THE IMPACT OF MODERATE OR LATE PRETERM BIRTH ON SOCIAL UNDERSTANDING

By

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ABSTRACT

Background: Preterm birth (<37 gestational weeks) accounts for an increasing proportion of global births each year. Moderate or late preterm birth (MLPT) ($32^{+0/7}$ - $36^{+6/7}$ gestational weeks) accounts for over 80% of preterm births yet represents only a fraction of research into prematurity. Whilst outcomes of MLPT were previously considered similar to those of individuals born full-term, more recent evidence suggests this is not the case. Despite the frequency of MLPT, there is a paucity of information surrounding the prevalence of common neurodevelopmental outcomes and association with gestational age. Neonatal follow up is prioritised towards those born at the earliest gestations, with no current guidelines addressing the potential cascading impact of MLPT for children or their parents.

Method: A large scale systematic review and meta-analysis was employed to delineate the prevalence of autism characteristics for individuals born preterm. Two empirical studies to define the prevalence *and* profile of social abilities within a sample of MLPT children were conducted. These studies combined eye-tracking, behavioural tasks and standardised questionnaires to address these questions in a robust manner. A qualitative interview study was conducted to explore mothers' perspectives of having a child born MLPT. Healthcare provision, clinical support and educational needs were discussed.

Results: The prevalence of autism characteristics in preterm individuals was estimated at 6-20%, with lower estimates obtained for diagnostic assessments compared to screening tools. Only a small proportion of MLPT children scored above clinical threshold on validated parent

report screening measures. Mothers of MLPT born infants highlight the need for further information and support *prior* to the birth of their child.

Conclusions: Preterm birth is associated with an increased prevalence of social cognitive and neurodevelopmental difficulties, with screening tools an efficient strategy to identify MLPT children for whom further neurodevelopmental assessment may be warranted. Subsequently, service provision and routine additional developmental follow up is encouraged to ensure every child has appropriate and timely support. Future research should actively involve parents and caregivers of MLPT born children as co-researchers to ensure future directions are in line with their priorities.

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CHAPTER ONE

PRETERM BIRTH, AUTISM AND SOCIAL COGNITION: AN INTRODUCTION

1.1 Introduction

This chapter provides an overview of preterm birth, including definitions and potential downstream neurodevelopmental consequences. Definitions, conceptualisations and frameworks for understanding autism are explored, with detailed consideration of diagnosis and screening in relation to preterm birth. Social cognition is explored, with specific reference to early development and putative associations to preterm birth.

1.2 Preterm Birth

1.2.1 What is preterm birth?

Preterm birth is defined as birth at a gestational age of less than 37 weeks (Howson et al., 2013) and accounts for 15 million births worldwide each year (World Health Organization, 2018). Prematurity presents unique medical risks to both mother and baby and is common even in women[1] considered to be progressing through a healthy and low-risk pregnancy (Kiserud et al., 2017). The number of babies born preterm globally each year is increasing (Vogel et al., 2016), although true prevalence estimates are particularly difficult to

[1] This thesis acknowledges the widening debate around the correct use of language in the maternity context and the importance of adopting terminology that is representative of *all* family contexts. However, given the infancy of these discussions the terms 'mother' and 'woman' are used throughout this thesis, in line with current maternal and health care policy (Darwin & Greenfield, 2019). It is acknowledged that these terms may not be preferred by all.

quantify given socioeconomic disparities and differing reporting methods internationally. Concomitant to the rise in the prevalence of preterm birth, is the global acknowledgement of the health burden that prematurity poses. Premature birth is the leading cause of childhood mortality worldwide, with heightened risk of poorer outcomes in less economically developed countries (Katz et al., 2013). The United Nations recently highlighted preterm birth as a focal point for future research and support as part of their global sustainable development goals, with Goal 3 specifying an aim to end preventable deaths of new-borns and children aged under 5 years by 2030 (United Nations, 2018). While rates of prematurity continue to rise worldwide, it is imperative that organisations such as the United Nations continue to highlight the need to develop both research and medical resources to improve global outcomes for those born preterm.

1.2.2 Causes of preterm birth

Although there is no singular cause of preterm birth, there are several risk factors associated with babies born before 37 weeks. Preterm birth is described as occurring for one of three main reasons (Vogel et al., 2016). First, preterm births can be clinically initiated through medical induction or by planned caesarean section. Foetal indications represent around 30-35% of all preterm births (Ananth et al., 2005) and are often the result of considerations of medical risk for both mother and baby in allowing pregnancies to continue past 37 weeks. Over the last ten years, medically indicated preterm births have risen by almost 50% (Goldenberg et al., 2008). The sharp rise in preterm birth through medical induction has been directly linked with changes and advances in obstetric practices, whereby immediate health risks to both mother and baby are more widely known and therefore medical intervention is considered the best outcome (VanderWeele et al., 2012).

Second, preterm birth can be spontaneous, accounting for 40-50% of all preterm births (Mattison et al., 2001). Spontaneous preterm births are usually categorised separately from those that are medically induced, as clinical intervention has played no role in the preterm birth. The cause of spontaneous preterm birth is thought to be multi-factorial (Blencowe et al., 2012). Given that early identification of spontaneous preterm birth is complex, understanding contributing risk is vital from both a medical and caregiver perspective (Chang et al., 2013). Lower socioeconomic status, poorer nutritional status, substance abuse, older maternal age, multiple pregnancy and higher body mass index are all associated with an increased likelihood of spontaneous preterm birth (Blencowe et al., 2013; Kramer et al., 2001; Moutquin, 2003). Prior obstetric history of preterm birth is also a risk marker, with women who have had a previous preterm delivery more likely to have another (Ferrero et al., 2016). Clinicians and medical professionals often take a rounded approach to risk when planning the best course of care for women, who through various pathways are considered to be at greatest risk of spontaneous preterm birth.

Finally, premature rupture of membrane (PROM) can occur, representing 20-30% of preterm births (Meis et al., 1987). PROM is defined as a rupture of membrane occurring before contractions (Furman et al., 2000), with the cause of rupture often unknown. Research suggests infections and tobacco use are two of the main contributing risk factors of PROM (Mercer et al., 2000). PROM is accompanied with significant medical concern due to its links with foetal mortality, as babies are at increased risk of sepsis, hyperplasia and asphyxia (Canbek, Imerci, Akgün, Yesil and Aydin, 2015). PROM usually proceeds the onset of labour within a short time frame for most women, highlighting the need for immediate medical intervention to promote positive outcome (Romero et al., 2011).

