement than there is capacity to offer as a result of the biofeedback **Equity –** Some NAYP may need assistance from AS to review information, others will be able to do it independently
10.1 Non-specific reward (4)	**Affordability** – local settings need to ensure any rewards (e.g. offering experiences for achieving progress) are affordable **Practicability -** local settings need to ensure any rewards (e.g. offering experiences for achieving progress) are practical. Digital rewards e.g. medals / unlocking need ability to individualise to suit NAYP needs **Effectiveness** – unknown. Will need to be assessed in piloting. Likely to vary between settings as rewards offered could be very different. **Acceptability** - Any activities offered as rewards need to be appropriate to families and individuals needs and resources. **Side-effects/ safety -** Any activities offered as rewards need to be safe **Equity** - variable contexts will have a negative effect on the **equity** of using this techniques rewards available will depend on local resources and opportunities.
10.4 Social reward (4)	**Affordability** – No concerns where reward is recognition of achievement. Local settings need to ensure any other rewards (e.g. offering experiences for achieving progress) are affordable.

	Practicability - no concerns where reward is recognition of achievement. Local settings need to ensure any rewards (e.g. offering experiences for achieving progress) are practical. Digital rewards e.g. medals / unlocking need ability to individualise to suit NAYP needs. **Effectiveness** – unknown. Will need to be assessed in piloting. Likely to vary between settings as nature of rewards offered will vary. **Acceptability** - No concerns where reward is recognition of achievement. Any activities offered as rewards need to be appropriate to families and individuals needs and resources. **Side-effects/ safety -** No concerns where reward is recognition of achievement. Any activities offered as rewards need to be safe **Equity** - No concerns where reward is recognition of achievement. Variable contexts will have a negative effect on the **equity** of using this techniques rewards available will depend on local resources and opportunities.

Note: NAYP: Non-ambulant young person AS: Adult supporters



Mobile App Handbook

Introduction



Welcome to the MoveMore App!

This handbook explains:

- **Who** the app is for
- **What** the app is for
- **Why** we developed it
- **Key Ideas**
- **How to use** each section
- **How** we developed it

If you have any questions about the app, please contact our team using this email address:

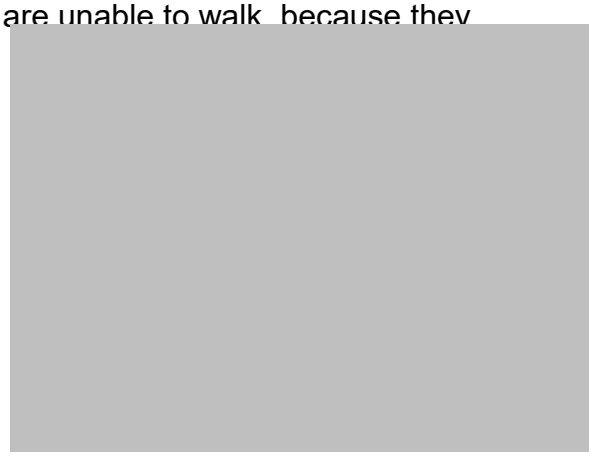
bchc.movemorestudy@nhs.net

We hope you find the app helpful and you enjoy using it!

Who the app is for

This app is for:

- **13 – 25 year-olds** who use a **wheelchair** and are unable to walk because they have a **long-term disability**.
- **Adults** who **support young people** who are unable to walk because they have a long-term disability (adult supporters).



The adult supporters who can use the app are:

- parents / guardians,
- carers,
- healthcare professionals,
- education staff,
- family members.

Young people who walk short distances indoors, using a walker that supports their body, perhaps as part of a physiotherapy programme or for exercise / fun can use this app. If the young person regularly uses a handheld wheeled walker, we'd advise choosing a different way to help them to move more.

What the app is for



This app **encourages** young people who use a wheelchair to **move more**. It uses a **Fitbit** to monitor how much the young person has moved. If you would like to know **more**, please **keep reading**. **If not, skip** to the **next section, "Why we developed it"**.

To explain in **detail**, the app aims to **reduce** the amount of **time** young people who use a wheelchair spend **sitting or lying down and not using much energy**. This is called sedentary time. We don't want to change anything about their sleep. We just want them to **move more during the day**, whilst they are **awake**.

The app helps the young person to **move** a **little more**, **more regularly**, throughout their day. The young person doesn't have to be exercising or moving enough to make them out of breath (although it is good to exercise!). The aim is for them to be **more active than they were before**.

Why we developed it



Research evidence tells us that young people with physical disabilities spend more time sitting or lying down and not using much energy (which is called sedentary time) than able-bodied young people. There is some evidence that differences in physical activity levels have widened during the covid-19 pandemic**. Sedentary time is linked to health risks such as obesity and higher blood pressure.** UK guidelines for disabled children and young people say being physically active helps with:

- meeting new people
- confidence and concentration
- sense of achievement
- mental health
- feeling calmer and less stressed
- balance and coordination

Some of the advice in the guidelines is below:

- For good health benefits, do 20 minutes of physical activity per day.
- When starting, build up slowly. Ask: can you do this today?
- Do bitesize chunks of physical activity throughout the day.
- Small amounts of physical activity are good for you as well.

The MoveMore app helps young people and their adult supporters with following this advice.

Key ideas

To develop the app, we held virtual workshops and interviews with **young people who could use the app,** their **families** and **health professionals**. We **made decisions** based on **what people in the workshops said to us**. We decided on 5 goals for the app, which are in the table the below.

MoveMore Goals	Goal description
1. Why move?	Know and understand the benefits of moving more and the risks of spending a long time sitting or lying still.
2. Planning to move	Identify and plan when and how young people can move more during daily routines. Review the plan regularly.
3. Preparing to move	Ensure the young person and their adult supporters feel confident about a movement and the young person feels safe before moving.
4. The experience of moving	The young person having a positive experience of moving.
5. Optimising comfort	Young person and adult supporters communicate about comfort and act to improve it if needed.

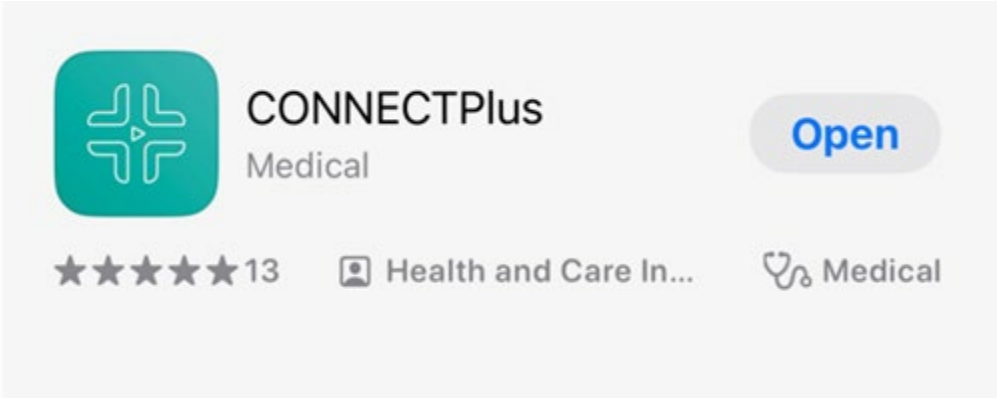
There are other key ideas that are central to choices we have made. They are:

- The **young person** should have as much **choice and control** over **when** and **how** they move as possible.
- The "magic ingredient" of the app is to **improve communication** and **generate conversations**. The app is a **tool** to help everyone to **know what**

the young person wants, what's being done in **different places they go to**, what is working and what could be improved.
- As much as possible, moving more should be **fun** or **meaningful**, or both!
- The app **supports transition** points (times of change) in young people's lives, e.g., moving from school to college, by recording their routines and achievements relating to movement.

Set up

- Download the CONNECTPlus app onto a device the young person can regularly access. The app looks like this:



- Young people accept the terms and conditions then create an account using their email address.
- They create a password.
- They verify their email by entering a code which is emailed to them into the app.
- We will email a link which the young person needs to click whilst they're on the same device that the CONNECTPlus app is downloaded onto. The MoveMore section of the app will then appear. Click on the MoveMore logo twice to enter the app.
- Once in the app, the young person can choose a picture to represent themselves or upload a photo of themselves by clicking the head and shoulders icon in the top right hand corner of the screen, clicking "Account" then "Profile Image" to upload a photo. This helps adults using the app with more than one young person to know whose account they are viewing.
- The Fitbit app also needs to be downloaded onto the same device. **Please sign in via google using the email account and password we will provide for you.**
- To link the young person's Fitbit to the MoveMore app: in the MoveMore app, click the head and shoulders icon or profile picture in the top right hand corner of the screen, click "Connections", select "Fitbit" and choose to log in via google.

- Enter the gmail email address and password we provided for your Fitbit log in and the Fitbit will be connected to the app.
- Please note, the “Conditions” and “Notifications” menus you see when you click on the head and shoulders icon / profile picture are not relevant to the MoveMore app.
- Your phone sends notifications to the Fitbit Versa 3 watch about messages / calls and physical activity levels. This includes notifications about reminders to move. For the MoveMore app, we’d advise turning these notifications off, as they won’t be appropriate for wheelchair users. There is information below about how to turn notifications off, from this website (Notifications from your phone | Fitbit Versa 3 User Manual):

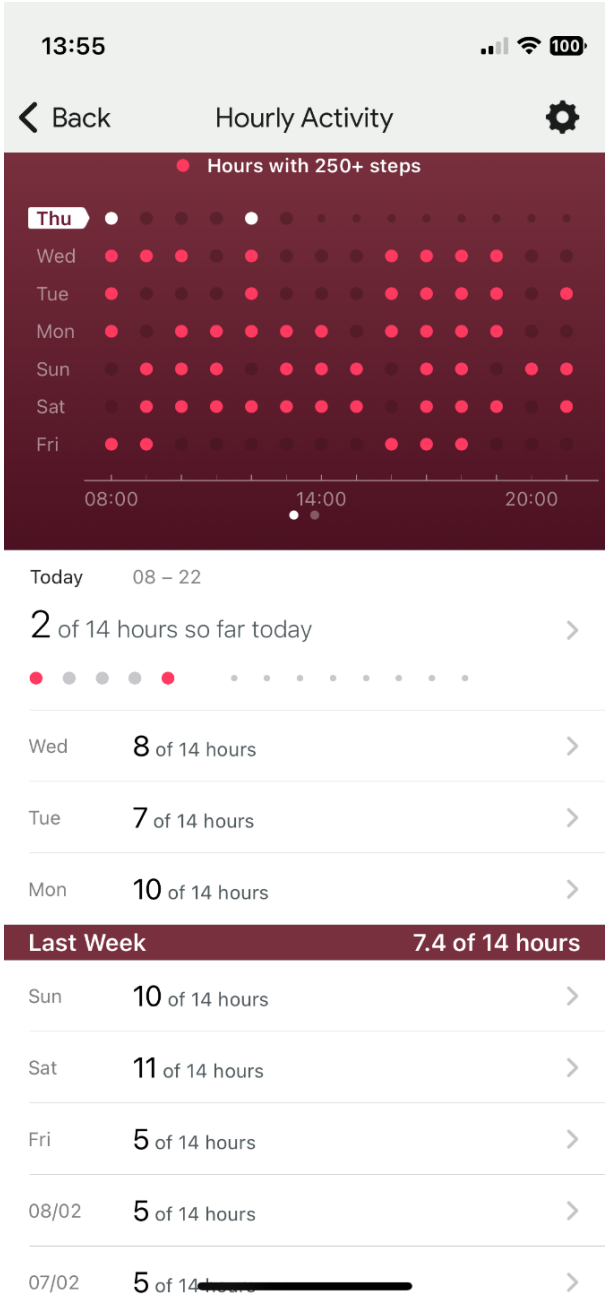
“To turn off certain notifications:

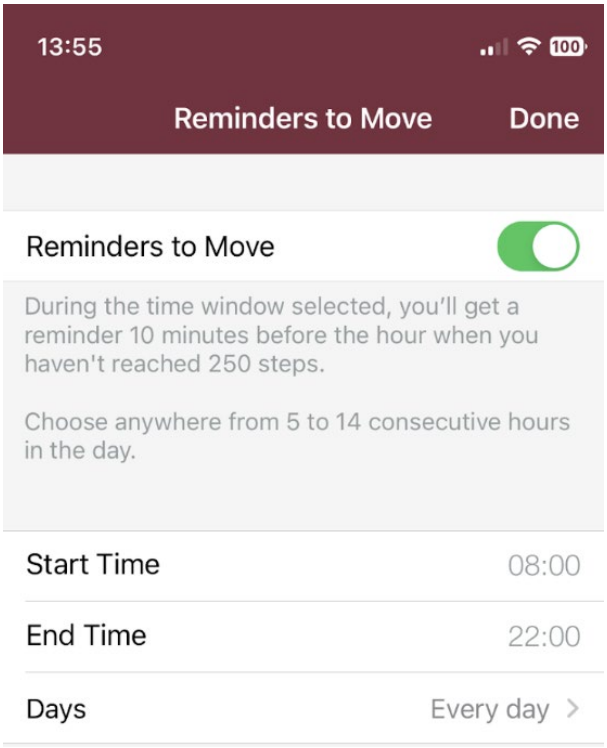
1. From the Today tab in the Fitbit app on your phone, tap your profile picture › Versa 3 tile › **Notifications.**
2. Turn off the notifications you no longer want to receive on your watch.

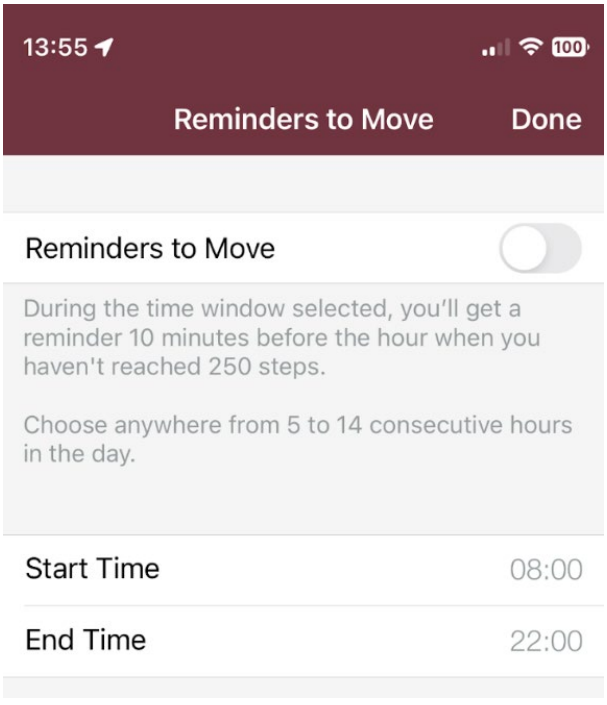
To turn off all notifications:

1. From the clock face, swipe right to access quick settings.
2. Tap the do not disturb icon All notifications, including goal celebrations and reminders, are turned off.”

You also need to go into the “hourly activity” function and press cog in top right hand corner of that menu. Click the slider on “reminders to move” so the bar is grey not green.


13:55
100
Back
Hourly Activity
Hours with 250+ steps
Thu
Wed
Tue
Mon
Sun
Sat
Fri
08:00
14:00
20:00
Today
08 – 22
2 of 14 hours so far today
Wed
8 of 14 hours
Tue
7 of 14 hours
Mon
10 of 14 hours
Last Week
7.4 of 14 hours
Sun
10 of 14 hours
Sat
11 of 14 hours
Fri
5 of 14 hours
08/02
5 of 14 hours
07/02
5 of 14


13:55
100
Reminders to Move
Done
Reminders to Move
During the time window selected, you'll get a reminder 10 minutes before the hour when you haven't reached 250 steps.
Choose anywhere from 5 to 14 consecutive hours in the day.
Start Time
08:00
End Time
22:00
Days
Every day


13:55
100
Reminders to Move
Done
Reminders to Move
During the time window selected, you'll get a reminder 10 minutes before the hour when you haven't reached 250 steps.
Choose anywhere from 5 to 14 consecutive hours in the day.
Start Time
08:00
End Time
22:00

Places I Go

Here young people make a list of the **places they go** to regularly.



- The young person creates a tile for each place they regularly go to. They can upload a photo of the place.
- For each place, the **young person nominates** an adult they would like to be their **key contact** to help them move more. It's important the **young person chooses** this adult. We know it's important for young people to have a **trusting and positive relationships** with their key contact. If the person they nominate is not able or does not want to be key contact, the young person should be asked for their next choice.

Adult Supporters

Here young people **invite adult supporters** to access and add to their MoveMore information from this section of the app.



- Young people invite adult supporters by entering the adult supporters email address. This is so everyone who supports the young person can use the adult supporter's online dashboard and see the information in the app.
- Young people and adult supporters can see who the key contacts are and their email addresses. The names and roles of other adult supporters are also shared here, but their email address may not be.
- Key contacts / adult supporters can upload a photo of themselves.
- **Key contacts and adult supporters who are added to this section are sent an email invite allowing them to set up access to the adult supporters online dashboard.**

Being Comfortable

Talk about comfort and actions to take if a young person finds a movement uncomfortable. It's important to find a quiet place to talk about it, where you won't be interrupted.



There are 4 sections in this menu:

“How comfortable am I?”



The young person and a key contact visit “How comfortable am I” in this area when they start using the app and answer 3 yes / no questions in the “Answer comfort questions” section.

1. “Is discomfort a problem for you?”

    If the answer is no because the young person doesn’t have discomfort regularly, the “Being Comfortable” area of the app doesn’t need to be used any further. However, please be aware that **pain is under reported by children and young people with disabilities.** Research shows wheelchair users usually experience some discomfort, so this will be relevant for most young people. They may not have spent time thinking or speaking about it before.

2. “Have you and a key contact talked about your discomfort?”

    If the young person says they experience some discomfort, we encourage key contacts to talk about **where** they feel discomfort, **when, how often** and **what makes it better or worse**. This helps with completing other sections in this “Being comfortable” menu. We don’t record what the young person says in the app as it’s personal and they may not wish to share it with all their supporters.

3. “Does moving make you more comfortable?”

    It’s not obvious how comfort links to moving more. In our workshops, young people and their parents told us young people are **often more comfortable when they move regularly.** Also, they are **more likely to want to move when they are comfortable.** This is why we included “being comfortable” in the app goals. **Being comfortable can be a great motivation to move more**, which is what the app is all about! If the young person is more comfortable when they move regularly, we want them to **share how often they need to move in order to stay comfortable** with their supporters.

After completing these questions, young people choose how they would like to rate their comfort. The options are: a yes / no question (this may be the only communication the young person has), a thumbs up / down, traffic light system, faces scale or text box to answer open questions.

- Young people can select how often they want to be reminded to complete this.

- Young people and adult supporters can **see how the ratings change over time**. They can monitor whether comfort improves, or identify patterns of when young people feel uncomfortable, so it can be addressed.

In our workshops, we decided having different ways to rate comfort was important. So was making sure the rating scale **doesn't** have a **negative impact** on young people who are often uncomfortable by focussing on it.

We have included **flexibility** in **frequency** and **ways** of rating comfort so key contacts and young people discuss comfort in a **positive and helpful** way.



- **If discomfort is frequently reported this should be an early warning sign and professionals should support identifying and addressing the physical / psychological needs.**
- If it's likely young people will frequently report discomfort, the free text option may be better to explore why they are uncomfortable and what can be done. If the young person has chronic pain, less frequent reporting may be advisable.

The information notifications young people receive will include differences between discomfort related to exercise (that is normal, healthy and inconvenient, but not harmful) and discomfort that should be reported, addressed and not tolerated.

Things I want to say about my comfort



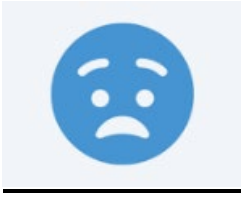
- **Optional section:** only complete if helpful.
- **Record anything young people want their supporters to know about their comfort, e.g.**
- one hip is painful and that leg needs extra support / careful handling,
- asking for help to move position every couple of hours.

Comfort action plan



- Young person and their key contacts can **make a list** of what **helps** the young person to **feel more comfortable**.
- E.g. spending time in a different position out of the wheelchair such as standing or lying.
- Things on the list can be **linked** to a specific **place** or **thing you want to say about your comfort**.
- Supporters may record here **who initially responds** to the young person feeling uncomfortable and **what to do next** if it doesn't improve.
- This action plan is helpful if: adult supporters haven't worked with the young person before, the young person finds communicating difficult or may not be able to / have chance to ask the person supporting them to follow the plan.
- Key contacts may need to discuss this plan with other supporters, so their **ability to act when discomfort is reported** is considered.

How I show you I'm uncomfortable



- **Optional section:** only complete if helpful.
- Young people **make a list** of **signs that they're uncomfortable**, to help supporters to be aware of them.
- This may help young people:
    - with limited communication who show non-verbal signs of discomfort,
    - who aren't confident telling adults they're uncomfortable.
- If a lot of people support the young person and there are new adult supporters frequently, this may help them with getting to know the young person.

My Movement

There are 4 sections in this area.



1) My activities



The young person makes a list of all the movement activities they do.

- It's important the activities are **fun or meaningful to the young person** wherever possible. If you are searching for **inspiration**, take a look in the **"Movement stories"** and **"Resources"** area for ideas! Other adult supporters may know of local opportunities to be active.



- For new activities, the key contact **considers whether there are potential risks**. An appropriate supporter, e.g. a parent / guardian or health care professional, should confirm the activity is **appropriate before** adding it to the plan.

2) My plan



There is a **calendar** where **daily activities can be planned**, then **ticked off** when they are **finished**.

- Key contacts should find a **quiet and private** place to plan activities with young people.
- Key contacts share the plan with other adult supporters to ensure they are happy with it and it's **realistic for them to support**.
- Wherever possible, **young people** should be able to **choose when activities are done**, so the timing suits their needs.
- Activities can be set to reoccur on certain days, or a number of times per day.
- Activities need to be ticked off **within 7 days** of when they were carried out. .
- If you're having an **amazing day** doing lots of moving, you can **add unplanned "bonus activities"!**
- **Optional:** Times can be added against activities. Adding times allows reminders to do the activity to be set up. The young person / adult supporters can choose how long before the activity they want to be reminded.
- To help with organisation, notes can be added to the activity and / or the reminder (e.g. the equipment needed)

3) How much am I moving?



The young person can see **feedback** about their **progress** from their **Fitbit** device and **ticked off daily activities.**

Completed activities

- The **number** of **planned** and **bonus activities** the young person **completed**.

Moving minutes



- The **amount of time** the young person has spent **moving**. This information comes from the **Fitbit watch** the young person wears.

4) My equipment



The young person makes a list of the equipment they use to support movement.

- **A list of the specialised equipment the young person uses**, e.g. a supportive chair, a standing frame or a walker.
- A **photo** of each piece of equipment can be added. Select where it's used from the "Places I go" list. This helps everyone to know what equipment is being used and what it looks like.
- Adult supporters from different places will be able to see what the young person uses elsewhere.
- Young people can **describe** what they **like or dislike** about their equipment and whether they'd like to **change** anything about it. Key contacts can talk to the young person about this, to **involve them in choices about their equipment**.

My Movement Goals

This is where young people can set goals. It's good to think about what the young person might want to be able do in the future and choose goals that are stepping stones to help them. You can record and celebrate their success here. The young person decides what their goals are, so they are meaningful. Remember changes to **achieve small amounts of movement** are really **worthwhile.**



My current goals



- Young people can set a maximum of **4 goals** at a time.
- There are some example goals you can choose from when you click on “add a goal”. You can edit the examples to meet your needs.
- There are questions to answer about the goal to set a deadline and to make sure it’s clear when it’s been achieved.
- Young people might need help to know what’s realistic and how long they’ll need to achieve the goal.
- When a goal is achieved, a new one can be set.
- Young people can upload a **celebration photo** for achieved goals and **certificates** can be generated and printed**.**
- **Optional:** goal certificate PDFs can be downloaded to **print** or share on **social media** to celebrate achievements with friends and family and **build a sense of community and** belonging. This was important to young people in our workshops.



- **Please ensure everybody pictured in celebration photos are happy for the photo to be uploaded and shared. If you do not wish for your photo to be shared, please email** bchc.movemore@nhs.net **and let us know.**
- Goals can be edited, be removed and sent to the goal history or be removed completely from here if you select the goal.

About goals



- If you haven't set goals before or you want to learn more about how to set goals, there is some information to guide you in this section.

Goal history



- Any previously achieved goals can be viewed here and certificates can be downloaded for previously achieved goals.
- Any goals that were removed and sent to the goal history will be listed here as uncompleted goals, so you can revisit them in the future.

How I Move

Here you'll find a description of how the young person likes to be moved, the equipment they use and support they need to feel safe and confident to move.



How I like to move



- The young person **talks to** the key contact in each place they go to about **how they feel about the way they are moved** and **if they'd like any changes**.
- The key contacts check suggested changes with other adult supporters, then **make a guide** in the app **with** the young person which describes how tasks are done, e.g. getting from a wheelchair to the floor.
- There is a box to add any **moving and handling equipment used** (e.g. sling make and size, hoist model, transfer board etc).
- **Photos** can be uploaded to show how the movement is done.

- Task descriptions can be linked to the “Places I Go” list. If a task is done the same way in several places, it can be linked to each place, so it only needs to be described once.
- The young person and adult supporters can **feedback** to **each other** about how the plan is going using the “Our Journal” function (see later).
- A **review date** for the guide is set. On this date, a key contact or adult supporter needs to review and edit the guide if needed (with the young person’s involvement), then check a box to show it’s up to date in the adult supporter online dashboard.

Am I ready to move?



- Here the young person records how much time they need to prepare to move.
- This is to make sure they are ready, so the movement doesn’t happen unexpectedly and they feel confident about moving.
- The young person can make notes here about anything else they need to be prepared to move.

Things to try if I’m not sure about moving



- The young person and their key contacts talk about **what helps** the young person if they **aren’t sure about moving**. They **make a list** of things that help them **feel more safe and confident**.
- E.g.:
- checking whether the young person has specific pain they frequently get, so extra care needs to be taken,
- needing reassurance if they’ve had a bad experience with a particular movement or piece of equipment,
- needing time to prepare for a movement / to do it slowly.

- This can help if adult supporters haven't worked with the young person before, or the young person finds communicating difficult.
- **"Things to try"** can be linked to a **place**, e.g. at school, it might help to go to a particular room that's quiet or more comfortable.

How I'm feeling about moving



Here, the young person **rates how safe and confident they feel about moving**.

- The young person selects **how often** they want to do this and **how**. They can answer a yes / no question or choose an emoji from 6 pictures of faces.
- Young people can select how often they want to be reminded to complete this scale, e.g. once a day or three times a day.
- If possible, the rating should be completed in **a quiet and private place,** so the young person can discuss any concerns.
- Young people and adult supporters can see how the ratings **change over time**.
- If a young person is fearful of moving / feels unsafe, this function can monitor whether confidence improves over time or identify patterns in when they don't feel confident. This can help to identify and address their concerns.

"How I like to move – archive"



- Previous versions of the guides will be saved in an archive under this heading and will show the date range the guide applied to.

Our Movement Journal

Young people and adult supporters can talk about what went well / what was a challenge that day. This journal can be used to record positive or negative emotions

and feelings that the young person may experience whilst working towards moving more. Maybe things to never try again! Pass messages between places the young person goes to e.g. about things they've tried / changes or feedback / suggestions about movement or action plans.

- Upload dated and timed entries at any time and for any reason.
- Entries can be typed or entered using your device's voice to text function
- Only the young person, their team of supporters, app admin, research teams can see this information. It can't be accessed by the public or others outside that young person's team of supporters.



- The journal should not be used to share urgent messages, as messages could be missed if an adult supporter isn't regularly accessing the online dashboard

Movement Stories

Read stories about what other young people have done or achieved! Young people can write their own stories to share with other people or to remind themselves of things they've done.

My movement stories



- Young people can **create a story** about an activity and upload a photo.
- **Optional:** send stories to admin to approve for **publication** to other young people using the app, to **share ideas and inspiration**.
- The young person can create stories **just for themselves** and **their supporters**.
- The aim of sharing these experiences is to **build a sense of community** and **belonging,** whilst avoiding risks associated with young people using the app communicating directly with people outside their team of supporters.
- A collection of stories the young person has **created themselves**.
- This allows them to reflect positively on things they've done and share stories with family, friends and supporters **without needing to publish them**.

- This can be useful to reflect on when the young person is finding moving hard, so they can **see their progress** and remind themselves that they'll be able to do those things again another day.

Movement stories Collection



- A collection of stories about things other young people have done.
- The collection is **categorised** according to what people in the stories are able to do. This helps young people to look at stories about **people with similar abilities to themselves.**
- Young people can give published stories a **thumbs up**.
- If young people publish a story, they can see how many "thumbs up" they have from others.

My resources

Find resources to inspire young people about moving here.



- A collection of links to information to support young people with moving more, e.g. inclusive sports opportunities, disability charities providing support with funding / equipment / transport.
- Use this information for inspiration and to overcome barriers when making the movement plan.
- This information is at national level. Unfortunately, we do not have the resources to keep local information up to date. Please consider creating / finding / sharing local resource lists in your area.
- If you have information which could be added, please email to:bchc.movemore@nhs.net.

Messages

This is an archive of the information notifications young people receive, so they can view them again.



- It's helpful if key contacts and adult supporters **look** at the information notifications **with young people** at a good time. Talk about how the information is relevant to them and help them understand it. This might include how it **links** to their **future plans and goals.**
- In the adult supporters online dashboard, a reference list shows the sources of our information notifications and other relevant resources.

PDF reports

PDF reports can be exported from the app for all plans, lists, rating scale scores and activity levels.

- We would like information stored in this app to be helpful to the young person and their team of supporters in as many ways as possible.

- These PDF reports can be printed, uploaded to medical record systems, used in Education and Healthcare Plans or taken to appointments by family members to provide evidence / for outcome measurement.

How we developed the app

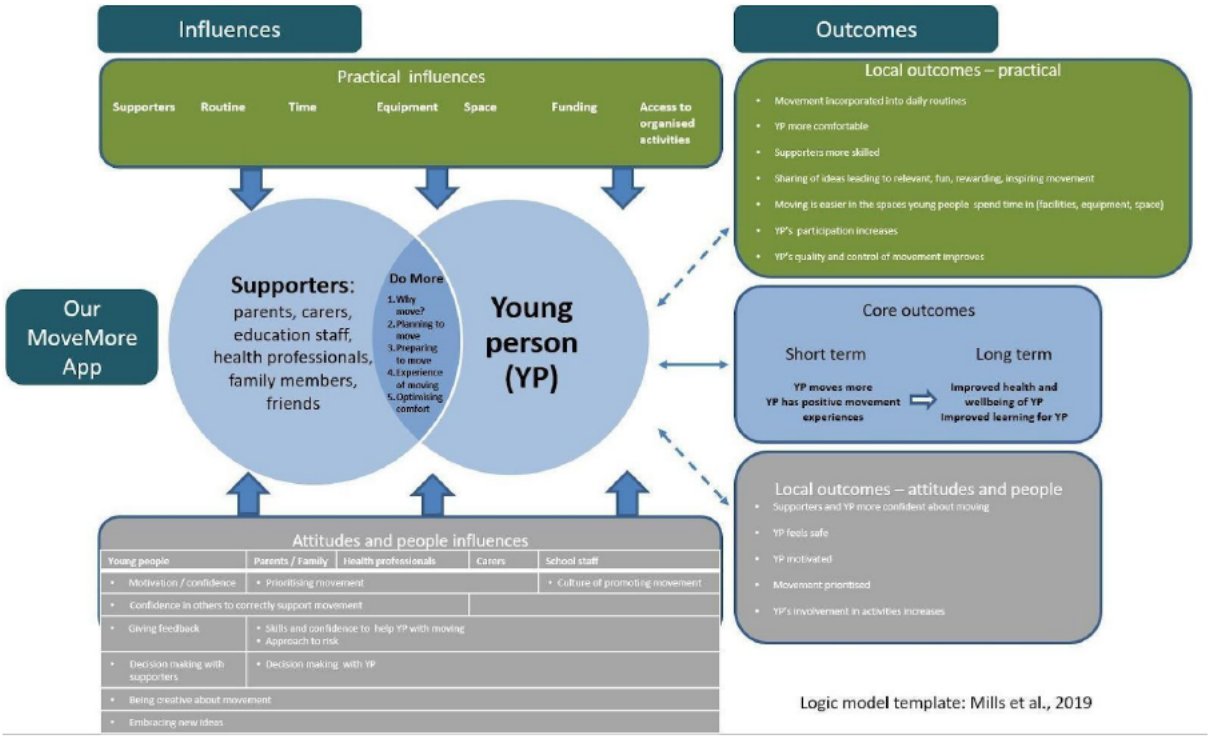
We know it can be difficult to find **motivation** to move more and that **every person is different.** That's why the app includes a **variety** of ways to encourage people to move more. These include **setting goals**, looking at ways to **join in activities** with **other people** and considering and including the **whole family** and adult supporters when planning new things. The app has been developed **with young people, their families and health professionals** using the latest **research evidence**. If you want to find out more check out the references section in the "about the app" section in this handbook.