1.2.3 Classifications of preterm birth

While the World Health Organisation's definition of preterm birth was established in 1969 (World Health Organization, 2018), it was agreed that further classifications of prematurity would be beneficial in assessing risk and health consequences and providing clearer avenues for research and policy guidelines (Engle, 2006). Given foetal development is a continuum, there is value in further subdividing prematurity into categories based on gestational age, rather than simply categorising babies in two mutually exclusive groups (preterm or term). Although there are discrepancies regarding conclusive definitions of subcategories, those presented in Figure 1.1 represent general consensus.

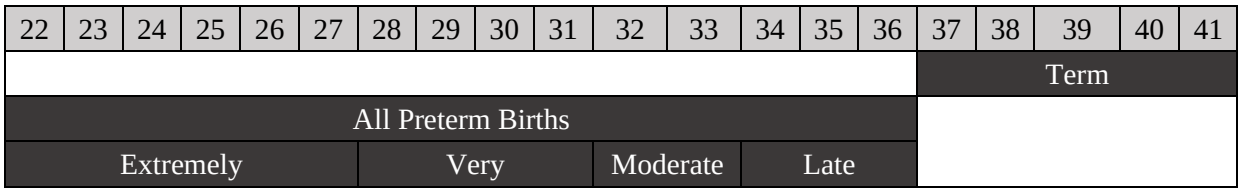


Figure 1.1: Definitions of preterm birth by gestational age

Those born at the earliest gestational ages are classified as extremely or very preterm (VPT) (extremely preterm = <28 weeks; VPT = $\geq$28 - $31^{+6/7}$), and represent roughly 15% of all preterm births (Wolke et al., 2019). Much research has focussed on the outcomes of those born at the earliest gestations, as babies born within this category present with the most immediate and long-term health complications (Baumann et al., 2016). Babies born VPT are more likely to require immediate medical assistance and have lengthier hospital stays before they are able to be discharged (Petrou et al., 2011). Despite the significant impact that having a baby born VPT has on parents and caregivers (Treyvaud et al., 2011), research also highlights the particular strength and resilience against long-term psychological impact present in parents of babies born VPT (Wolke et al., 2017).

Babies born between $32^{+0/7}$ – $36^{+6/7}$weeks gestation are classified as moderately or late preterm (MLPT) (moderate = $32^{+0/7}$ - <$33^{+6/7}$ weeks; late = $34^{+0/7}$ - $36^{+6/7}$) and comprise 84% of all preterm births (Blencowe et al., 2012). Despite the majority of preterm births occurring within this category, the categorisation of MLPT has only recently been widely adopted and accepted. As immediate medical need is often considerably less compared to those born VPT, it was initially presumed that being born MLPT was equal to being born at term (Raju, 2017). However, research over the past decade has highlighted that although immediate medical risk may be less pronounced, there may be downstream neurodevelopmental differences in those born MLPT compared to their term peers (Boyle & Boyle, 2013). Further evidence is therefore necessary to evaluate any downstream effects of being born at an earlier gestation, as outcomes are not confined to those born VPT (Johnson et al., 2015).

1.2.4 Healthcare provisions / guidelines around preterm birth

Within the United Kingdom, current governing bodies detail extensive guidance on the degree and depth of medical information that should be offered to those at greatest risk of preterm birth (NICE, 2019). This guidance aims to support families, enabling them to make informed decisions regarding their child's care. Since the publication of these guidelines highlighting the significance of preterm birth, there has been a 44% increase in the number of specialist preterm labour clinics across the UK with evidence of high uptake in recommendations across healthcare trusts (Care et al., 2019). These guidelines are complimentary to other government and parliamentary priorities regarding preterm birth, with prediction, prevention and preparation all noted as areas for development across healthcare settings (Story et al., 2019).

There are healthcare provisions specifically focusing on developmental outcomes following preterm birth. Recently, a comprehensive plan of developmental follow up for preterm children across the UK was published (McKinnon & Huertas-Ceballos, 2019). Guidance details the prevalence and subsequent likelihood of various outcomes and specifies those for whom enhanced developmental surveillance and support is necessary (primarily those born ≤30 weeks). Beyond the routine two-year development check, guidance suggests neonatal follow up is reserved for those born at the earliest gestations only. There are currently no requirements for educational settings to obtain information about prematurity, with disclosure falling to parents' individual discretion. Combined, this suggests that those born MLPT are not likely to receive *any* additional medical or neurodevelopmental follow up as a result of preterm birth, either in the immediate or long term. More recently, attempts have been made to create a package of support for preterm born children, for example a new e-learning resource tailored towards educational professionals to improve developmental support for children born preterm (Johnson et al., 2019). It is imperative that emerging research surrounding the support needs for those born preterm, including those born MLPT, is reflected in guidelines for developmental follow up.

1.3 Consequences of preterm birth

Advances in clinical care over the last decade have meant that survival rates following preterm birth have increased dramatically (Stoll et al., 2015). The consequences of preterm birth have therefore been the focus of recent research, informing immediate medical care and advice (Fellman et al., 2010). While there are numerous consequences of being born preterm, outcomes can differ based upon both the degree of prematurity and the type of preterm birth.

Although estimating outcomes as a result of preterm birth is complex, there have been many advances in further understanding the challenges conferred by being born early.

1.3.1 Consequences of very preterm birth

Those born at the earliest gestations present with the greatest immediate medical risk of adverse consequences (Papastefanou et al., 2020). Physically, babies born VPT are more biologically immature then their other preterm or term peers, with vital organs such as the brain and lungs underdeveloped (Nosarti & Froudist-Walsh, 2016; Simpson et al., 2017). Those born at the earliest gestations are significantly more likely to require advanced neonatal medical care to increase survival outcomes, often with lengthy stays in neonatal intensive care units necessary before discharge home (Baía et al., 2016). Infants must display a functional maturation in many areas to be considered fit for discharge, including respiratory stability, adequate feeding and weight gain (Jefferies et al., 2014); milestones their term peers typically reach immediately after birth.

Alongside the physical consequences of VPT birth, various behavioural outcomes are also evidenced as infants mature. Research focussed on behavioural outcomes explores areas such as social and emotional development, attentional capacity and mental health. Neurodevelopmental outcomes of those born VPT are well defined, with differences identified in areas of language, social and emotional skills as well as specific difficulties with eating behaviours (Johnson et al., 2015). Broadly, there is consensus that those born VPT are more likely to experience difficulties with attentional focus, emotion regulation, and executive functioning (Reijneveld et al., 2006; Stålnacke et al., 2019). This cluster of outcomes has been termed the ‘preterm behavioural phenotype’ (Johnson & Marlow, 2011; Trickett et al., 2020).