We held virtual workshops and interviews and **made decisions based on what participants in the workshops told us** to decide on our 5 goals.



We produced a **diagram** showing how these goals fit alongside the things that influence how much young people move and what outcomes we wanted the app to achieve. After this, we discussed what menus and features would need to be included to achieve our outcomes.



Logic model template: Mills et al., 2019



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Appendix 13 Full table of changes, produced following the MoveMore app prototype evaluation

Full Table of Changes produced following the MoveMore app prototype evaluation, using the template from the Person-Based Approach.

Intervention Element	Positive Comments	Negative Comments / Things to improve.	Possible Change	Reason for Change	Agreed change / No change (NC)	MoScoW
Logging in	Family member 1: *"Easy to login."*	Family member 1: *"Login not possible on laptop"*	Not applicable (NA). Log in will be via mobile phone or tablet in live version.	NC	NC	
	Professional 7: *"I thought this was easy"* Expert 1: *"I followed the instructions as per the email and it was simple and straight forward to log in :)"*	Professional 4: *"Unable to accept terms & conditions to open app. Possibly as using a laptop to access? Might be being blocked by organisational security"* Researcher comment: *"Will need to check for Adult supporter dashboard if this is an issue in the future"* Developer comment: *"Difficulty scrolling to bottom*	Ensure terms and conditions can be accepted on lap top and PC for AS.	ESS	Terms and conditions can be accepted on lap top and PC for AS.	M

	Expert 3: *"Looks straightforward but feels a bit different to an app sign in looks more like a website sign in page"*	*of terms and conditions a glitch"*				
Home Screen	NAYP 2: *"It's easy to use once you get the hang of it"*	NAYP 1: *"Use communication aid symbols everyday* [so would be familiar with using these instead of icons]*"* NAYP 1's carer: *"People using the app might be familiar with widget symbols, which would be good* Expert 1: *"Likes the idea of using communication icons too. See what is fed back about icons in feasibility to decide whether to change them* [for communication symbols]"	Use communication aid widget symbols instead of current icons.	NC. Copyright not granted.	NC	Not possible

	Family member 1: *"Photo and icons would work"*	NAYP 1: *"Can it work with my grid pad by smart box - from ACE - assisted communication"* Family member 2: *"*[Would be] *nice to be able to look at the app on the i gaze screen. Good* [for NAYP with I gaze] *to be able to view navigate around independently"*	Build integration with communication aids	EXP (stakeholders), NCON.	NC. Not possible within project resources (time and funding).	W
	Family member 2: *"Clear, uncluttered. Tend to look at words rather than symbols, so doesn't matter what symbol"*	NAYP 2: *"I prefer the logos* [to photo icons]*"* Family member 2: *"Photos would be too small"* Professional 1: *"Photos too small, icons look better"* Professional 2: "*The photos* [an alternative to icons that was also presented] *are quite busy colours and distracting so I wonder if*	Use logos / icons, not photos on home screen.	REP, EXP (stakeholders), NCON	Use Logos / icons on home screen	S

		better further in the app and not on the launch screen. Could have a central photo that changes when you select the relevant icon so you don't have to look at all the photos to select but the icon you choose is illustrated in the middle" Professional 4: "*Prefer icons to photos, photos too small"* Professional 7: *"I prefer the logos"* Expert 3: "*Icons are more inclusive. Person using the app may not relate to the photo."*				
	Professional 7: *"I like the fact being comfortable is first"*	Professional 1: "*Uploading their own photos or a selection to choose from.* [suggestion]*"*		NC. Preference of the majority was for simple icons not photos	NC	

		Professional 4: *"If using a central photo could it be personalised?* [suggestion]" Expert 3: *"Too many options can get complicated if personalising, uploading a photo too complex for some people. Can take away from the process"*		on the home screen		
	Professional 2: "*The icons are quite clear and visually straight forward."*	Professional 6: *"Very plain, pedestrian, not very engaging doesn't draw you in"* Expert 3: "*Icons could be different colours to aid navigation"*	Introduce different colours / more dynamic home screen	NC. Contradictory positive feedback about home screen being clear and simple.	NC	
	Professional 7: *"Looks good, very clear and easy to navigate"*	Professional 7: *"Am not sure of the symbol for my movement. Not sure what I would use though. Probably not something relating to equipment"*	Review of icons selected with PPI reps to select more meaningful ones	EAS, REP, NCON	New icons selected for several functions	S

		Expert 3: "*The icons could be more descriptive - better linked to the text*"				
	Expert 1: *"Loves calming blue and icons, active wheelchair picture."* Expert 3: *"*[Icons] *Simple, nice and clean layout"*					
Being Comfortable: How comfortable am I?	NAYP 1: *"Options on rating comfort – traffic lights etc"*	Professional 1: *"Increase size of icons, faces, thumbs etc"* Professional 4: *"Larger icons of faces and thumbs up/down* [on comfort rating scales] *to make it easier to see and press (thinking CVI and/or dyskinetic CP presentations)"*	Increase size of icons in rating scales for comfort and confidence (in How I'm feeling about moving)	EAS, REP, NCON	Icons made larger	S
	NAYP 2: *"It looks straightforward. The traffic lights and options are good"*	Professional 7: *"Key contacts may have very different approaches to discussing comfort depending on background.*		NC. Additional detail for key contacts in handbook, which wasn't		

		Are more prompts needed for key contacts?"		shared in prototype.		
	Professional 7: *"Like multiple options available to rate comfort"*	Professional 7: *"Can you link comfort scores to the activities being done on a particular day to build up a picture of pain and fatigue etc?"*	Developer suggestion: *"Could flag entries to journal / activity etc against the pain scores on adult supporter dashboard"* Professional 7 response: *"Would be good for YP to be able to see this view also, so they have opportunity to reflect on links between activities and pain for example, not just adult supporters"*	IMP	NC. Not possible within project resources (time and funding).	S
	Expert 1: "*I like that it's the first icon in the list – showing how important it is to consider this element, and make a plan for it."*	Expert 1: *"Under Step 1, 'Rate my comfort,' I would put the two intro sentences on two separate lines, to assist with*	Put text onto separate lines.	EAS, NCON	Put text onto separate lines.	C

		clarity/breakdown the steps a little more."				
	Expert 3: *"Good selection of options to personalize"*	Expert 1: *"If doing the 'Being Comfortable' section 1st eg. Pre definition elsewhere, is 'key contact' a phrase that "I" should know? Would it be helpful to give examples of who these ppl might be?"*	Make handbook made the top left icon in the app. Key contacts explained in the handbook. Move "Adult Supporters" and "Places I Go" so they come before being comfortable and key contacts will already have been nominated if following the order of icons on the app.	EAS, NCON	Re-order icons so key contacts have been selected prior to reaching "Being Comfortable"	S
		Expert 3: *"Some explanation about what comfort is would be useful"*	Add a definition of being comfortable.	EAS, NCON	New "What is being comfortable?" info item on being comfortable menu page, defining what being means in this context.	S

		Expert 3: *"Add text to icons so that users know what the icons mean* [icons on comfort rating scales]*"*	Add text below each image on the comfort rating scales.	EAS, NCON	Add text below icons in comfort and confidence scales in "How I'm feeling about moving"	S
		Expert 3: *"Traffic lights could just be coloured dots – the icon is too detailed"*	Change traffic light icons to coloured dots	EAS, NCON	Choose simpler traffic light icon, so its still clear the colours of a traffic light are beings used to rate comfort.	C
		Expert 3: *"Thumbs up and down could be different colours"*	Change blue thumbs up and down icons to green thumbs up, red thumbs down.	EAS, NCON	Change colour of icons.	C
Being Comfortable: How I show you I'm uncomfortable	NAYP 2: *"Good for people who can't communicate when they're uncomfortable"*	NAYP 2: *"Consider adding option for photo upload"*	Add option for photo upload for each item placed on this list.	EAS, EXP (stakeholder), NCON	Add photo upload here.	S
	Family member 1*: "Useful because young*	Professional 1: *"If they are uncomfortable this needs*	Adult supporters are notified if	IMP	NC. Not possible	W

	people deny being uncomfortable"	*flagging up to supporter/carer to improve their comfort"*	there are consecutive low comfort scores (2 or more).		within project resources (time and funding).	
	Professional 1: *"Lots of information can be recorded and made very individual to the person"*	Expert 3: *"Make folders within the comfort section related to different things"*		NC	NC. Adds to complexity.	
	Professional 7: *"Good for AS to be aware of subtle ways discomfort can be communicated, or system child has, e.g. turning over a red card to show they're in pain"*	Expert 3: *"Could use examples of what comfortable / uncomfortable might be instead of a definition e.g. temperature"*	Add examples to the new "What is being comfortable?" info item on being comfortable menu page,	EAS, NCON,	Add examples to the comfort definition	C
Being Comfortable: Things I want to say about my comfort	NAYP 2:*" Like these functions"*	Expert 3: *"Be able to categorise anything that makes you comfortable / uncomfortable e.g. sitting / temp then link to the strategy to resolve it"*	Be able to link a thing you want to say about your comfort to an action in the action plan.	NCON	When adding an action in comfort action plan, the action can be linked to a "Think I want to say about my comfort", but not vice versa.	S

Being Comfortable: Comfort action plan	Professional 7: *"Like these features"*					
	NAYP 2: *"Like these functions"*	NAYP 2: *"You could have an option to upload a picture"*	Add option for photo upload for each action in the action plan.	EAS, EXP (stakeholder), NCON	Add photo upload here	S
	Professional 7: *"Like these features"*	Professional 1: *"Needs to be first thing that is seen"*	Move comfort action plan to top left of "Being Comfortable" menu page.	IMP, EAS, NCON	Move action plan icon to top left on this menu page.	S
		Professional 4: *"Combine the "problems" with the action plan so it's clear what to do if someone displays signs of discomfort on one screen."* Expert 3: *"A matrix for comfort items after they've inputted it showing different types of discomfort. Two might be addressed by the same strategy"*	Researcher comment: *"Show the suggested matrix in the AS dashboard, not the app? Reduce number of menus so info side by side in YP's view."*	NCON	When adding an action, the action can be linked to a "Thing I want to say about my comfort", but not vice versa. Is technically difficult to link multiple "Things I want to say" to one action, or multiple actions to one "Thing I want to say"	W

					and produce a matrix.	
Adult Supporters		Professional 2: "*Photo added for adult supporters so the child can quickly select the individual they want*"	Add option for adult supporter to upload photo via AS dashboard. The AS's chosen photo displays in the NAYP's app	EXP (stakeholder) NCON.	AS can upload a profile photo in AS dashboard which displays against their name in NAYP's app.	S
Places I go	Professional 2: "*That you can add a photo of the location*"	Professional 2: "*To clarify that upload file means that you can upload a photo*"	Change wording for photo uploads throughout app.	EAS, EXP (stakeholder) NCON	Change wording at all photo upload points to "Photo" then "Take a photo" or "Choose from library"	S
My Movement: Menu screen		Professional 2: *"The sub menu and the main menu are very similar so easy to forget you are in a sub menu and there are other lists to return to. Use a logical flow - my activity first then diary plan"*	Change appearance of main menu and sub-menu so it's clear where you are in the app.	EXP (stakeholder), NCON	Place icon of the submenu you are in at the top centre of the submenu screen with submenu	C

					items below it.	
My Movement: My Activities	NAYP 2: "*I like the option to choose from the list"*	NAYP 2:*" You could have an option to include a visual of the activity. Less words, more pictures"*	Add option for photo upload for each activity.	EAS, EXP (stakeholder) NCON.	Add photo upload here	S
	Family member 1: *"Useful to have the list of equipment. Once set up would be easy to use. Easy to understand how to use"*	Family member 1: *"Who will be responsible for adding all the activities. Some people will be motivated, others may not"*		NC. Key contacts will support NAYP to add activities via their app only. Risk of NAYP losing autonomy if AS's can add activities via AS dashboard without involving them, which is key to the theoretical underpinning of the intervention.	NC	
	Professional 1: *"Very flexible and can be added to easily"*	Professional 2: *"Can we have a few activities as an example to choose- eg walking, motomed, swimming and then add other activities that they complete"*	Produce a drop down list of suggested activities, but can also add your own.	EAS, NCON	Standard list of activities that can be chosen and put onto plan, plus able to	S

					add your own.	
	Professional 4: *"Opens up conversations about what activities young person enjoys as it allows for open input, not selecting from a set list"*	Professional 4:"*Can we add PDF attachments to activities e.g. therapy programmes?"* Researcher comment: *"Does AS needs to be able to upload any PDFs from the AS dashboard, and can do from YP's app?"*	AS able to upload documents related to a particular activity.	EXP (stakeholder)	NC – could threaten autonomy as NAYP has no control over content of uploaded program. AS can't edit activities section.	
	Professional 7: *"Nice that the activities aren't just exercise focused"*	Expert 3: *"I think engagement might drop off for this section - it's a lot. Can it be linked with outlook calendar?"* Expert 3: *"Reduced touch points would be better - the less the user has to do the better"*	Link with "My Plan" so a new activity can be added from my plan and will get listed here automatically.	EXP (stakeholder), NCON	New activity can be added from my plan and gets listed here automatically.	C
	Expert 1: *"Likes that activities can be added in plan or my activities"*	Expert 3: *"Are there 'push notifications' with the app? It might be difficult to remember to do the planned*		NC. Reminder can be set for an activity from "My Plan" to trigger a notification.	NC.	

		activities without a reminder"				
	Expert 1: *"Adding activities is straight forward"*	Expert 3: *"The summary of what was input popped out of the screen - what does it look like in the app?"*		NC. Summaries appear in app also. Can submit if info correct, or press cancel or the cross in top right corner, which takes you back so you can edit the info.	NC	
		Researcher comment: *"May need multiple places for an activity"*		NC. Place is added in "My Plan" rather than "My Activities". The same activity could be done at school in the morning then home in the afternoon on the plan.	NC	
		Researcher comment: *"Does AS need to be able to add activities from dashboard, not just the app?"*		NC – could threaten autonomy as NAYP has no control over content uploaded by AS.	NC	

				AS can't edit activities section from dashboard.		
My Movement: My Plan	Family member 1: *"Like the idea of reminders!"*	Family member 2: *"Good* [for NAYP] *to be able to navigate around independently* [using i gaze]*"*	Build integration with communication aids	EXP (stakeholders), NCON.	NC. Not possible within project resources (time and funding).	W
	Professional 1: *"The details that can be added are great, the journey it shows could be really motivating"*	Family member 2: "Do *you get reminders about which activities you still need to complete?"*		NC. Option to set a reminder to complete an activity for each activity added to the plan.	NC	
	Professional 1: *"Could help create routines for people which will help them physically and mentally"*	Professional 1: *"Think some young people are going to need a lot of support to add information"* Professional 1: *"Keeping activities up to date will need someone to help YP to do it. YP may get demotivated about the app if its not being done"*		NC. Team of key contacts to support NAYP with creating and updating plan. Giving AS's ability to add to plan via dashboard reduces NAYP's autonomy. AS's can tick activities in plan as complete	NC	

				from AS dashboard.		
	Professional 2: "*I like the summary page to confirm what you have put in"*	Professional 2: *"Can we make the 'Add' and plus sign a stronger colour green/blue as it looks greyed out so I did not try to click on it"*	Change colour of "Add" button.	EAS, EXP (stakeholder), NCON	Change colour of "Add" button to bold colour from theme colours used in app.	S
	Professional 4: *"The recurring function when adding an activity is very useful & will make scheduling activities easier"*	Expert 3: *"Would be better to be able to click you've done the activity from the plan list for the day without opening the activity"*	Developer suggestion: *"Will be able to tick you've done an activity from the notification for that activity"*	EXP (stakeholder), NCON.	Able to tick activities as complete directly on the plan without clicking on the activity first. AS's able to tick as complete from "Timeline" view of movement plan.	S
	Professional 7: *"Ability to edit then tick an activity if you did it on a different day to when*					

	you originally planned is helpful" Expert 1: *"It's intuitive!! Adding activities is straight forward"*					
My Movement: How much am I moving? (My Progress in prototype)	NAYP 1: *"Like bonus activities"*	NAYP 2: *"Can understand bar charts well. Would like being able to see history of tasks completed in a bar chart too as it gives you more information than just the circle view."* Family member 1: *"Would be useful to be able to look at different days"* Professional 1: *"Closing the ring, comparing days, weeks and months to see patterns and challenges and to work out why they are happening"* Professional 2: *"Use multiple circles to show day-*	Be able to see patterns of % completed activities and bonus activities over time more clearly in app and AS dashboard. This could be multiple circles or bar charts, as preferred by NAYP 2.	IMP, REP, EXP (Literature – self monitoring behaviour change technique), NCON	To show patterns over time in a bar chart via app and AS dashboard.	S

		by-day or week-by-week or month-by-month” Professional 4: *“Being able to review activity break down by day will allow overview of patterns when less activities are completed.”* Professional 6: *“Detailed breakdown?”*				
	NAYP 2: *“I like the circle and how you can go back and fourth between dates”*	Professional 4: *“Add a flag for "reasons why I couldn't move today" e.g. school holidays, illness, hospital admission etc.”*	Add being able to add a barrier into the movement plan, and what dates that barrier affected movement. This is then is written on the ring in “How much am I moving” also, if relevant dates selected.	IMP, EXP (stakeholder)	NC. Not possible within project resources (time and funding).	W

	Family member 1: *"My daughter really liked the pink! Too many colours on this screen could be off putting. One colour was nice"*	Professional 6: *"How to celebrate achievements and activities"* Professional 7: *"Would be good to have the bonus activities more celebrated as previous groups suggested"*	Make bonus activities more celebratory by using a present icon to represent them. Goals can be set around planned activities to gain certificates or achievements shared via the "My Stories" or publishing to the "Stories Collection"	IMP	Present icon used to celebrate bonus activities.	S
	Family member 2: *"Adding bonus activities is clever"*	Expert 1: "*Add quick date range selection in addition to date range. e.g. last week, last month as on AS dashboard"*	Add quick select options on AS dashboard to see last day, week, month etc.	EAS, NCON	Quick select option added to AS dashboard.	C
	Professional 7: *"This screen really focuses on what has been achieved"*	Expert 1: *"Change naming of my progress so its clearer what it is and the difference between moving minutes and my progress"*	Change to "How much am I moving?" to match original software spec.	EAS	Function name changed to "How much am I moving"	S
		Expert 1: *"Link my progress and moving minutes together, not toggle between"*	Under "How much am I moving" have "Completed Activities" and "Moving Minutes".	EXP, NCON	To change titles in app and AS dashboard. Single date	C

		Expert 1:*" Date selection stays when moving between my moving minutes / my progress"*	Date range is just selected once and data is shown in		range to show date for both in AS dashboard only for this project. To add to app in the future.	
		Expert 3: *"More colourful would be more engaging. Different activities could be different colours"*		NC – In conflict with positive feedback from Family member 1 – who felt single colour was good.	NC	
		Expert 3: *"Have you looked at Garmin Connect?"*	Use wearable activity recognition to automatically tick off activities.	NC – not possible within project resources to investigate automating this section with activity recognition.	NC	C
		Facilitator comment: *"If you select not to see the percentage figure it should be remembered for future visits to that page"*	App remembers for future visits to this page if user selects not to see	EAS, NCON	Percentage figure won't be shown again once user selects not to display	S

			the percentage figure.		it unless they change this setting. EAS, NCON	
My Movement: My Equipment	NAYP 1: *"Like that can write what you do / don't like about equipment"*	Professional 2: *"Options of addition of 2 equipment pieces for a single activity eg standing - using the wheeled stander at school and static at home"*	Able to add more than one item of equipment to an activity.	EXP (stakeholder), NCON	NC - not possible within project resources. To add in future.	W
		Professional 4: *"Add pictures for positioning in certain pieces of equipment like a postural management plan"*	Facilitate this this by making it possible to upload more than one image per item of equipment.	EXP (stakeholder), NCON	NC - not possible within project resources. To add in future.	C
		Professional 4: *"Add who purchased the equipment, user manuals / service date for adult supporter dashboard"*	Add upload of docs to AS dashboard for these items.	EXP (stakeholder), NCON	NC - not possible within project resources. To add in future.	C
		Professional 4: *"Add service history and instruction manuals for each pieces of equipment on the adult dashboard"*				

		Expert 3: *"Icons would work well rather than detailed images. Garmin and Strava do the gear listing very well"*		NC – detailed image allows upload of NAYP's posture in the equipment.	NC	
My Movement: Moving Minutes	NAYP 2: *"I like the bar charts that show how many minutes I have moved when wearing the fitbit. I can understand bar charts better when collecting more information."*	NAYP 1: *"Not sure if I will be able to see the watch as screen is small"*		NC – minimal use of watch screen needed as relevant data is automatically moved into the app. May be needed for checking battery level but AS's can support this.	NC	
	NAYP 2: "*Looking back at what I have done will help me move more"*	Family member 2: *"Need to think about orthotics / wrist straps obstructing the fitbit"*	Problem solving in feasibility study.	IMP, EXP (stakeholder), NCON.	Identify any change necessary in feasibility study.	W
	NAYP 2: "*Seeing moving minutes will motivate people to move more"*	Family member 2: *"May pick up heart rate increases when* [name] *gets excited and interpret them as movement"*		NC- to be assessed in feasibility study by comparing activPAL™, fitbit accelerometer	NC	

				data and paper diaries.		
	Professional 2: *"I like the moving minutes feedback"*	Expert 3: *"Can fitbit be used to enter the activities, rather than it being manually added in this app"*	Developer comment: Explore this and pulling activities from the fitbit also, can manually add activities or pull from Fitbit data.	EXP (stakeholder), NCON	NC – not possible within project resources to investigate automating this section with activity recognition.	C
My Goals: Current Goals	Family member 1: *"Really like this - my kids love to focus on goals!"*	Family member 2: *"How do goals link to other things e.g. activities"*		NC – Goals can be set based on activities if NAYP wishes to do that, but no link between these areas in the app at present. Could explore if there is demand for this in feasibility study.	NC	C
	Family member 1: *"Teaches a life skill of setting a goal then working out the steps*	Professional 6: *"Draw goal completion through automatically"*	Automate so relevant goals are completed using data from	NC – Automation may remove an opportunity to enhance competence	NC	

	you need to do to achieve it"		"How Much am I Moving"	construct of SDT. NAYP enters what they could do and what they can now do at goal completion. This is displayed on their goal certificate to celebrate achievement. Highlighting progress may contribute to motivation via enhancing feelings of competence.		
		Professional 4: "E*xplanation of time periods of short & long term goals"* Expert 3: "*Saying your intention by a specific date is the motivating bit"*	Will be individual variability in what is considered long and short term so difficult to provide an explanation. Remove short and long term goal screen altogether as NAYP picks their	IMP, NCON	Long term and short term goals removed. Autonomy enhanced as NAYP sets timescale for each individual goal.	S

			deadline date for each goal.			
		Expert 1: *"Change "my goals" to "my movement goals""*	Change name so it's clear goals are intended to relate to moving more.	EAS, NCON"	Change "My Goals" to "My Movement Goals	S
		Expert 3: *"Goals can be motivating but need to be carefully set and may need support with them"*		NC – Goal setting done with support of AS. Info about goal setting for AS's in handbook and "About Goals" text. Assess if this is sufficient support in feasibility study.	NC	
My Goals: Goal History	Family member 1: *"Love certificates"*	Expert 1: *"Certificate needs editing to suit MoveMore"*	Certificate to be themed to match MoveMore colours / logo etc.	EAS, NCON	Complete certificate design to be in keeping with app themes and graphics.	S
	Professional 1: *"Rewards/certs/badges good for motivation"*					

	Professional 4: *"Love the certificates"* Expert 1: *"Likes idea of certificate"*					
My Goals: About Goals (suggestions about text)	Family member 1: *"Really like notice idea"*	Professional 2: *"Clarify that there are up to 3 short term goals and one longer term"*		NC– Short and long term goals removed (see "Current Goals" above).	NC	
	Professional 2: *"Short term goals - up to 3 - can we have a pop up to guide the process initially - a boy with a speech bubble - try setting a goal you think you will manage in the next month. You may be able to make your short term goals weekly once you have the hang of it"*	Expert 1: *"Could add prompts to think about different time frames of goals, rather than enforcing short term / long term"*	Add prompts to handbook and "About Goals" text in app to encourage thinking about a variety of time frames for goals.	IMP	Edit goal setting advice to include thinking about variety of timeframes	S
My Goals: Sample Goals		Family member 2: *"Change to future tense, currently past tense"*	Change tense of example goals.	EAS, NCON	Change tense of example goals.	M
		Professional 4: *"Important to give options that people can*	Make sample goals editable.	IMP, EXP (stakeholders)	Remove Sample goals	S

		use for a starting point (list of examples that they can select and use/edit)" Professional 6: "[Make it so you] c*an click on the sample goal so it opens it to add as a current goal and complete / delete the editable fields e.g. a specific time or distance"* Expert 1: *"A lot of text on the screen. Make a list of headings so less text, one for each goal, then if they click the heading the full text comes up"* Expert 3: *"Use speech bubbles with the goals inside instead of a straightforward list"*			section and put the sample goals in a drop down list when you go to "Current Goals" to add a goal. If you click on them, you can then edit the text to tailor the goal to the NAYP.	
How I Move: Being ready to move	Family member 1: *"Love the time to be notified to move"*	Family member 2: *"Preparation time is different to the time the YP needs to prepare - do we need both? Preparing to move - need to*	Add a preparation time and finishing time to individual activities in my activities. This	EXP (stakeholders), NCON	NC – not possible within project resources	W

		be able to tailor what the task is"	pulls through to my plan, or able to add this in my plan also. Prep and finishing time is added to the length of time allocated to an activity overall in my plan.			
		Expert 1: *"The word preparing sounds like the movement is quite imminent, maybe a different word? Change wording so clear the young person is saying how long before a movement they want to be prompted"* Expert 1: "*Make sure its clear the YP plans when they will be moving, not the AS"*	Change wording so it's clearer that this section is about NAYP's autonomy to control when they are moved.	IMP, EXP (stakeholder)	Change title of section to "Am I ready to move?". Change wording to "Let me know I'm going to be moving x minutes before the movement needs to happen, to make sure I'm ready to move"	S
		Expert 3: *"Add notes anything else what the*	Add a notes section below the information about	EXP (stakeholder), NCON	Add free text box labelled "Other things	S

		young person needs to prepare"	time needed to be ready to move.		that help you to be ready to move"	
How I Move: How I like to move	Family member 1: *"How one family member and another does a movement can differ. Important thing is app users app work together as a team and understand points of view."*	Family member 2: *"Include how long a task takes"*	Add how long the task takes to each guide.	EAS, EXP (stakeholder), NCON	Add how long the task takes to each guide.	S
	Professional 4: *"I like that it captures the young person's wishes regarding their moving & handling plan. Good that this sparks a conversation about what the YP / family want. How it might be different to movement in school"*	Professional 1: *"To be clear who the guidance if for and who can follow it. Can family put how they do something at home, that can be different to what would be done professionally."*		NC – A place can be selected for each guide, so having different instructions for the same task at school and at home already possible. Guidance applies to all AS in the place the guide relates to. NAYP controls content of guide for autonomy.	NC	

		Professional 4: *"Needs to be clear that this is not a formal risk assessment/moving & handling plan, rather young person's wishes/thoughts about their moving & handling plan. Ensure not seen as a replacement for a moving and handling plan, so review date isn't a legal aspect, disclaimer"*	Add disclaimer	EAS, EXP (stakeholder)	Add following text to the "Guides" section. "These guides advise adult supporters about how the young person likes to be supports to move. They are not legal documents / risk assessments. They are not part of an electronic health record."	M
		Expert 1: *"YP and AS have to approve new plan at review date, not just the AS"*		NC – YP produces plan in the app with AS – should only be edited in consultation with NAYP, so they	NC	

				shouldn't need to approve.		
		Researcher comment: *"Adult supporters need to be able to mark as unchanged or archive if out of date when review date is up"*	AS able to either mark guide as unchanged or archive it if it is out of date from the AS dashboard.	EXP (stakeholder), NCON	Add this function to AS dashboard.	M
How I Move: Archive – How I like to move		Researcher comment: *"Shouldn't be able to remove previous plans from the archive. Previously existing plan needs to be visible with a date range of when it applied / was replaced"*	Ensure previous guides can't be edited in the archive or removed from it via app or AS dashboard.	EXP (stakeholder), NCON	Ensure archive content non-editable and date range it was active for is visible. Important for safeguarding in case of any incident when guides on the app were being followed.	M
My Stories: Menu page		Professional 2: *"Personalise my stories with photo or icon"*		NC – keep simplicity of colour themed icons in keeping with positive feedback about	NC	

				appearance of menu's in other sections.		
My Stories: Create a story	Professional 1: *"Really good feature which allows them show others what they have been doing and what they can do!"*					
	Professional 4: *"Really engaging feature! I know a lot of young people who really enjoy writing & it will allow adults to see voice of the young child."*					
	Professional 4: *"Publishing options also a good safeguarding feature* [YP selects whether to publish story to other users or not]*"*					
My Stories: My Stories	Professional 4: *"Categories are focused on ability, rather than disability &*					

	it's a good safeguarding feature"					
My Stories: Stories Collection	Family member 1: *"I really like this idea"*	Professional 2: [Change category title to] *"walking stories rather than walker"* Professional 2: [Add category] *"water stories"* [for any activities in water / bathing / showering] Expert 1: *"Change wording to My movement stories, movement story collections etc. "*	Wording changes as suggested by stakeholders.	EAS, NCON.	Make wording changes	S
	Professional 4: *"Categories are focused on ability, rather than disability & it's a good safeguarding feature"* Expert 1: *"Really like this feature, including that other participants can "like" a story"*					

Our Journal	Professional 4: *"Flagging system"*	Professional 2: *"Edit the handbook so adults know it is for supporting the child's moving activity so may flag barriers but not use to highlight problems between adults"*		NC – moderate via flagging system rather than drawing attention to potential for inappropriate use in the handbook.	NC	
Online dashboard for adult supporters	Family member 1: *"Good to have access to a lot of information"*	Family member 1: *"Check layout on ipad"*	Developers to check AS layout on tablets.	EAS, NCON	Developers to check AS layout on tablets.	S
	Expert 1: *"Likes being able to see time period for average moving minutes. Nice that you can change the date range you are seeing the summary data for."*	Professional 4: *"Can parents input contact details for healthcare professionals?"*	AS name, role, place pulled onto dashboard from app. Individuals can add their own contact details if they are happy to share them but not share other AS's contact details. Key contact email address will be shared.	IMP	Parents not able to input details of other AS's. AS can add their own contact details and select what they wish to share. Email address of key contact will always be shared.	S
	Expert 1: *"Likes equipment tab as it will*	Expert 1: *"YP needs to be able to* [see] *graph from*	NAYP can view previous comfort	IMP	NAYP can view previous	M

	work for carers / assistants"	*comfort / confidence scores in the app also"*	and confidence scores in the app.		scores, however they are listed in a text format and not a graph, due to the complexity of multiple measures being available.	
		Expert 1: *"Is there a way of flagging something that is really important for others to see urgently, e.g. a journal entry."*	App not intended to be used for urgent communication, as could easily be missed. Add a statement when submitting entry that it shouldn't be used for urgent messages.	EAS, NCON	Statement added to menu page for our movement journal in app and AS dashboard saying "This journal is not intended to be used to share urgent messages. For urgent messages, please use an alternative method to	M

					ensure they have received your message e.g. email / telephone.”	
		Expert 1: “*On Progress tab in movement plan, instead of "planned" "not completed" change words to Completed / Uncompleted”*	Wording changes as suggested by stakeholders.	EAS, NCON.	Make wording changes	S
		Expert 1: “*On Progress tab in movement plan, change wording "unplanned activities" to "Bonus activities" to match app”*				
		Developer comment: *“AS to be able to tick activities off as complete”*	AS able to tick off activities from AS dashboard	IMP, NCON	AS able to tick off activities from AS dashboard	M
Other		Family member 2: *“Photo library - anything you've uploaded”*		NC – Unclear what benefit this function would add.	NC	
		Facilitator comment: *“When in your account from top*	Back button from account settings	NCON	Make change – see if users	C

		right icon takes you back to where you were, would it better to go back to main menu"	returns to main menu, not the sub menu you were in. .		comment on this in feasibility study.	
		Facilitator comment: "*Can users customise the appearance to their preference e.g. a 3d view or different background / foreground colours"*		NC – keep simplicity of colour themed icons in keeping with positive feedback about appearance of menu's in other sections.	NC	
		Expert 1: *"Accessibility on phones good now, e.g. text size, other access opportunities. Need to add handbook of where accessibility functions are on phone. Link to video in resources"*	Add info to handbook / resources about how to use accessibility features.	EAS, NCON	Add info to handbook / resources about how to use accessibility features.	S
		Expert 1: *"Can you use the app on communication aids?"*	Build integration with communication aids	EXP (stakeholders), NCON.	NC. Not possible within project resources (time and funding).	W

Note: Text in square brackets [ ] added to give context to quotes. ESS: Essential change for intervention to function, IMP: important for behaviour change or practical / ethical / safety reasons, EAS: Easy and uncontroversial, REP: repeated by more

than one participant in the co-design, EXP: change supported by experience, for example of public and patient involvement reps, stakeholders (including those with lived experience, health / education professionals, experts), literature (evidence base), NCON: does not contradict the logic model or guiding principles, NC: No change, plus justification of why, M: must have, S: should have, C: could have, W: would have (if resources available), AS: Adult supporter, NAYP: Non-ambulant young person, YP: Young person, KC: Key contact.