Recent literature has extended our understanding of outcomes following VPT birth by suggesting neurocognitive processes, such as working memory, are a specific mechanism through which those born VPT experience later academic difficulties (Twilhaar et al., 2020). Advanced understanding of the potential challenges those born VPT may face as they grow older is advantageous to both parents and caregivers (Enlow et al., 2019), as well as clinicians aiming to promote positive outcomes.

1.3.2 Consequences of moderate to late preterm birth

The immediate medical consequences of MLPT birth are less pronounced than those of VPT birth. However, when compared to their term peers, clinical outcomes are considerably poorer. Although those born MLPT may be of sizes that are near to their term peers, a MLPT baby is more likely to suffer respiratory distress, have problems regulating their temperature, experience sepsis or intravenous infusion and display signs of clinical jaundice (Wang et al., 2004). Those born MLPT are also twice as likely compared to their term peers to be re-hospitalized after neonatal discharge within the infancy period (Escobar et al., 2006). Taken together, these outcomes evidence the substantive increased health risk conferred by being born MLPT and highlight the importance of the last few weeks of the gestational period for health outcomes.

Long term developmental outcomes following MLPT birth had previously been considered similar to those born at term. Consequently, for many years long term follow up was not conducted (Raju, 2006). While some believe that downstream outcomes are limited to those born VPT and thus those born MLPT are at no greater risk than their term peers (Pérez-Pereira & Baños, 2019), others suggest that outcomes are present but less pronounced and

therefore often overlooked (Gill & Boyle, 2017). Indeed, following MLPT birth children are at an increased likelihood of psychiatric disorders and behavioural problems than their term born peers (Jong et al., 2012). A recent systematic review outlined late preterm born infants are at increased likelihood to show differences in cognitive functions, having a cascading impact on later school performance (Martínez-Nadal & Bosch, 2021). Wider research confirms school outcomes for those born moderately *and* late preterm are impacted following preterm birth, with children showing specific difficulty in Mathematics and English (Townley Flores et al., 2021). More broadly, it is now understood that children born MLPT are at an increased risk of poorer mental health outcomes (Sammallahti et al., 2017) language difficulties (Saigal & Doyle, 2008) and hospital readmission as a result of co-occurring medical difficulties (Sharma et al., 2021). Outcomes are perhaps unsurprising when considering the increase in cortical volume that occurs in the final six weeks of pregnancy (Adams-Chapman, 2006) and that this process occurs outside the shielded environment of the womb for MLPT new-borns. Given the biological implications of being born MLPT and emerging evidence exploring developmental outcomes, it is likely that those born MLPT may have downstream behavioural implications later in life.

1.4 Autism

1.4.1 Definition and prevalence of autism

Autism[2] is a neurodevelopmental condition characterised by differences in domains of social communication skills that present alongside restricted and stereotyped repetitive

[2] The use of the term 'autism' is in acknowledgement of the wider debate surrounding person first and identity first language (Botha et al., 2021). I acknowledge the particular responsibility research, such as this thesis, has in promoting preferred language of autistic people when exploring social differences within infancy. I have therefore opted to use phrases such as 'those more likely to later receive an autism diagnosis' in contrast to previously held narratives using descriptors such as 'at risk' (Fletcher-Watson et al., 2017).

behaviours and interests (Lord, Elsabbagh, Baird, & Veenstra-Vanderweele, 2018). Autism was first categorised in the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) in the 1980's, a tool used to diagnose various clinical presentations (American Psychiatric Association, 1980). Since this initial classification, the diagnostic criteria and categorisation of autism have shifted over time, with a range of sub-threshold categorisations such as social communication disorder and pervasive developmental disorder-not otherwise specified considered. The most recent manual arguably provided the most substantive change to date (American Psychiatric Association, 2013). The release of the DSM-5 saw the combination of domains of social and communication impairments, and the adoption of 'autism spectrum disorder' as an umbrella term that can be further distinguished through additional specifiers. General population estimates of autism are around one in 59 (Centers for Disease Control and Prevention, 2019), with prevalence estimates rising to between 30-40% for individuals with an intellectual disability (Myers et al., 2019). Given the considerable changes regarding definitions of autism outlined, and the high levels of heterogeneity when using the term autism, it is unsurprising that there is considerable variety in prevalence estimates across populations and settings.

The diagnostic medical model is only a small part of our wider understanding of autism and has limitations in its usefulness in understanding the experiences of autistic people. The last decade has seen a considerable positive shift away from historical frameworks through which autism was previously considered. The neurodiversity movement embodies this shift in thinking and refers to the natural human diversity that occurs across human neurodevelopment (Singer, 1998). At its heart, neurodiversity acknowledges the natural variation in our human makeup and therefore our experience of the world around us, and is an integral part of developing a more inclusive sociality for all (Fletcher-Watson.,

2022). The movement highlights that within any given population there are groups of individuals that are neurotypical and groups of individuals that are neurodivergent. Neither group's perspective is 'right', despite one perspective perhaps being more frequent or considered to be 'normal' through a prevailing social narrative. The neurodiversity approach is incompatible with the historic deficit models, drawing instead on social models of disability by considering the wider context and society in which individuals live as a core mechanism conferring disability. The approach can conflict with existing theoretical models of social cognition which often derive from a 'normative' stance on optimal behaviours and perspectives. Conversely, others may argue the neurodiversity approach can also be considered in harmony with social cognitive models, promoting strength within differences. The neurodiversity movement should therefore be considered to have utility at an individual level throughout the diagnostic process, encouraging professionals to discuss the strengths associated with an autism diagnosis as well as the challenges (Brown et al., 2021). Early identification and population-based prevalence designs are compatible with this narrative. The exploration of early indicators that may help clinicians further understand who may go on to later receive an autism diagnosis can help to ensure support needs are met for autistic children from an early age (Brown et al., 2021). These early screening and identification process could also be considered neurodiversity-affirmative; identifying and describing diversity to provide support, rather than normalising through early intervention. A strength-based approach to further understanding autistic individuals represents a positive change in the landscape of autism research and understanding.