This protocol has regard for the HRA guidance and order of content

FULL/LONG TITLE OF THE STUDY
Feasibility of the MoveMore digital intervention: reducing sedentary behaviour in non-ambulant young people with long term disabilities.

SHORT STUDY TITLE / ACRONYM

MoveMore

PROTOCOL VERSION NUMBER AND DATE

MoveMore Study Protocol_v3_24/01/2024

RESEARCH REFERENCE NUMBERS

IRAS Number:	327188
SPONSORS Number:	BCHCTrustWide327188.P
FUNDERS Number:	ICA-CDRF-2018-04-ST2-021

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature: Date:

.....
.....

Name (please print): Christine Burt

Position: Research and Innovation Director

Chief Investigator:

Date: .....

Signature:
.....
.....

Name: (please print): Marilyn Bradbury

KEY STUDY CONTACTS

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Key Protocol Contributors	**Professor Joan Duda,** Professor of Sport and Exercise Psychology, School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham, Edgbaston, Birmingham, B15 2TT, UK, **Dr. Sally Fenton,** Lecturer in Lifestyle Behaviour Change, School of Sport, Exercise and Rehabilitation Sciences, University of Birmingham, Edgbaston, Birmingham, B15 2TT, Email: **Dr. Susan Neilson,** Lecturer, School of Nursing, School of Nursing, Institute of Clinical Sciences, University of Birmingham, Edgbaston, Birmingham, B15 2TT, UK Tel: **Dr. Elizabeth Croot,** Senior Lecturer, School of Health and Related Research (ScHARR), University of Sheffield, Room 3004, Regent Court, 30 Regent Street, Sheffield, S1 4DA **Patient and Public Involvement (PPI) representatives.**
Committees	No Committee.

STUDY SUMMARY

Study Title	Feasibility of the MoveMore digital intervention: reducing sedentary behaviour in non-ambulant young people with long term disabilities.
Internal ref. no. (or short title)	MoveMore
Study Design	Formative testing of the feasibility and acceptability of the MoveMore app digital

	behaviour change intervention. Assessment of the appropriateness of the selected outcome measures. Evaluation of continued use of the MoveMore app following the initial 12-week feasibility testing period.
Study Participants	**Participants:** • Children and young people aged 13-25 years, who are unable to walk due to a lifelong disability • Adult supporters of children and young people who are unable to walk due to a lifelong disability, including family members, carers, health and educational professionals.
Planned Size of Sample (if applicable)	10 -20 non-ambulant young people and a group of adults who support them will test the MoveMore app intervention. The number of adult supporters for each young person will vary in different contexts. There will be a minimum of 1 and a maximum of 10 supporting adults.
Follow up duration (if applicable)	After the initial 12 week period of testing the intervention and collection of outcome measures, participants will have ongoing access to the app for a 24 month period to evaluate their ongoing use of it over an extended time period, when the initial data collection period has ended.
Planned Study Period	Recruitment – September 2023– November 2023 Feasibility study - October 2023- March 2024 Follow up period- December 2023- March 2026 Data collection period: October 2023 – March 2026
Research Aims	1) To undertake formative (small scale) testing of the feasibility and acceptability of the intervention and assess the appropriateness of the selected outcome measures amongst the non-ambulant young people, their adult supporters and the organisations involved. Formative testing will identify adaptations that can be made to improve the intervention. 2) To evaluate continued use of the app over a 24 month time period following the initial 13 week feasibility testing period.

LAY SUMMARY

What are the aims?

• To test whether the MoveMore app (which helps young people with long-term disabilities, who are not able to walk to move more) can be used by young people and their adult supporters in the community.

- To test whether young people and their adult supporters find the MoveMore app helpful, and to which see which functions they like to use.

Why is this research being done?

• Long periods of sitting or lying without moving can lead to poor health, for example obesity, heart diseases, type II diabetes or mental health problems. Reducing and breaking up this sedentary time can help to prevent poor health.

• Research shows that children with disabilities spend more time being sedentary than other children. Older children who are unable to walk are more sedentary than other children with disabilities.

• There are no evidence-based interventions to help young people with disabilities to reduce their sedentary time.

• We are going to test an intervention which we have co-designed with young people, their families and professionals

Functions and menus of the MoveMore app have been decided in a co-design involving young people who are unable to walk, their family members, health and education professionals and experts from universities and industry

What are we going to do?

- Testing the MoveMore app:

- 10-20 young people (aged 13 – 25 years) who are unable to walk due to a long-term disability and the adults who support them (including parents / guardians, family members, education staff, carers and healthcare professionals) will test the app.
- To collect information about how much the young people move, they will wear a Fitbit device for 13 weeks and a device called an accelerometer, that collects information about their movements, for 2 weeks.
- The young people and their adult supporters will use the app for 12 weeks
- The young people and their adult supporters will take part in an interview after using the app for 12 weeks.
- Young people complete a questionnaire called the Children's Assessment of Participation and Enjoyment before the intervention and after they have used the

app for 12 weeks. The questionnaire is about the recreation and leisure activities young people do, and how they feel about them.

- Young people and their adult supporters will be able to continue using the app for 2 years after the 12 week testing period. Researchers will continue to collect and analyse information collected by the app in this time.

- The MoveMore app

The MoveMore app has 9 sections which are explained below:

Adult supporters

Here young people invite adult supporters to log into the app and manage their adult supporters list.

Places I go

Here young people make a list of the places they go to. This list allows them to say where they do activities, where adult supports are based or where their equipment is in other sections.

Being Comfortable

This section encourages young people and adult supporters to talk about comfort and record actions to take if a young person is uncomfortable and signs that they are uncomfortable. Young people can regularly rate their comfort and look back at their ratings here.

My Movement

In this section:

1) the young person makes a list of all the movement activities they do

2) there is a calendar where daily activities can be planned, then ticked off when they are finished,

3) the young person can see feedback about their progress from their Fitbit device and ticked off daily activities.

4) the young person makes a list of the equipment they use to support movement

My Movement Goals

This is where young people can set goals. They can record and celebrate their success here.

How I Move

Here you'll find a description of how the young person likes to prepare to move, be moved and support they need to feel safe and confident to move. The young person can rate how safe and confident they feel about moving.

Our Movement Journal

Young people and adult supporters can talk about what went well / what was a challenge that day. Maybe things to never try again! Information can be shared between places the young person goes to e.g. about things they've tried / changes or feedback / suggestions about movement or action plans

Movement Stories and Resources

Read stories about what other young people have done or achieved and find resources to inspire young people about moving! Young people can write their own stories to share with other people or to remind themselves of things they've done. The app handbook is stored in this section.

Did you know?

- This is an archive of the information notifications young people receive, so they can view them again.

Adult supporter access to the MoveMore intervention

- Adult supporters access and add information to some areas of the app via an online dashboard.

Only the young person uses the app to make changes, with support from their adult supporters.

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON FINANCIALSUPPORT GIVEN**
HEE/ NIHR ICA Programme (Clinical Doctoral Research Fellowship) NIHR Academy, 21 Queen Street, Leeds, LS1 2TW Tel: 0113 532 8401 , Fax: 020 8843 8001, Email: academy@nihr.ac.uk	Main funder of study Fellowship grant total was £349, 512, which included funding for this feasibility study that has been retained beyond the duration of the fellowship, with permission from the NIHR, to carry out this work.

ROLE OF STUDY SPONSOR AND FUNDER

As sponsors, Birmingham Community Healthcare NHS Foundation Trust (BCHC) are providing oversight of the conduct of the study. BCHC will review and approve study documentation produced by the research team and administer the grant for the research. BCHC staff have contributed to the design of this research and will be involved in data analysis and interpretation and decision making in relation to the choice of journal the work will be submitted to. BCHC may offer support with dissemination of the results and provide

support with any further work following feasibility testing. BCHC will be the owners of any Intellectual Property (IP) generated by the research and are responsible for data protection in relation to all aspects of the research.

The NIHR are funding the majority of this research. The CI is an employee of BCHFT, who fund the CI's salary costs.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

Patient & Public Involvement (PPI)

The West Midland's Clinical Research Network Young Persons Steering Group and two public and patient involvement (PPI) representatives who are non-ambulant young people are involved in this research, one of which has reviewed this protocol and the participant information sheets (PISs).

App developers (Health and Care Innovations Ltd. (Health and Care Innovations (hci.digital))**)**

- Built the app and a web-based dashboard as described in the software specification (appendix 3) and made the changes required following initial review by co-design
- participants and PPI reps (prior to opening of feasibility and acceptability testing)
- Ensure the app and dashboard are compliant with the NHS Digital Technology Assessment Criteria as described in the software specification so they are appropriate for current and future use in the NHS
- Continue to update and maintain the app and dashboard for a 2 year period so participants can continue to use it following the close of the study.

PROTOCOL CONTRIBUTORS

Professor Joan Duda Joan will have overall oversight of the research, supporting the CI with protocol development, application for ethical and HRA approvals, conduct of the research, data analysis, interpretation and dissemination.

Dr. Sally Fenton and Dr. Sue Neilson will contribute to supporting protocol development, application for ethical and HRA approvals, conduct of the research, data analysis, interpretation and dissemination.

They are employed by the University of Birmingham and are independent of BCHC and the NIHR.

Expert advisor

Dr. Elizabeth Croot is an expert advisor employed by The University of Sheffield. She will support protocol development, conduct of the research, data analysis, interpretation and dissemination in relation to complex intervention development.

Elizabeth is independent of BCHC and the NIHR.

BCHFT (Sponsors)

BCHC will review and approve study documentation produced by the research team. BCHC will be involved in data analysis and interpretation, manuscript writing, and decision making in relation to dissemination of results. BCHC are responsible for data protection in relation to all aspects of the research.

PPI representatives

Public and patient involvement (PPI) representatives who are non-ambulant young people have been involved in developing the intervention and have reviewed this protocol and the PISs.

KEY WORDS: Sedentary behaviour, disability, children and young people, digital interventions, feasibility, acceptability.

STUDY PROTOCOL
Feasibility testing the MoveMore intervention to reduce sedentary behaviour in non-ambulant young people with long term disabilities.

GLOSSARY OF ACRONYMS

AS Adult supporter
BCHC Birmingham Community Healthcare NHS Foundation Trust
BSW Body support walker
CP Cerebral palsy
GMFCS Gross Motor Function Classification System
LPA Light physical activity
METS Metabolic equivalents
MRC Medical research council
MVPA Moderate to vigorous physical activity
NHS National Health Service
NICE National Institute for Health and Care Excellence
NIHR National Institute for Health and Care Research
PIS Participant Information Sheet
PPI Public and patient involvement
REC Research Ethics Committee
R&I Research and Innovation
SDT Self determination theory
SMG Study management group
YP- Young Person
YPSG Young Persons Steering Group

1 BACKGROUND

Sedentary Behaviour is defined as “any waking behaviour characterized by an energy expenditure ≤1.5 METs while in a sitting or reclining posture” [1]. In adults, higher levels of total sitting time or TV viewing time increase the risk of all cause and cardiovascular disease mortality and the incidence of type two diabetes [2]. This increased risk is highest when total sitting volumes exceeds 8 hours per day (all-cause mortality) or 6 hours per day (cardiovascular disease) and TV viewing exceeds 3-4 hours / day [2].

In children, evidence suggests that sedentary time (particularly recreational screen time), is associated with poor health outcomes such as reduced fitness, poor cardiometabolic health, spending less time sleeping and higher adiposity [3]. Spending large amounts of time TV viewing and playing video games is associated with behavioural difficulties [3]. High levels of screen time can be associated with poor mental health [3]. It appears that spending less time sedentary improves health outcomes for children, however, a dose–response relationship cannot be demonstrated at present [3]. As a result, it is not possible to provide evidence-based thresholds for how long can safely be spent doing activities such as recreational screen time [4]. Importantly, it appears that these adverse health risks occur

irrespective of the levels of moderate to vigorous physical activity (MVPA) engaged in [5].

Physical activity guidelines for adults and children and young people aged 5-18 years in the UK state that individuals should “aim to minimise the amount of time spent being sedentary, and when physically possible should break up long periods of not moving with at least light physical activity” [4].

Children with physical disabilities spend more time sedentary than able-bodied children [6]. A recent rapid evidence review relating to physical activity for disabled children and young people concluded that the risks associated with a sedentary lifestyle were outweighed any risks associated with participating in physical activity [7]. This review acknowledged that there is currently an evidence gap about the association of sedentary behaviour and health outcomes for this population, and therefore it is not possible to give anymore specific guidance than that previously issued, which advises limiting sedentary time, particularly recreational screen time [7]. A similar rapid evidence review was undertaken for adults with disabilities [8] resulting in an infographic being co-produced with adults with disabilities [9]. This infographic gives the following advice relating to sedentary behaviour; “Don’t be still for too long” and “Even a little movement is better than nothing”.

Lower levels of gross motor function [15-17] and increasing age [16, 18-20] lead to increased sedentary behaviours in children with disabilities. Young people who are non-ambulant (i.e do not walk or walk short distances as part of their physiotherapy programme, with support of a body support walker [BSW]) are therefore at greatest risk of experiencing negative health outcomes associated with sedentary time. These young people face barriers to undertaking MVPA [21-25], so intervening to help them reach the recommended levels [11] is challenging. A more achievable approach to increasing this population’s physical activity is reducing sedentary time by displacing it with light, rather than MVPA [26, 27]. Adult studies suggest interventions promoting physical activity in general do not reduce sedentary time as effectively as interventions specifically targeting this behaviour [28, 29]. No evidence-based interventions to reduce and break up sedentary time, by encouraging light physical activity (LPA), have been developed for non-ambulant young people with long-term physical disabilities [6]. The MoveMore app aims to address this unmet need. Examples of activities that could result in accumulation of LPA include using equipment such as BSW’s or standing frames, encouraging young people to be active whilst on the floor and whilst sitting (e.g. self-propelling a wheelchair), or using active computer games [27, 30, 31].

2 RATIONALE

Research related to improving engagement in physical activity for children with disabilities has been prioritised by the James Lind Alliance [43]. In the population targeted, a realistic method of achieving this is replacing sedentary time with LPA (>1.5 METS), and interrupting prolonged periods of sedentary time. LPAs can be achieved using equipment such as BSW’s or standing frames [27], encouraging young people to be active whilst on the floor and whilst sitting, or using active computer games [30, 31].

For those engaging in high volumes of sedentary behaviour, small increases in activity could lead to profound health gains [26, 44]. Interventions utilising computer, mobile and wearable technology have reduced sedentary time in other populations [45]. A targeted digital behaviour change intervention to interrupt sedentary time and increase LPA in non-ambulant young people has been co-designed with non-ambulant young people and other key stakeholders in a previous study (DoMore, IRAS number: 271259). The co-design followed the first four steps of the Six Steps of Quality intervention development (6SQuID) [46]. This study is the fifth step in this intervention development model, which involves testing and refining the intervention on a small scale, prior to collecting evidence of effectiveness in order to justify more rigorous evaluation or implementation, which is step 6.

This feasibility study will include non-ambulant young people with a range of diagnoses, to maximise impact of the intervention, by ensuring the results are generalisable to a wide population.

3 THEORETICAL FRAMEWORK

We used the 6SQuID model [46] to co-design the intervention. Step 1 involved: defining and understanding the problem and its causes from the perspective of a range of stakeholders. The factors influencing sedentary behaviour, including barriers and facilitators of undertaking LPA were identified. These factors were classified according to the Systems of Sedentary Behaviour Framework [49], which captures a system-based map of determinants of sedentary behaviour, grouped into 6 clusters: Physical Health and Wellbeing, Psychology and Behaviour, Built and Natural Environment, Social and Cultural Context, Institutional Settings and Politics and Economics). Step 2 of the 6SQuID model involved identifying which causal or contextual factors are malleable and have greatest scope for change. Step 3 involved identifying how to bring about change. A logic model was produced, and data collected informed the decision to underpin the intervention using self-determination theory [50]. The COM-B behaviour change wheel [51] was used to identify intervention functions and behaviour change techniques. A behaviour change technique taxonomy which is specific to self-determination theory was also utilised [52]. Step 4 involved deciding how to deliver the change mechanisms by producing a software specification for the app with co-design participants which was used to produce a prototype app. Co-design participants fed back on this prototype and their suggestions have been incorporated into the version of the MoveMore app and adult supporter dashboard that will be used for this feasibility study. In this feasibility study, we will focus on the fifth step of the 6SQuID which involves formative feasibility testing of the intervention.

4 RESEARCH OBJECTIVES

4.1 Objectives

1. To determine the feasibility of the app and assessment methods evaluating:
    - acceptability of the intervention and elements of the trial protocol to participants, practitioners and the organisations delivering it

- recruitment methods and rates
- training requirements for those delivering the intervention
- structure and content of the intervention and delivery requirements (access to equipment, support needed by users, time commitment from those using the app, cost)
- sensitivity and appropriateness of outcome measures
- adherence to the intervention
- attrition
- estimation of achievable sample sizes.

2. To collect sufficient data to: allow optimisation of the intervention, demonstrate whether short-term outcomes are improving (i.e. preliminary evidence of effectiveness) and ensure there are no unintended negative effects prior to undertaking a controlled, randomised pilot study.

3. To evaluate continued use of the app over a 24 month time period following the initial 12 week feasibility testing period.

4.2 Outcome

1. The intervention is successfully delivered, with key contacts (chosen by the young person) and adult supporters using the app in partnership with young people.

2. Describe the acceptability of the intervention to young people, key contacts and adult supporters.

3. Young people, key contacts and adult supporters report any successful attempts for behaviour change as a result of the intervention via the app or at exit interview,

4. Young people, key contacts and adult supporters provide feedback on their experience of using the intervention to allow optimisation of the intervention.

5. Physical activity data collected via a wearable device demonstrates a reduction in the median amount of sedentary time per day (in hours) between baseline and the close of feasibility testing.

6. Outcome measures that will provide evidence of the effectiveness of the intervention in future studies are acceptable to participants, relevant and show sufficient sensitivity (evidence of change).

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

STUDY DESIGN:

A mixed methods design will be used to collect qualitative data assessing the acceptability of the intervention and outcome measures and quantitative data measuring changes in sedentary time and LPA accumulation.

It is expected that the intervention will require optimisation prior to undertaking a larger pilot study including a control group to assess effectiveness.

MoveMore Intervention:

The MoveMore app has been developed using the COM-B intervention development process to determine the behaviour change techniques. Self-determination theory has underpinned selection of behaviour change techniques and the way in which these techniques will be delivered. A logic model for the intervention has been developed with input from the co-design participants, using a template designed for interventions that will be delivered in multiple contexts [53] (figure 2). The contents of the app is described in the lay summary above. A handbook has been produced to accompany the app to provide additional information to all who are using it (see supporting documents). The handbook will be available via online dashboard that the adult supporters use and within app as well. Young people do not need to read the handbook, unless they wish to. A prototype version of the app was built based on the software specification written following the co-design. Co-design participants fed back on this prototype and their suggestions are being incorporated into the first full version, which will be used for this study.

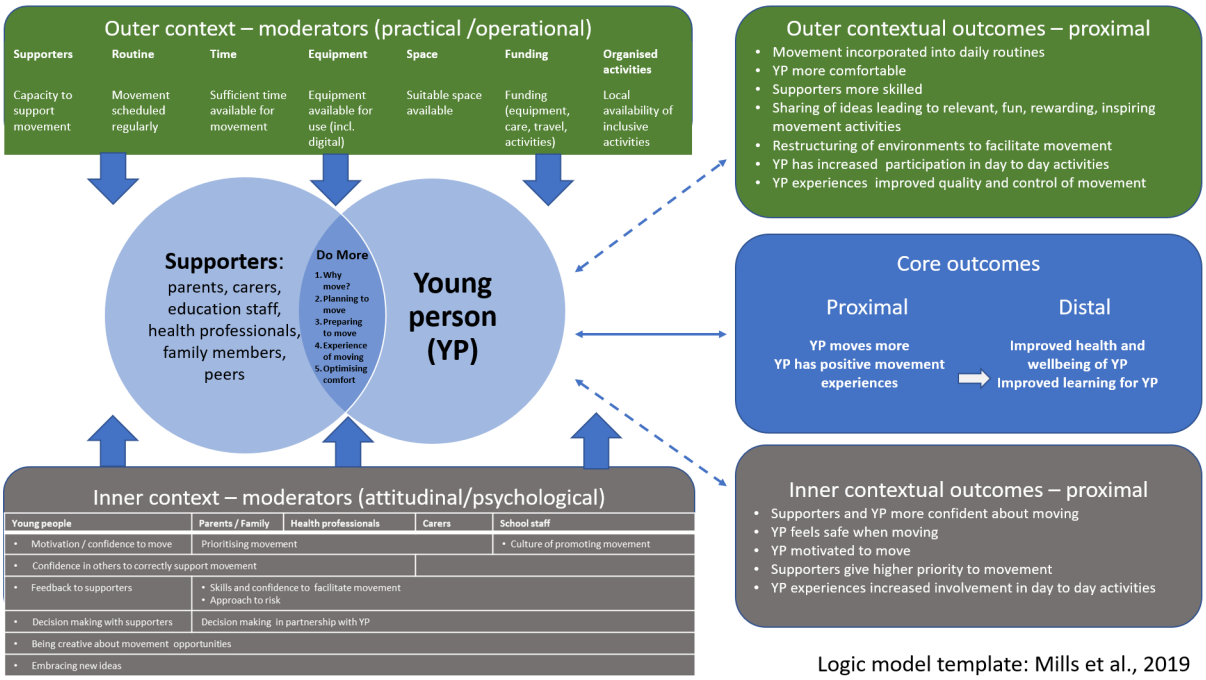


Figure 2- MoveMore App logic model. Scientific version.

MoveMore Goals	Goal description
1. Why move?	Know and understand the benefits of moving more and the risks of spending a long time sitting or lying still.
2. Planning to move	Identify and plan when and how young people can move more during daily routines. Review the plan regularly.
3. Preparing to move	Ensure the young person and their adult supporters feel confident about a movement and the young person feels safe before moving.
4. The experience of moving	The young person having a positive experience of moving.
5. Optimising comfort	Young person and adult supporters communicate about comfort and act to improve it if needed.

Table 1 MoveMore intervention goals

Procedures and outcome measures:

The YP (or Parent/carer if YP is between the age of 13-15) and ASs will need to consent to participate before they can create an account to use the MoveMore app / AS dashboard (see section 7.4 and Figure 1).

The YP (and one or more ASs if under 16 / needs support) will meet a researcher virtually on Microsoft teams to:

- re - confirm consent / assent if aged 13-15
- provide demographic and basic clinical information and information about current physical activity and function for case report form
- confirm start date,
- discuss completion of the activity diary (on paper or in a Microsoft word document) and QYPP questionnaire in week 2 and week 13,
- learn how and when to use each wearable device,
- ask questions,
- provide a mobile phone number for contacting the research team during working hours
- Choose a pseudonym for the YP to use in the Fitbit app (which needs to be downloaded to the same device the YP is using to access the app).
- Name their AS so their consent to join the study can be sought.
- Complete multiple choice quiz

Once it is known which AS have consented to participating in the study and have completed an AS case report form on RedCAP, the YP is provided with details of how to download the MoveMore App to a device they can regularly access and is given the names of the AS who have consented so they can invite them to the online dashboard from the app.

- The YP downloads the MoveMore app and creates an account.
- The YP's real name / email address is their user name. There is identifiable information such as images and the free text / upload functions where names are likely to be used within the app, therefore there is minimal advantage to be gained by selecting an alternative name. Using real names will also assist adult supporters (AS) who are involved in the care of multiple YP who are using the app.
- From the YP's MoveMore app, a team of their AS (including parents / guardians, carers, education staff, family members) who have consented are invited to create their own log in via email.
- After entering the access code provided following consent, AS can login via a web browser to an online dashboard and create their own username and password, using their real name / email address.
- The AS can view (but not edit) all information in the YP's account and add new content to some features.
- The YP nominates a "Key Contact" (KC) in each place they regularly go to. This person will help by supporting and co-ordinating efforts of the YP and AS to support behaviour change.
- There are 5 intervention goals, which are shown in Table 1.
- The detailed contents of the app, designed to help the YP to reach the 5 goals is described in the app handbook (see supporting documents).
- YP downloads / is assisted to download Fitbit app to a device they can regularly access
- Researchers will access data collected from relevant data fields from the Fitbit via a web-based dashboard.
- The YP will receive 2 wearable devices (FitBit and activPAL4^{TM} posture sensor) by post. An ID number, corresponding to the YP, will be assigned to each of the activPAL4^{TM} posture sensors in order to identify which sensor was given to which YP. The YP will also be sent an activity diary and be given online access to the Questionnaire of Young People's Participation(QYPP) questionnaire.
- YP can fill in the activity diary on word or the diary sheets can be printed and filled out. YP will be assigned an ID number, the assigned ID number will be on the on the activity diary sheets / app use log that each YP will receive. This will ensure all paper activity diary sheets remain anonymous. These paper documents will be stored in accordance with BCHC's IG policy.

Baseline data will be collected in week 1, and YP will access the app and undertake the intervention in weeks 2-13.

YP / YP's parent / guardian will receive a follow up phone call in week 3 to address any problems or answer questions. Further contact with participants during the intervention will only be arranged where troubleshooting is required to use the intervention effectively.

ActivPAL4™ accelerometers will be returned by recorded delivery after baseline data collection and be posted back again for the final week of the intervention, reducing participant burden.

Details of the outcome measures to be collected and in which weeks are shown in Table 3:

Outcome Measure	**Description of what is collected**	**Collection method**	**When outcome is collected**	**Why is this being collected**
Time spent in target heart rate zone (above or equal to 20% of HRR)	Heart rate	Fitbit (Versa)	Waking hours weeks 1 to 13 apart from swimming	Objective measurement of sedentary time. Biofeedback (Goal 4)
Estimated sedentary minutes	Minutes spent sedentary, estimated from Fitbit accelerometer using Fitbit algorithms (for general population)	Fitbit (Versa)	Waking hours weeks 1 to 13 apart from swimming	Objective measurement of sedentary time via Fitbit for comparison with activPAL4™
Estimated metabolic equivalents	A measure of energy expenditure estimated using Fitbit algorithms (for general population) by combining a number of data fields	Fitbit (Versa)	Waking hours weeks 1 to 13 apart from swimming	Objective measurement of sedentary time via Fitbit for comparison with activPAL4™
Daily sedentary time, standing time, and stepping time	Minutes per day spent sitting/lying, standing and stepping.	activPAL4™ posture sensor	Weeks 1 and 13	To provide a more objective (relative to self-report) measure of sedentary time
Activity diary	Description of what activity the young person was doing during their waking hours divided into 30 minute time intervals	Paper or word document diary	Waking hours weeks 1 and 13	To give context to and assist with validating activPAL4™ - assessed sedentary time.
% of daily activities in the “My movement	Activities in movement plan are ticked off a	MoveMore app	Weekly from the date the	Measuring increased frequency /

plan" which are completed	minimum of weekly, bit will be encouraged to tick off daily. The percentage which are completed in 1 week is reported weekly		plan is created in the app.	duration of light – vigorous physical activity Self-monitoring (Goal 2)
Multiple choice movement quiz	Short multiple choice quiz about risks of sedentary time and benefits of moving	Word document	Week 1 and end of week 13	Assess achievement of goal 1.
Safety / confidence with moving rating scale	How safe / confident YP feels about moving via Likert scale with 5 faces or yes / no checkbox (YP selects)	MoveMore app	Set by participant. Minimum daily. Weeks 2-13	Assess achievement of goal 3.
Number of SMART goals achieved	Record of / number of SMART goals being achieved	MoveMore app	Week 13	Assess achievement of goal 4.
Comfort feedback	Data from the YPs selected method of feeding back about their comfort (choice of yes / no, thumbs up / down / traffic lights / 5 point faces scale / open question with text box	MoveMore app	Frequency set by participants Week 2 - 13	Assess achievement of goal 5.
Qualitative journal entries	Journal entries that YP or supporters upload in the app/ online dashboard whilst using it.	MoveMore app	Frequency set by participants Weeks 2-13	Assess achievement of goals 1-5
Questionnaire of Young People's Participation (QYPP)	Identifies changes in the activities YP choose to participate in	Validated online questionnaire	Week 1 and end of week 13	Assess changes in participation / involvement / enjoyment of activities.

May be modified by removing some items if they are not relevant to the intervention.	and their affective responses within those activities			
Qualitative exit interview data	Data collected at close of intervention about feasibility and acceptability of the app.	Microsoft teams virtual interview with researcher	After week 13 closes	Assessment of feasibility and acceptability of app / progress against goals, which elements of app worked well / did not work well for them.
Completion of Key Contacts information	Key contact name name has been entered in for at least one setting	MoveMore app	Week 13	Assess if key contacts system is used
Using “My movement plan”	Evidence of a) entering and b) reporting against activities in the app yes / no	MoveMore app	Week 13	Assess if goal 2 delivery method is appropriate
Completion of “How I move” plan	Has the plan been completed in the app yes / no / partially	MoveMore app	Week 13	Assess if goal 3 delivery method is appropriate
Completion of “Suggestions to try when YP doesn’t feel safe / confident” list	Has the list been completed in the app yes / no / partially	MoveMore app	Week 13	Assess if goal 3 delivery method is appropriate
Number of stories or goal certificates sent to admin	Number of YP who have used function of sending stories or goal certificates to admin for publication	MoveMore app	Week 13	Assess if stories / goal certificate publication function is used to support goals 2 and 4
Number of clicks on resources links	Number of YP / supporters who have followed links to resources	MoveMore app	Week 13	Assess if resources function is used to support goals 2 and 4
Completion of equipment list	Has the list been completed	MoveMore app	Week 13	Assess if equipment list function is used

	in the app? Yes / no / partially			to support goal 3 and 4
Completion of SMART goals section	Have SMART goals been listed in the app? Yes / no / partially	MoveMore app	Week 13	Assess if SMART goals function is used to support goal 3 and 4
Completion of 3 yes / no check boxes for comfort questions and selection of preferred comfort rating method	Have yes / no check boxes and preferred comfort rating method been completed in the app/ Yes / no / partially	MoveMore app	Week 13	Assess if optimising comfort functions are used to support goal 5
Completion of comfort action plan	Has the action plan been completed? Yes / no / partially	MoveMore app	Week 13	Assess if comfort action plan is used to support goal 5
Completion of “How I show I’m uncomfortable” list	Has the “How I show I’m uncomfortable” list been completed? Yes / no / partially	MoveMore app	Week 13	Assess if “How I show I’m uncomfortable” list is used to support goal 5
Completion of “Things I want to say about my comfort” box	Has the “Things I want to say about my comfort” box been completed? Yes / no	MoveMore app	Week 13	Assess if “Things I want to say about my comfort” box is used to support goal 5
Uploading of “Our journal” entries	Number of journal entries and who uploads them (YP / AS)	MoveMore app	Week 13	Assess if “Our Journal” is used to support goals 1-5
Time taken to train YP / AS to use the app	Log of time spent with YP and supporters to train them to use the app. Record the role of the person being trained and how long was spent with them	CI keeps log on excel spreadsheet.	Weeks 2-13	Assess the amount of training time required to deliver the intervention.