1.4.2 Diagnosis and screening

While there have been many changes over recent years regarding the definition of autism, methods of identification have remained more stable. Diagnosis of autism in

childhood recommends two elements that consider both developmental and behavioural presentations, with NICE guidelines promoting the availability of a multidisciplinary team active within the process (NICE Guidelines., 2011). First, a detailed developmental history is required. This is usually obtained from a parent or caregiver and commonly collated in a structured interview with a trained professional (Randall et al., 2018). Frequently used validated interviews include 'The Autism Diagnostic Interview-Revised' (Lord et al., 1994), 'The Diagnostic Interview for Social and Communication Disorders'(Wing et al., 2002) and 'The Developmental, Dimensional and Diagnostic Interview' (Skuse et al., 2004). Whilst these interviews differ in form, principally they function in the same way, asking familiar caregivers to report on behavioural and social interactions during early development, with a trained professional scoring responses against a pre-defined algorithm. This information allows clinicians to develop a complete profile of strengths and difficulties for each individual, which can then be used to contribute to an overall autism diagnosis, or inform alternate differential diagnoses to explore (NICE Guidelines, 2011).

Second, numerous clinical observations, ideally across multiple settings, in a structured manner are advised (Lord et al., 2018). Using the gold standard clinical assessment 'The Autism Diagnostic Observational Scale' (ADOS), trained professionals can assess behaviours in a structured way from toddlers through to adulthood (Lord et al., 2000). The assessment allows for a brief observation that is structured around questions or play based activities dependent on age, where behaviours and responses are then recorded against a validated algorithm. Shifting the reliance from sole clinical judgement to the consideration of a robust standardised algorithm outcomes ensures clarity between professionals that use these measures and may even be more reliable, especially when considering infants and toddlers (Luyster et al., 2009).

In practice, most autistic children do not receive a clinical diagnosis until school age at the earliest (Mandell et al., 2002), yet there is also consensus that early identification of autism promotes a more positive outcome (Kasilingam et al., 2019; Lord, 1995). Clinical interest has thus shifted over the past decade to develop reliable and robust screening tools that are successful in identifying individuals with an increased likelihood of receiving an autism diagnosis to be used prior to, or in conjunction with, full developmental histories and behavioural assessments (Johnson et al., 2007). Screening tools offer clinicians and researchers the ability to identify those that are in most need of further neurodevelopmental assessment briefly and succinctly. Some argue too little is known about the psychometric properties of the high number of measures available, and consider detailed information about a handful of psychometrically robust tools most useful (Charman & Gotham, 2013). Others highlight potential issues in the routine implementation of screening tools that are deemed to be poor quality (Al-Qabandi et al., 2011). Nonetheless, while caution should be taken to avoid relying on screening tools as a sole source of diagnostic information, they are clearly useful when correctly considered as part of a wider clinical evaluation (Levy et al., 2020). Routine screening is now more common and is recommended at regular intervals during the developmental period (Duby et al., 2006). As such, although screening tools do not result in a diagnosis of autism when used in isolation, they hold utility in stratifying need across populations.

1.4.3 Prematurity and autism

The links between preterm birth and neurodevelopmental outcomes are well established, with many suggesting those born preterm are significantly more likely to later receive a diagnosis of autism (Atladóttir et al., 2016; Maramara et al., 2014; Xie et al., 2017).

While prevalence estimates of autism in preterm populations are described as significantly higher than in the general population (~ 7%: Agrawal, Rao, Bulsara, & Patole, 2018), variations within subcategories of prematurity mean overall estimates may not be accurate. A recent large scale multinational population study highlighted the increased likelihood each week of prematurity poses of autism diagnosis (Persson et al., 2020). Week by week analysis highlighted that relative risk of autism increases the greater the difference of gestational age from 40 weeks (typically described as full term); an association that was independent of sex and birth weight for gestational age. Notably, the increased likelihood began to increase again for those born between 40 – 42 weeks completed gestation, indicating a non-linear association between gestational age and autism likelihood. Given the positive impact of early identification and support, improved understanding of the association between gestational age and autism should direct resource allocation and service provision within these groups.

1.5 Social Cognition

1.5.1 Definitions

Social cognition is an umbrella term that refers to the mental processes relevant to understanding oneself and other agents (Beaudoin & Beauchamp, 2020). Social cognition comprises cognitive mechanisms that are considered important for 'normative' social interactions. Social cognitive processes can meaningfully be considered to comprise two broad categories: implicit and explicit, though in truth, such clear-cut distinctions are often reductionist or lack specificity. Implicit social cognitive skills rely on relatively unconscious processes that occur spontaneously and are relatively inflexible (Frith & Frith, 2008). Explicit social cognition on the other hand a is slower, more flexible, and more effortful process (Callenmark et al., 2014). Both implicit and explicit processes have benefits when in group interactions and are considered advantageous in social settings. For example, in following the

gaze patterns and shifts of others, we are able to attend to objects around us jointly and thus understand the world from others' perspectives (Tomasello & Carpenter, 2007). Social cognitive process can also aid prosocial behaviours such as sharing, where having a clear understanding of shared intentionality and desires is necessary to complete actions. Understanding intentionality and engaging in prosocial behaviours to achieve mutual goals can be seen in infants as young as 18 months old who are able to spontaneously help those around them (Warneken & Tomasello, 2006).

Throughout this thesis, when referring to the term 'social cognition' a broad approach will be taken, reflecting the range of cognitive processes encompassed by the phrase. The term will be used when referring to ones understanding of another's thoughts, desires and beliefs (often called Social Understanding, Theory of Mind or Mentalizing), but also lower level perception of others as social agents. Given its suggested importance in relation to reciprocal social interactions outlined above, individual cognitive aspects of 'social cognition' will be considered both cross sectionally (Chapter 2) and individually (Chapter 4) collated through both informant report and behavioural tasks. Important to consider alongside these cognitive process is an individual's 'Social motivation' referring to a person's willingness to participate in a social situation (Contreras-Huerta, Pisauro and Apps, 2020). Social motivation may be related to concepts such as broader social cognitive abilities or more predominantly driven by perceived level of enjoyment in social situations. To explore these nuanced links further and their association with broader social cognitive abilities, pilot data from direct assessments of a battery of spontaneous helping behaviours and attentional profiles in the presence of social stimuli are presented within this thesis (Chapter 4).