Time YP and AS spend on using the app (accessing info / looking at feedback / creating plans / lists / goals)	Daily log of time YP and supporters spend using the app.	Investigate with app developers collecting this via app stats create word doc for teams of YP and their AS	Weeks 2-13	Assess the amount of time supporters / YP devote to using the app.
Recruitment rate	Length of time taken to recruit 10-20 young people to undertake feasibility testing.	Record time taken to reach an acceptable sample size for feasibility testing.	Opening to closing of recruitment period	Assess length of time taken to recruit to inform future study designs.

Table 3. Outcome measures for feasibility testing. HRR = Heart rate reserve. YP = Young person. AS = Adult Supporters. CI = Chief Investigator. SMART = Specific, measurable, achievable, realistic, timed.

To support behaviour change through biofeedback (a specific form of self-monitoring), the YP will wear a Fitbit Versa on their dominant wrist during the day throughout the study. They will need to install the Fitbit app on their device (using a pseudonymized username), but they will not be expected to access data via the fit bit. They will access the biofeedback, based on their % Heart Rate Reserve (HRR) via the MoveMore app. The MoveMore app will show them the number of minutes they spend at or above an exercise intensity of 20% of their HRR, which is the accepted divide between sedentary and light physical activity [54]. This is calculated by the “Active Zone Minutes” function on the Fitbit. This function counts exercise intensities of 40% and above (moderate physical activity) as active zone minutes when it is being used in the standard way. The % HRR data will act as part of the intervention (biofeedback) and as an alternative outcome measure to the activPAL4TM accelerometer (see below) to estimate sedentary time. Estimated sedentary minutes and metabolic equivalents will also be collected via the Fitbit to compare with the activPAL4TM data. This data is generated from algorithms in the Fitbit based on the general population. This data will therefore not be fed back to participants, only to the researchers via the web-based dashboard. Having several methods of recording physical activity level to compare (%HRR, Fitbit estimates of sedentary minutes and metabolic equivalents, activPAL4TM and self-report diary) will assist with ascertaining whether %HRR is an appropriate biofeedback measure to use in the intervention.

If the YP wishes to leave the Fitbit on at night time they can, provided it is charged overnight when required. Data collected overnight will not be analysed, but may improve the quality of %HRR measurement, as overnight data will contribute to the accuracy of resting heart rate estimation. Researchers will access data from the MoveMore app and the relevant data from the Fitbit via the web-based dashboard.

To evaluate whether the intervention resulted in any changes in the YP’s sedentary time, the YP will wear an activPAL4TM accelerometer on their thigh during week 1

(baseline) and during week 13 (final week of the intervention period). The activPAL4 TM will be worn continuously, for 24 hours a day for 7days [55]. The manufacturers recommend the device worn on the midline anterior aspect of the upper thigh, and the standard of attaching it to the right thigh for research purposes will be followed [55]. The activPAL4TM uses proprietary algorithms to estimate daily sedentary, standing and stepping time, and is considered the gold standard for device-based measurement of sedentary time. The activPAL4TM 's criterion validity has been demonstrated in groups of ambulant young people with diplegic CP [56], but not those who are non-ambulant. Note: due to the protected algorithms and lack of blue tooth connectivity, it is not possible to integrate activPAL4TM data into the MoveMore app software. Therefore, as a validated method of measuring sedentary time in non-ambulant young people is yet to be established, both the Fitbit Versa and activPAL4TM accelerometer are needed in order to; 1) support behaviour change (Fitbit Versa), and 2) provide outcome assessment of changes in sedentary time (activPAL4TM and Fitbit Versa).

The QYPP's validity and reliability have been established for children with disabilities up to the age of 21 [57].

Qualitative data will be collected via individual semi structured interviews, because unbiased personal experiences and opinions are being sought. Interviews allow exploration and clarification of participants responses, which is not possible via written questionnaires. All YP will be interviewed. AS will be invited to interview, however interviewing all AS is desirable but not essential. Interviews will be recorded on Microsoft Teams. See the supporting doumentation for the interview topic guide.

Data Analysis:

Qualitative data:

Acceptability of the intervention to participants will be assessed via thematic analysis of video footage of the interviews [58]. This formative analysis will assess the impact of the intervention and identify ways of optimising it. Initially, inductive thematic analysis will be utilised. This will be based on the method described by Braun and Clarke [59], but modified by extracting codes and themes from video footage rather than transcripts. The themes will then be related to theories and models that underpin the intervention development in a deductive manner, including: the Systems of Sedentary Behaviour Framework [49], self-determination theory [50] and the COM-B model [48].

Quantitative data

Summary statistics will be used to describe changes in quantitative data (for example, the median amount of sedentary time per day (in hours) between baseline and study exit), assess the appropriateness of outcome measures and provide evidence of short-term improvements in outcomes. Level of agreement between the methods of estimating sedentary time (%HRR, estimated sedentary minutes, estimated metabolic equivalents, activPAL4^{TM} and self-report diary) will be explored.

Study closure

Participants will have the option to continue using the intervention for a 24 month period following the initial 13 weeks of feasibility testing. Any data collected via the app will continue to be collected and analysed by the research team to evaluate continued use of the intervention. Participants can keep the Fitbit they were provided with. This is gifted to them and will no longer belong to BCHC.

6 STUDY SETTING

This feasibility study will be conducted remotely. The participants will carry out intervention activities from their home.

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

7.1.1 Inclusion criteria

YP receiving the intervention will:
1) be aged 13-25 years
2) have a lifelong disability
3) be non-ambulant
4) have sufficient understanding and communication to provide assent or consent and participate in an interview.
5) communicate using the English language (including use of a communication aid that uses English language).
6) live in the United Kingdom
7) have access to wifi and a device on which to access the apps

All AS who are accessing the intervention (including parents / guardians, carers, health or education staff, family members) will be participants in the study.
AS participating in the study will:

1) be aged 16 or over
2) be involved in supporting the YP in some way, for example (but not limited to) parents / guardians, carers, health or education staff, family members
3) have sufficient understanding and communication to provide consent and participate in an interview
4) communicate using the English language
5) live in the United Kingdom
6) will need to have access to appropriate equipment to safely carry out moving and handling tasks, have been trained how to carry out moving and handling safely and be confident in doing so.
7) have access to wifi and a device on which to access the online dashboard

7.1.2 Exclusion criteria

Exclusion criteria for YP:

5) under 13 years of age or over 25 years
6) not able to communicate using English
7) unable to access wifi or a device on which to access the app
8) have had orthopaedic surgery (excluding botulinum toxin injections) less than 6 months before participating in the study
9) have surgery planned during the trial period (excluding botulinum toxin injections)
10) live outside the United Kingdom

Exclusion criteria for AS:

1) aged 15 or under
2) not able to communicate using English
3) unable to access wifi or a device on which to access the online dasboard
4) do not have access to appropriate equipment to safely carry out moving and handling tasks, or are not trained/ not confident to use it,
5) live outside the United Kingdom

7.2 Sampling

7.2.1 Size of sample

A target sample size of 10-20 young people receiving the intervention has been selected for feasibility testing. This will be insufficiently powered to undertake evaluations of the intervention's efficacy or effectiveness. This small sample size has been chosen because time available for recruitment / data collection and analysis is limited. This is because the co-design phase of the study took longer than anticipated and there have been delays in the progress of the study due to the Covid-19 pandemic. The number of adult supporters for each young person will vary in different contexts. There will be a minimum of 1 and a maximum of 10 supporting adults.

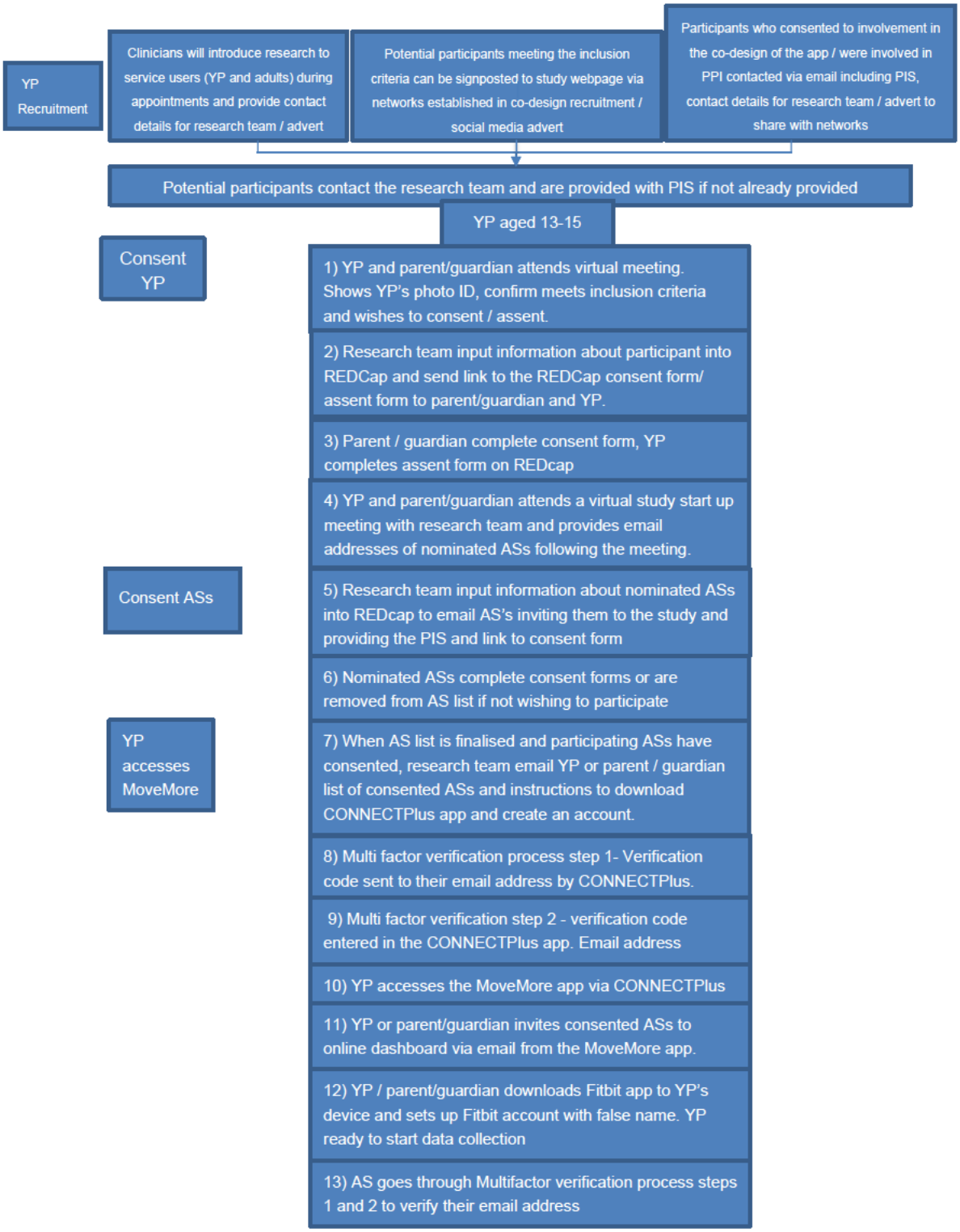
7.2.2 Sampling technique

Due to the small sample size and time limitations to undertake feasibility testing, convenience sampling will be employed to recruit.

7.3 Recruitment

See Figure 1 which summarises recruitment procedures. Staff at BCHC will distribute advertisements and discuss the research with service users/YP. In their appointments the research team's contact details will be given, so that they can get in touch regarding their interest in being involved, or verbal consent will be gained for the CI to contact them. An email will be sent to all YP's who consented to take part in the co-design inviting them to take part in feasibility testing if they are still under 25

years of age. The email will include a PIS and the contact details of the research team.



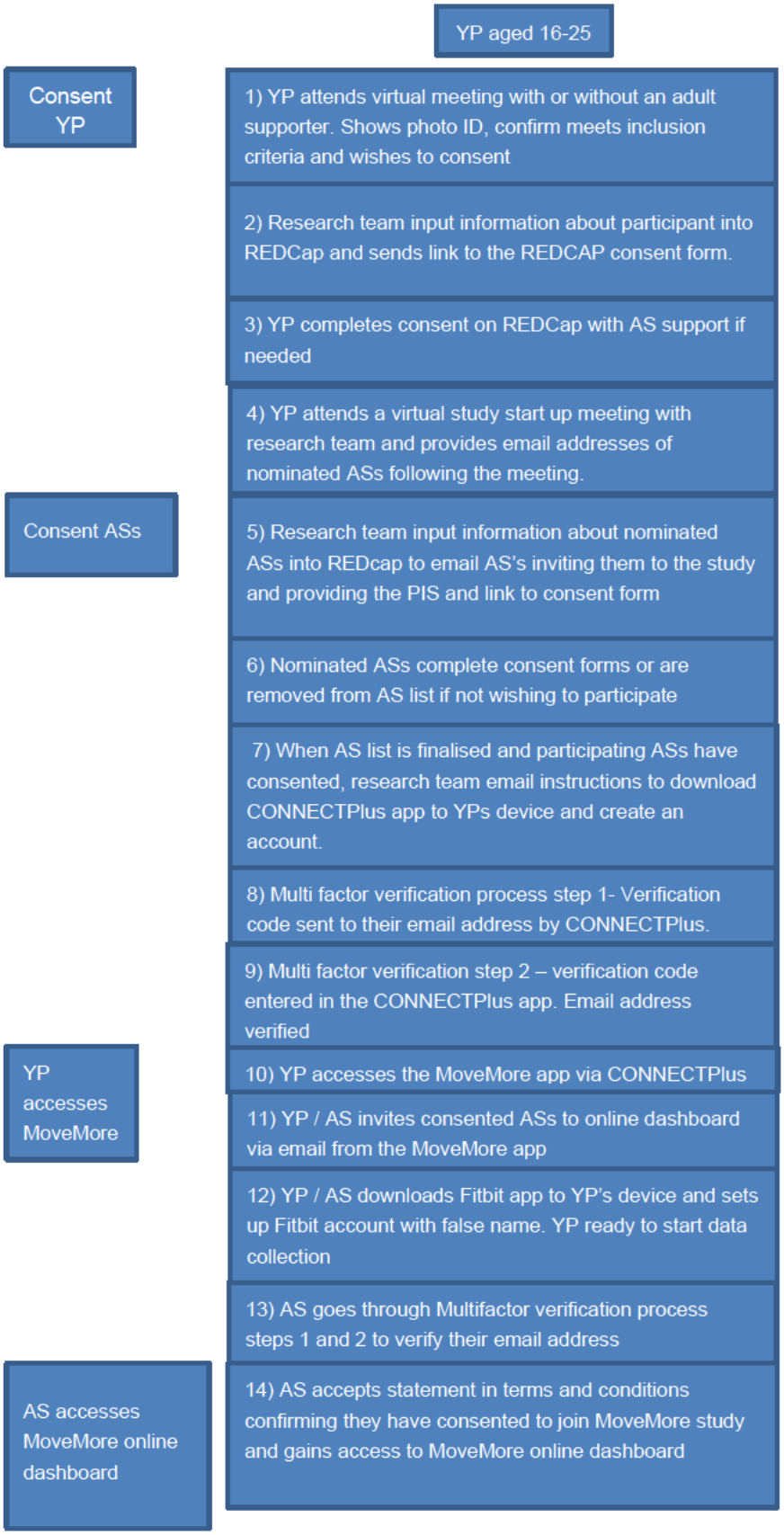


Figure 1. Consent and recruitment processes for the MoveMore Study

Everyone who consented to participating in the intervention co-design and indicated that they were happy to be contacted again in the future, or were involved in PPI for the co-design study will be emailed to encourage them to advertise this study via their own networks and encourage potential eligible participants to contact the CI. The email will include all PISs and the contact details of the CI.