1.5.2 Development of social cognition

Although there is no singular unified model of the development of social cognition through childhood, it is broadly agreed that through a combination of environmental, cognitive and biological factors these skills develop rapidly in the early years (Beaudoin, Cindy & Beauchamp, 2020). These skills are thought to be the foundations for later more complex social behaviours (Olson & Dweck, 2008), continuing to mature across the lifespan, such as in the case of recognising facial expressions (Garcia & Scherf, 2015). For many years the concept of 'theory of mind', the ability to perceive another agent's mental states, has been central to understanding the development of social cognitive abilities (Wimmer & Perner, 1983). Classically, theory of mind research has received high levels of attention, with 'false belief' tasks a popular way of operationalising such ideas (Wimmer & Perner, 1983). These tasks are simple, beginning with two agents and an object. Participants witness an action when notably one of the agents is not present and are later asked about that agents' thoughts or subsequent behaviours. Children as young as 4 are able to inhibit their own knowledge to take on the perspective of the missing agent (Wellman et al., 2001), with children as young as two evidenced to pass implicit eye-tracking versions of the same task (Onishi & Baillargeon, 1994; Southgate, Senju, & Csibra, 2007). However, more recently a wave of contrasting research has emerged with studies failing to replicate these early findings (Dörrenberg, Rakoczy, & Liszkowski, 2018; Grosse Wiesmann, Friederici, Disla, Steinbeis, & Singer, 2018; Kampis, Kármán, Csibra, Southgate, & Hernik, 2021; Kulke, Reiß, Krist, & Rakoczy, 2018). The use of a singular method to assess a single social cognitive ability, such as those mentioned above, neglects the range of social cognitive abilities required for successful navigation in the social world. Therefore, research that explores early social cognitive skills more broadly and throughout a range of measures is necessary.

1.5.3 Behavioural assessments of early social abilities

In contrast to measures that traditionally relied on a single task, an alternate method of exploring early social developmental skills is to assess spontaneous behaviour using direct observational measures. Some behavioural observational tasks exist, such as 'The Early Social Communication Scale' (Mundy et al., 2003), but, similarly to classic 'theory of mind' measures, these focus primarily on the presence or absence of social cognitive skills (such as joint attention and initiating social interactions). Examining the ways in which the tasks scale would allow for further understanding of the development of such skills. Infants' shared intentionality has been a specific area of interest when developing behavioural observations of early social cognitive skills. The development of shared intentionality requires successful attainment of core foundational skills; understanding of another agent's thoughts, sufficient motivation from an infant to act upon another agent's thoughts and co-operation with another agent to achieve a joint goal within a reciprocal social interaction (Tomasello et al., 2005). Supporting the theory that earlier foundational skills are required for later more complex abilities, researchers have found early social behaviours scale in a predictable cumulative pattern (Wellman & Liu, 2004). Recently, the creation of 'The Early Social Cognition Scale' (ESCogS) collated a battery of tasks assessing early spontaneous shared intentionality behaviour that statistically scale in a predictable way (Ellis et al., 2020). These tasks have since been used to describe patterns of development of this early skill for children with a wide range of neurodevelopmental conditions, including autism, Cornelia de Lange, Fragile X and Rubinstein–Taybi syndrome (Ellis et al., 2020; Ellis, Moss, Stefanidou, Oliver, & Apperly, 2021).

While traditional 'theory of mind' tasks allow for cross-sectional exploration of specific abilities across groups of children, alternative measures may provide richer data on

individuals' subtle profile of broad social cognitive development. Such approaches allow for further understanding of developmental trajectories, as well as proficiency in a highly specific area. There is a need for future research to combine both traditional 'theory of mind' type tasks with more ecologically valid behavioural observations to provide further clarification around both the development of early social development and the validity of classical tests.

1.5.4 Social Cognition and prematurity

As discussed, preterm birth is associated with a subset of neurocognitive outcomes, with effects apparent across the lifespan (see section 1.3). Development across the first years of life is reliant on core implicit mechanisms interacting with environments to assist learning, for example attending to faces or relevant stimuli within the environment to be able to attribute goals and imitate behaviours (Meltzoff, 1988; Tomasello et al., 2005). Early differences in these implicit processes have been identified between those born preterm and at term (De Schuymer, De Groote, Striano, et al., 2011), with differences in implicit processes considered to be precursors of later formal social behaviours such as reciprocal social interactions (Marleau et al., 2020). Social cognitive differences between those born preterm and at full term have been shown to persist into adulthood (Zmyj et al., 2017), which is concerning given the importance of these skills as an early foundation for later social relationships and development. Precise and early measurement of social cognitive abilities could be the key to identifying areas of strength and need, therefore facilitating and promoting positive long-term outcomes for children born preterm.

The relationship between prematurity, social cognition and autism is complex and not well understood. Multiple associations are hypothesised (see Figure 1.2 for three plausible, alternate models of association), with high levels of heterogeneity of both population

characteristics *and* construct assessment methods contributing to a lack of precision in existing models. Perhaps the most straightforward approach is that premature birth leads to an increased likelihood of later receiving a diagnosis of autism, which in turn is behaviourally manifested through a distinct profile of social abilities (Figure 1.2 [a]). Large scale systematic reviews exploring the prevalence of autism within populations of people born preterm (Agrawal et al., 2018) would be consistent with this proposed relationship, assuming first a formal diagnosis that then corresponds with an alternate social cognitive profile. An alternate theoretical relationship might propose that preterm birth is a precursor, in some instances, to an alternate profile of social cognitive profiles, which in some cases contributes to a child's overall presentation falling under the diagnostic umbrella of autism (Figure 1.2 [b]). The emerging description of the 'preterm phenotype' characterised by an increase in cognitive and social-emotional differences (Anderson, 2014; Johnson et al., 2018; Johnson & Marlow, 2011) that in turn may lead to a formal diagnosis of autism for some would support this theoretical relationship. Yet, a myriad of evidence suggests the precise relationship between prematurity, social cognition and autism is perhaps a more interrelated process (Figure 1.2 [c]) (Mcgowan and Sheinkopf, 2021) or one undescribed within Figure 1.2. Further detailed and precise evidence documenting the profile of social cognitive skills in a well-defined population of children born preterm using reliable and valid measures is necessary to further understand this complex relationship.

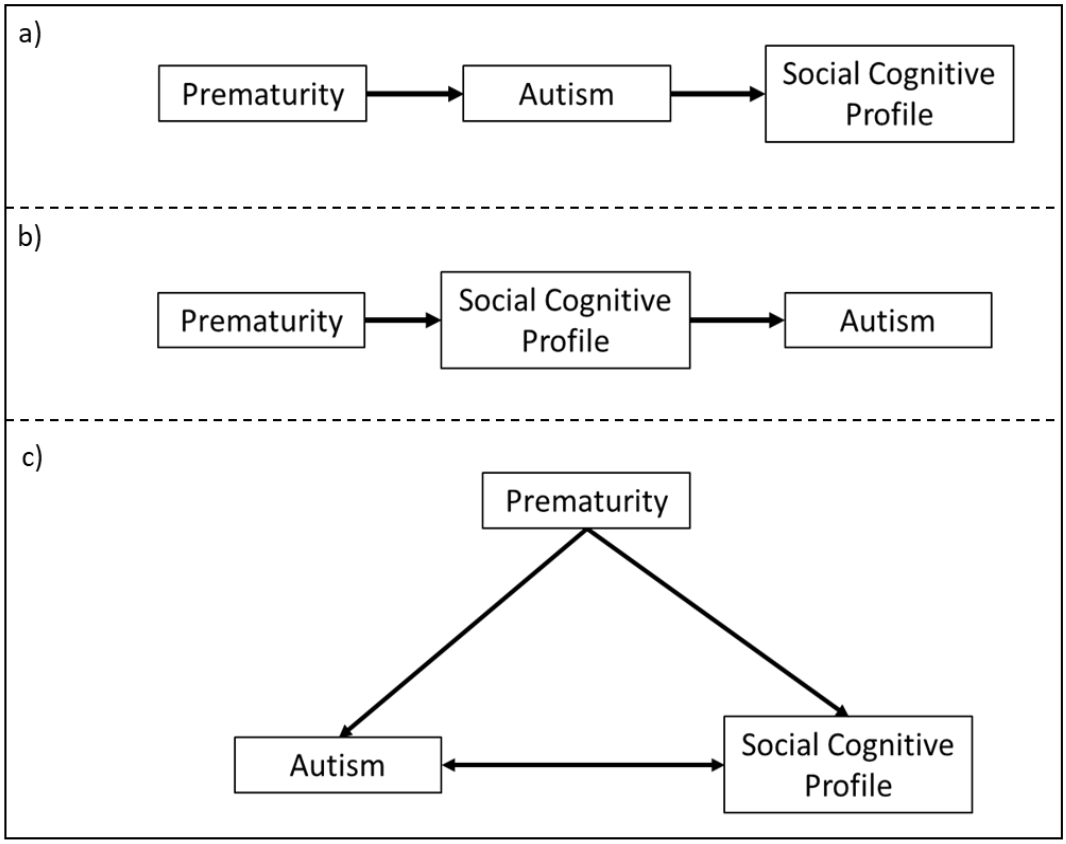


Figure 1.2: Proposed theoretical relationships between prematurity, autism and social cognitive profiles

1.6 Conclusions and Thesis Positioning

Thus far, the neurodevelopmental, physical and behavioural consequences following preterm birth and specifically those born MLPT have been documented and key areas for future research identified. There are however substantial questions remaining which this thesis seeks to address. A number of theoretical and methodological positions have been taken throughout the thesis and are outlined below.

Firstly, throughout this thesis those born moderately *or* late preterm will be combined and considered as a singular group. Those born MLPT are a notably underrepresented group

across prematurity research and considering their combined experiences within this thesis will provide substantial evidence to enhance our understanding of the consequences of preterm birth. This categorisation is also consistent with current taxonomy in prematurity and represents a move towards a more transdiagnostic model of research which avoids splitting findings based upon pre-defined groups (Astle et al., 2021). While this thesis may provide avenues for future research to look at those born moderately *or* late preterm as separate entities, documenting their experiences as a whole is an important first step.

Secondly, this thesis adopts mixed methods using both qualitative and quantitative approaches to address the aims outlined below. This choice of methods is in line with best practice research recommendations towards answering questions and exploring new areas within a field (Tashakkori & Creswell, 2007). Such approaches allow for a more complex understanding of findings and ensure that those who may eventually be recipients of *or* accessing research findings translated into practice (such as mothers of MLPT children) are involved with research from its outset. The general discussion will adopt a triangulation model of understanding (Heale & Forbes, 2013). Within this approach, qualitative and quantitative questions are treated as entirely separate, and findings from these approaches will be considered both individually *and* brought together for synthesis.

1.7 Aims

In order to address outlined gaps within our current understanding of preterm birth mentioned thus far and advance the literature described within this chapter, this thesis has a number of specific aims.

1.7.1 Aim One

Heightened rates of autism have been identified in individuals born preterm (Section 1.4.3). However, current prevalence estimates exclude screening measures; a method of identification commonly used for those born MLPT. Existing estimates are therefore biased towards those born at the earliest gestations presenting with the most typical presentations. This thesis aims to examine the prevalence of autism in preterm samples. Thus, Chapter 2 presents a robust meta-analysis of the prevalence of autism in preterm samples, based on diagnostic and screening measures of autism characteristics.

1.7.2 Aim Two

Although there have been a number of large-scale surveillance studies exploring the social and behavioural profiles of children born at the earliest gestations (as described in Section 1.3.1), there is a lack of detailed understanding of these profiles for children born MLPT. This thesis aims to provide a detailed exploration of social and behavioural profiles of children born MLPT. Thus, Chapter 3 provides the first detailed cross-sectional data on the profile of behavioural and social abilities in a cohort of children born MLPT. This profile is also considered in relation to the general population. The association between executive functioning skills and social abilities is also explored.

1.7.3 Aim Three

No study has yet considered solely the perspective of parents with a child born MLPT. Quantitative data should not be considered in isolation and instead must be grounded in the qualitative experiences of families of children born preterm. This thesis aims to document the experiences of parents of MLPT born infants. Thus, Chapter 4 provides the first in depth

qualitative interview study of mothers of children born MLPT. The entire journey of pregnancy through to coming home and starting school is explored, with parents detailing areas in which they feel future service provision could be targeted.

1.7.4 Aim Four

Finally, divergent developmental trajectories across multiple behavioural, attentional and cognitive domains for those born preterm have so far been identified (Section 1.3.2). The current evidence base regarding such skills is primarily derived from those born at the earliest gestations, less is known about those born MLPT. Additionally, commonly adopted designs comparing groups born at different gestational ages, miss nuanced differences within groups of preterm children. This thesis aims to provide detailed evidence of the behavioural profile of MLPT infants. Therefore, Chapter 5 explores the behavioural profile of a cohort of infants born MLPT through the use of a gold standard autism assessment and behavioural assessments of intentionality.