Anyone meeting the inclusion criteria who wishes to be part of the study can contact the CI, whose details will be shared on the study website. The PIS will also be available to download from the study website.

£10 payments will be offered to YP and AS to thank them for their contributions.

7.4 Consent

See Figure 1 which summarises these consent procedures. Informed consent will be obtained before any research activities commence. Four PISs have been produced: one for young people aged 13- 15, a second for young people aged 16 -25, a third for parents/guardians of young people who are participating and a fourth for AS who are not parents/ guardians. PISs will be emailed to anyone who contacts the study team and will also be available on the study website.

A consent meeting will be arranged with YP aged 13-15, their parent / guardian and a member of the study team via video conferencing, in which consent of parents / guardians and assent of the YP can be ascertained face to face prior to them completing the digital consent form. YP aged 16-25 will also need to attend a virtual meeting, however their parent/ guardian does not need to attend. During the virtual meeting the YP will need to show a form of identification, to confirm their identity, and also confirm that they meet the inclusion criteria of the study.

Following the meeting, the research team will input information about the participants into REDCap and then a link to a digital consent form will be emailed to the parent/guardian/YP. If the YP is aged 13-15, their parent/ guardian will need to complete the consent form. YP aged 16-25 can complete the consent form or complete it with the support of a parent / guardian / carer if needed. YP aged 13-15 will be sent an assent form via email which they can complete, or they can complete it with the support of a parent / guardian / carer if needed.

Once the digital consent forms have been completed, the YP (and their parent/ guardian, if aged between 13-15) will attend a virtual start up meeting. After this meeting they will provide email addresses of who they wish their AS(s) to be. The research team will then input information about nominated ASs into REDcap to email AS's inviting them to the study and providing the PIS and link to consent form. The nominated ASs complete consent forms or are removed from AS list if they do not wish to participate.

When AS list is finalised and participating ASs have consented, the research team email YP or parent / guardian list of consented ASs and instructions on how to download the CONNECTPlus app and create an account. Once an account has been created, the YP or parent/guardian will need to verify their account. A verification code will be sent to the email address used to set up the account on CONNECTPlus.

The YP/Parent/guardian will need to enter this code into the CONNECTPlus app in order to verify their account. The YP will then be able to access the MoveMore app using CONNECTPlus. The YP will then need to invite their ASs from within the MoveMore app. The YP / parent/guardian will need to download the Fitbit app to YP's device and set up a Fitbit account with under a false name. After this, the YP ready is to start data collection.

When ASs are invited by the YP, the ASs will also need to go through a multifactor authentication process of verifying their email address. Once this is complete, AS will need to accept the terms and conditions confirming they have consented to join the MoveMore study to gain access to the MoveMore online dashboard.

8 ETHICAL AND REGULATORY CONSIDERATIONS

8.1 Assessment and management of risk

Risks associated with trial interventions

☐ A ≡ Comparable to the risk of standard medical care

☒ B ≡ Somewhat higher than the risk of standard medical care

☐ C ≡ Markedly higher than the risk of standard medical care

Justification:

Young people with disabilities are a vulnerable population. Their risk of experiencing physical and emotional abuse is elevated in comparison to children and young people without disabilities. Digital interventions such as apps which are intended to be used by young people with disabilities create a risk of the app being abused by communicating with young people with the intention of causing harm. Multiple safeguarding measures have been put in place within the app to mitigate this risk. Only adult supporters the young person invites can access their information and use the online dashboard. Also all adult supporters can see everything that is posted, so no communication can be carried out in private via the app. Young people using the app can only communicate by liking each others stories.

The intervention is likely to result in increased demand for moving and handling tasks to be carried out by supporters, and for participants to change their routines in order to be more active, potentially increasing their risk of injury related to this increased activity.

Management of the data being collected via the app in relation to security, GDPR and safeguarding of young people needs to be carefully considered. Consideration of who can access / edit what data and what data are identifiable / where and how identifiable data are stored is important.

What are the key risks related to therapeutic intervention you plan to monitor in this trial?		How will these risks be minimised?		
Intervention/ Activity	Hazard	Activity	Frequency	Comments

Digital intervention delivered via app and online dashboard.	Musculoskeletal injury to participant during activities intended to achieve increased level of physical activity.	Adequate assistance and supervision from supporters. Prompts within the intervention handbook to assess risk of any new activity or change in routine and seek approval of an appropriate adult prior to starting new activities.	On-going throughout testing	Low risk, similar to that associated with all standard rehabilitation. (A)
	Cardiovascular event during activities intended to achieve increased level of physical activity.	Adequate assistance and supervision from supporters. Prompts within the intervention handbook to assess risk of any new activity or change in routine and seek approval of an appropriate adult prior to starting new activities.	On-going throughout testing	Low risk in this age group, similar to that associated with all standard rehabilitation. (A)
	Injury to supporters due to increased moving and handling of participant	Stated in inclusion criteria that parents/carers have access to appropriate equipment to safely carry out moving and handling tasks, have been trained how to carry out moving and handling safely and are confident in doing so.	On-going throughout testing	Medium risk (B) as frequency of moving and handling will increase to achieve the intended outcome of the intervention.
	Loss / damage to equipment provided as part of the intervention	Ensure equipment is adequately insured and can be replaced if it is lost/damaged to avoid participant needing to withdraw from the trial.	Ongoing	Low risk – safety of participants is not at risk if equipment is lost / damaged. (A)
	Malfunction / loss of access to digital intervention due to connectivity	Participants have multiple methods of contacting the research team to report problems and issues resolved promptly to avoid loss of data/reduction in data quality.	Ongoing throughout testing	Low risk – safety of participants is not at risk if they are unable to access the intervention. (A)

	Unintended identification of participants	App has functions which allow sharing of “stories” including an image with admin who can then publish the story to all app users. Can be disabled in settings by parents of those under 16. Admin will check this with parents / guardians of those under 16 prior to publication. App has ability to export goal achievement certificates as PDFs to share on social media if young people choose to do so. Co-design work suggests some young people may be motivated by purposefully identifying themselves via social media.	Ongoing throughout testing	Low risk – If young people are identified as being part of the study, this is unlikely to be harmful. Goal certificates do not contain senitive information and the choice to share them is under the control of the YP.
	Malicious attacks on the app via malware / virus / hacking events	Management of app via developers HCI who are experienced in producing secure health apps that are used in the NHS.	Ongoing	Low risk (A) as HCIexperienced in anti-virus software and app will need to comply with the NHS governance standards
	Safeguarding of vulnerable young people using the app.	All other identifiable data is for sharing amongst YP and ASs only. Only accessible to YP, ASs, researchers. Pseudonym used for user name on Fitbit account so all data stored in the USA are anonymised Participants can’t communicate with each other via the app. They only have the ability to	Ongoing	

		like stories / goal achievement certificates published by admin.		
	Data breach	There will be a Data sharing agreement between the app developers and BCHC. A DPIA is being undertaken and approval of the BCHC Information Governance team is being sought.	Ongoing	Low risk (A). Stipulations of DPIA / data sharing agreement will be followed. App will need to comply to the NHS governance standards so data breach unlikely.
Outline any other processes that have been put in place to mitigate risks to participant safety (e.g. DMC, independent data review, etc.) Safeguarding: The PIS will state that any disclosure that raises concerns in relation to the safety and wellbeing of participants or criminal activity will be shared with relevant services. Any concerns will be managed in line with BCHCs Safeguarding Children and Safeguarding vulnerable Adults policies.				
Outline any processes that have been simplified based on the risk adapted approach.				

Adverse events will be defined as; any untoward medical occurrence, unintended distress, disease or injury or any untoward clinical signs whether or not considered to be causally related to the intervention.

Serious adverse events will be defined as an adverse event that:

- Led to death
- Led to a serious deterioration in the health of the participant that either:
- Resulted in a life-threatening* illness or injury
- Resulted in a permanent impairment of a body structure or a body function
- Required in-patient hospitalization or prolongation of existing hospitalization**
- Resulted in medical or surgical intervention to prevent life threatening illness or injury, or permanent impairment to a body structure or a body function
- Other important medical events***

* the term life threatening here refers to an event in which the patient is at risk of death at the time of the event; it does not refer to an event that might hypothetically cause death if it was more severe (eg a silent myocardial infarction)

** Hospitalisation is defined as an in-patient admission, regardless of length of stay, even if the hospitalisation is a precautionary measure for continued observation. Hospitalisation for pre-existing conditions (including elective procedures that have not worsened) do not constitute an SAE

*** Medical judgement should be exercised in deciding whether an AE is serious in other situations. Important AEs that may not be immediately life threatening or result in death or hospitalisation, but may seriously jeopardise the participant by requiring intervention to prevent other undesirable outcomes.

A detailed digital record of any adverse events or serious adverse events which occur as a result of this study will be made according to guidelines for adverse event reporting. A serious adverse events report form will be used for serious events. This will be saved on the BCHC's study folder on the common drive. The date, time, nature and people involved in any adverse events will be logged on a table to identify any recurring issues.

The study will stop if:

There is one incident of a serious advert adverse event - it may resume if appropriate once the event has been fully investigated and if the sponsors and collaborators consider it to be safe to do so.

There are 3 or more similar adverse events. Key study contributors would meet to discuss the events in this case and decide on the actions to be taken.

8.2 Research Ethics Committee (REC) and other Regulatory review & reports

Before the research commences, a favourable opinion will be sought from an NHS Research Ethics Committee for the study protocol, informed consent processes and other relevant documents e.g. advertisements.

Any substantial amendments that require review by NHS REC will not be implemented until that review is in place and other mechanisms are in place to implement the amendments at each site.

An annual progress report will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended.

The Chief Investigator will notify the REC of the end of the study.

If the study ends prematurely, the Chief Investigator will notify the REC, including the reasons for the premature termination.

Within one year after the end of the study, the Chief Investigator will submit a final report with the results, including any publications/abstracts, to the REC.

Regulatory Review & Compliance

Before any site can enrol patients into the study, the CI/PI will ensure that appropriate approvals from participating organisations are in place and comply with the relevant guidance.

For any amendment to the study, the CI or designee, in agreement with the sponsor will submit information to the appropriate REC in order for them to issue approval for the amendment. The CI or designee will work with sites (R&D departments at NHS sites as well as the study delivery team) so they can put the necessary arrangements in place to implement the amendment to confirm their support for the study as amended.

Amendments

If the sponsor or CI wish to make an amendment to the REC application or the supporting documents, they will use the amendment tool to determine what action is required to make the amendment. The sponsor will decide whether any amendments are substantial or non-substantial for the purposes of submission to the REC.

If applicable, other specialist review bodies will be notified about substantial amendments in case the amendment affects their opinion of the study.

Amendments will be notified to the HRA where the lead NHS R&D office is based (England) and communicated to the participating organisations (R&D office and local research team) and departments of participating sites to assess whether the amendment affects the NHS permission for that site.

Substantive changes will be communicated to relevant stakeholders (e.g., REC, R&D, regulatory agencies) via email.

Version control in the sponsors R&I folders on the common drive will ensure the amendment history is tracked to identify the most recent protocol version.

8.3 Peer review

The proposed methods have been reviewed by the academic partners at the University of Birmingham and the Research governance and Information Governance Teams at BCHC.

8.4 Patient & Public Involvement

Patient & Public Involvement (PPI)

Members of the West Midlands YPSG, four public and patient involvement (PPI) representatives who are non-ambulant young people and two parents of young people with disabilities have been involved in developing the application to undertake this research. PPI representatives with lived experience of long-term disability have reviewed this protocol.

The PPI representatives have been involved in developing the PISs and have contributed to production of the MoveMore website. They will assist with

disseminating study information via relevant networks they are members of, opportunities in their local communities and face to face activities to support recruitment. They have assisted with the patient facing elements of the software, carrying out early testing prior to the feasibility study commencing. Some of the PPI representatives offered to be involved with analysis of data and writing and reviewing dissemination materials such as journal articles and reports, presentations and posters, and this will be arranged.

PPI representatives will have an opportunity to produce a short video to disseminate the findings of the feasibility study and contribute to presenting the findings at conferences.

The population of Birmingham is very diverse. Ensuring this diversity is reflected in research carried out in this area is challenging due to cultural differences and language barriers. Encouraging more underserved groups to become involved in research as PPI representatives or participants is important. Funding has been allocated for working alongside Birmingham Community Healthcare NHS Foundation Trust's dedicated Equality, Diversity and Human Rights Manager, to reach out to local communities to improve understanding of and trust in health research.

8.5 Protocol compliance

Any accidental protocol deviations will be documented on the relevant forms and reported to the Chief Investigator and Sponsor immediately.

Deviations from the protocol which are found to frequently recur are not acceptable, and immediate action will be taken to prevent any further incidences. An emergency meeting of the TSC may be required if this situation arises.

8.6 Data protection and patient confidentiality

All investigators and study site staff must comply with the requirements of the Data Protection Act 2018 with regards to the collection, storage, processing and disclosure of personal information and will uphold the Act’s core principles. A data protection impact assessment (DPIA) is being undertaken to ensure the intervention is compliant with GDPR

Identifiable data will be stored and transferred in accordance with BCHC’s Information Governance Policy and the data sharing agreement between the app developers and BCHC. The app developers are registered on the NHS Data Security and Protection (DSP) Toolkit. Identifiable data will only be accessed by the CI and members of BCHC’s Research and Innovation team. Pseudonyms will be chosen by participants to create anonymised log in details for the Fitbit.

Anonymised data may be stored on personal devices, to allow access to analysis software. Identifiable and anonymised data will be archived by BCHC for a maximum of 5 years.

A penetration test of the MoveMore app will be undertaken prior to feasibility testing.

Auditors may require access to any of the data collected in line with study.

Any paper documents, for example the activity diary that can be printed by the YP and sent to the research team will have an ID number rather than a name on them. This number will be added to the document by the study team prior to sending to the participant. This will ensure all paper documents will only contain anonymous data. Any paper documents will be stored in a locked filing cabinet in accordance with BCHC's IG policy.

8.7 Indemnity

The sites included in this study will be covered by the NHS indemnity scheme to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research, design of the research and conduct of the research.

The collaborators from outside the NHS will be responsible for their own indemnity insurance arrangements. This is specified in the contract with BCHC

8.8 Access to the final study dataset

BCHC will keep study data for 5 years, as stated on the PIS.HCI will keep data for 24 months after the close of the feasibility study, whilst participants have ongoing access to the app. HCI will then destroy data unless they come to an agreement with the participant following commercialisation of the app. Data collected by BCHC will not be shared with any other parties prior to publication. It is included in the consent forms and PISs that anonymised data may be used for secondary analysis.

9 DISSEMINIATION POLICY

Dissemination policy

The sponsors (BCHC) own the data arising from the study. On completion of the study, the data will be analysed and tabulated and a final study report will be prepared to share with the REC and funders (NIHR). Sections of this report will be published on the NIHR website, and the full report may be accessible via the NIHR on request.

A final report will be submitted to the REC within 12 months of the study ending. The study participants and PPI representatives will be informed of the findings via the study website following publication. Some PPI representatives and participants may be involved in producing a video and/or attending conferences to disseminate the findings.

Following the main publication of study findings, participating investigators can request permission from BCHC to publish further papers.

Participants will receive feedback about their progress throughout the intervention. They will not be able to specifically request personal data once the study has closed, but will have access to their data in the app for 24 months after the close of the feasibility study.

9.2 Authorship eligibility guidelines and any intended use of professional writers

Authorship eligibility will follow the International Committee of Medical Journal Editors authorship criteria for manuscripts submitted for publication [61]. Professional writers will not be used.

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