CHAPTER TWO

THE PREVALENCE AND PROFILE OF AUTISM IN INDIVIDUALS BORN PRETERM: A SYSTEMATIC REVIEW AND META-ANALYSIS

2.1 Preface

The literature summarised in Chapter One revealed that heightened rates of autism have been identified in individuals born preterm, with studies using diagnostic assessments that have primarily focussed on those born at the earliest gestations. However, current prevalence estimates often exclude screening measures; a method of identification commonly used for those born MLPT. Existing estimates are therefore biased towards those born at the earliest gestations presenting with the most typical presentations. Focussing on diagnostic assessment alone presents prevalence estimates that reflect only the subsection of individuals meeting threshold across diagnostic criteria. The consideration of screening tools alongside diagnostic measures is inclusive of individuals showing differences in autism-related characteristics that are not sufficient for diagnosis, but may reflect meaningfully different presentations or sub-threshold differences. To address the first aim of this thesis, this chapter determines the prevalence of autism characteristics across those born preterm through a robust systematic search and meta-analysis. Separate analyses are presented for both screening tools *and* diagnostic assessments.

2.2 Introduction

Preterm birth is defined as birth occurring at a gestational age of less than 37 weeks (Howson et al., 2013) and accounts for 15 million births worldwide each year (Eisfeld, 2014). Many infants born preterm experience immediate and significant health complications, which often lead to extended periods of hospitalisation on neonatal units (Escobar et al., 2006). Longitudinal research demonstrates that even babies born preterm who *do not* present with immediate health complications show significantly increased likelihood of later adverse neurodevelopmental outcomes such as intellectual disability (Johnson, 2007; Soleimani, Zaheri, & Abdi, 2014). This increased likelihood perseveres across the lifespan for all those born preterm, with employment rates, educational qualifications and socioeconomic status negatively impacted into adulthood (Bilgin et al., 2018). As a result of medical and technological advances, survival rates for infants born preterm are rising (Saigal & Doyle, 2008). It is therefore of growing importance to quantify the neurodevelopmental trajectory of children born preterm.

Preterm birth is associated with heightened rates of autism when compared to birth that occurs at term (Agrawal et al., 2018; Singh et al., 2013). Classically, autism is characterised by differences in social communication and interaction, and restricted patterns of repetitive behaviour (American Psychiatric Association, 2014; Eisfeld, 2014; Wong et al., 2014). Advances in understanding of subtle and nuanced manifestations of autism now mean that individuals can be identified earlier, with diagnoses as early as two years old shown to be stable over time (Moore & Goodson, 2003). Advances in research also highlight that individuals may display difficulties in isolated areas comparable to those with autism, yet not meet criteria for formal diagnosis (Happé et al., 2006). Considering the presence of these

broader autism characteristics or an atypical autism phenotype is therefore imperative when aiming to meet individual need regarding support and service use.

A notable increased prevalence of autism has been identified for those born very preterm (4-6%; Treyvaud et al., 2013). Lower birth weight, earlier gestational age at birth and male gender have been associated with heightened rates of autism in preterm samples (Limperopoulos et al., 2008). Historically, clinical resources were focussed towards those born very preterm ($<31^{+6/7}$ weeks), who represent around 10% of all preterm births (Blencowe et al., 2013), with infants born closer to term often considered to be as biologically mature as term-born infants (Lantos & Lauderdale, 2018). Recent literature has documented a shift in understanding of the needs of those born MLPT ($32^{+0/7}$ - $36^{+6/7}$), who represent the majority of all preterm births (Office for National Statistics, 2019). Although children born MLPT often present without immediate medical complications, they are still more likely to develop a range of neurodevelopmental outcomes and at greater risk of infantile mortality than those born at term (Frey & Klebanoff, 2016). In an attempt to recognise the difficulties which those born closer to term experience, the definition 'near term' was changed to 'late preterm' to acknowledge that infants born closer to term are still at heightened risk, with clinicians now considering gestational age and subsequent increased likelihood as a continuum (Morgan & Boyle, 2018). It is therefore important that synthesis of current literature regarding neurodevelopmental outcomes reflects this and considers outcomes *across* gestational age, without being limited to those born at the earliest gestations.

A previous meta-analysis (Agrawal et al., 2018) examined studies identifying the prevalence of preterm individuals who met clinical cut-off for autism using comprehensive diagnostic assessments (see section 1.4.2 for a discussion of diagnostic versus screening tools for autism). A pooled prevalence estimate of 7% was returned. This strategy was important in

identifying the rates of preterm children who are likely to obtain diagnoses. It does not, however, address three vital concerns: i) Studies using diagnostic assessments have tended to focus on very preterm samples at the expense of MLPT samples. This indicates a clear bias within assessment methods and population samples, in which diagnostic assessments are used more in very preterm populations (Joseph et al., 2017; Pinto-Martin et al., 2011), whereas screening measures are utilised more in MLPT groups (Guy et al., 2015). ii) Studies using clinical cut-off on diagnostic assessments may miss children born preterm who show atypical presentations. Research suggests prematurity may impact development through distinct pathways, leading to distinct behavioural phenotypes and potentially alternate social cognitive profiles (Johnson et al., 2018). iii) Studies using diagnostic assessments provide no quantification of those children who show sub-threshold difficulties with social communication, interaction and restricted repetitive behaviours, who may still require support despite not reaching clinical thresholds. Screening tools are used more commonly in preterm populations as a method of risk stratification that is both cost and time effective (Moore, Johnson, Hennessy, & Marlow, 2012). Addressing these concerns is vital to ensure that prevalence rates are better understood in i) *All* children born preterm, ii) Children with *atypical presentations* and iii) Children who experience difficulties with social communication and/or repetitive and restricted behaviours but may fall short of full diagnostic criteria identified via screening tools.

In summary, heightened rates of autism have been identified in individuals born preterm. Whilst methods of early identification in samples with an increased likelihood for a later autism diagnosis have become more reliable, the precise profile of autism characteristics in individuals born preterm is not well documented. Most recent prevalence rates confirm that preterm populations are high risk groups, yet meta-analytic approaches have excluded

screening measures, limiting findings to predominantly very preterm groups, and those that have reached a threshold for diagnosis only. This approach excludes those with subthreshold nuanced social differences and potentially biases autism prevalence estimates to those born very preterm. Therefore, the present systematic review and meta-analysis aims to;

i. Synthesise existing literature and calculate pooled prevalence estimates for autism characteristics[3] based on diagnostic *and* screening measures of autism characteristics in preterm samples.
ii. Compare pooled prevalence estimates in the preterm population with estimates of autism in the general population.
iii. Delineate the profile of participant characteristics that may be associated with autism characteristics in preterm samples.

[3] The phrase 'autism characteristics' is used when referring to evidence drawn from both screening tools and diagnostic assessments, given neither used in isolation are sufficient for a formal diagnosis of autism.

2.3 Method

2.3.1 Search strategy

This meta-analysis was preregistered on PROSPERO prior to database searching. Search terms (See Table 2.1) were generated from inspection of relevant high impact papers and recent meta-analyses. Additionally, a recent meta-analysis was hand searched to identify further publications (Agrawal et al., 2018).

Table 2.1: Search terms used to search Ovid MEDLINE, Ovid PsychINFO, Ovid Embase, Ovid Embase Classic and PubMed from the beginning of creation to late January 2020

Search terms[1]	
#1 Autism	"autis*" or "autism*" or "autistic*" or "ASD" or "autism spectrum disorder*" or "PDD-NOS" or "PDDNOS" or "unspecified PDD" or "pervasive developmental disorder*" or "pervasive developmental disorder not otherwise specified" or "Asperger*" or "Asperger* syndrome"
#2 Preterm	"premature*" or "preterm" or "prematur*" or "low birth weight"

[1]Search terms #1 and #2 were combined with 'and'. All areas of the text were searched (inclusive of title, abstract and key words)

2.3.2 Study Selection

Initial searches returned 10,900 records that were systematically assessed for suitability and inclusion (Figure 2.1). An initial automatic 'de-duplication' process was run using EndNote software, followed by a manual inspection for any duplications that were missed. Papers were then assessed in three stages. For the first stage of selection, predefined inclusion and exclusion criteria was used to assess the titles and abstracts for inclusion. In the second stage full-text papers were reviewed against stage two criteria (Table 2.2 & Table 2.3). Finally, for the third stage, all included papers were rated against a multi-level quality matrix described below.

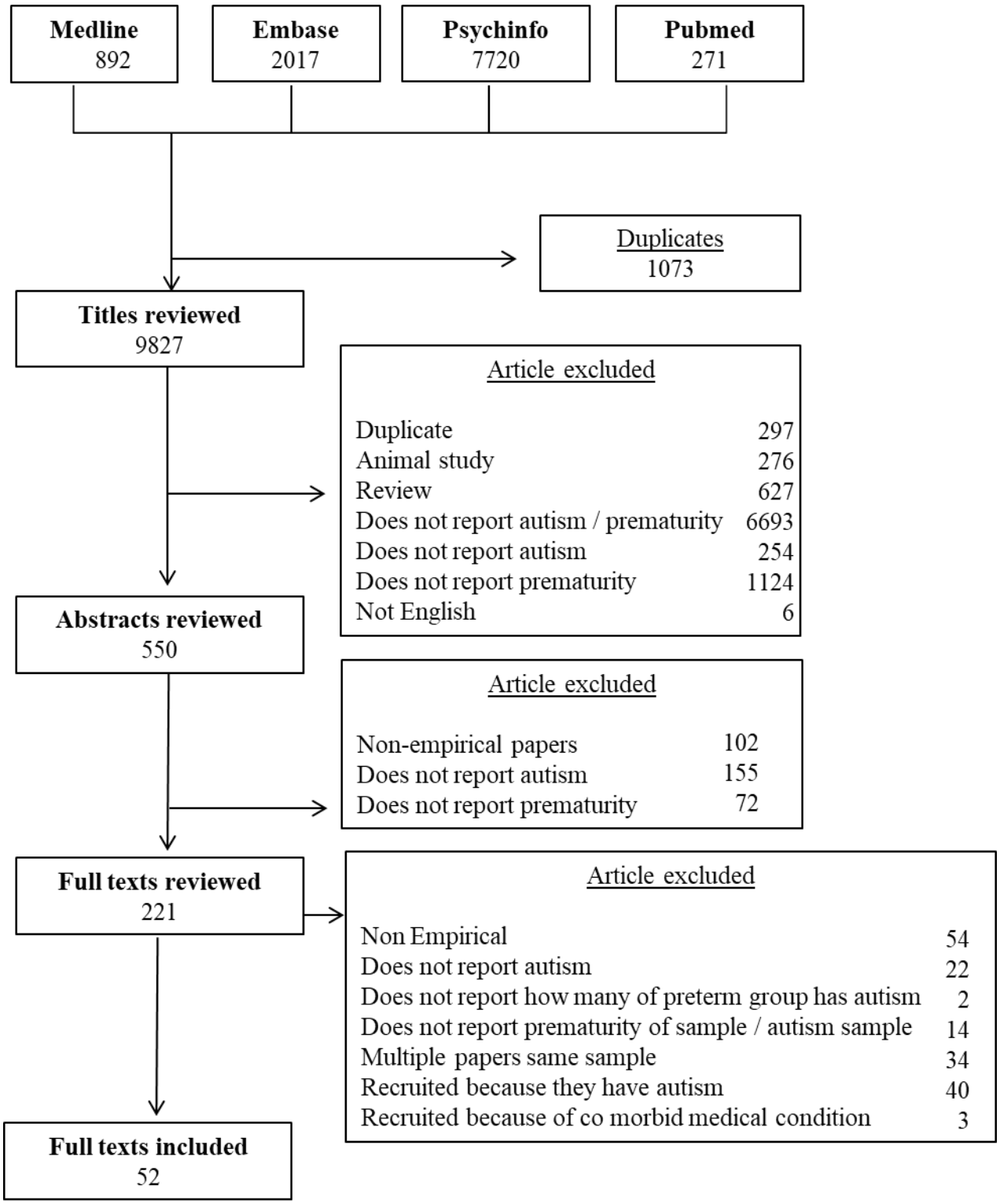


Figure 2.1: A flow chart detailing papers included and excluded at each stage of screening and review

Table 2.2: Inclusion and exclusion criteria for title and abstract screening

Inclusion Criteria	Exclusion Criteria
Empirical studies	Conference abstracts, conference papers, literature reviews or book chapters
Published or available in English	Published or only available in a language not English
Peer reviewed	Not peer reviewed
Human participants	Studies use animals
Title or abstract has autism reported / referenced or refers to sample as low birth weight	Title / abstract does not report autism refer to sample as low birth weight
Title or abstract has prematurity reported / referenced	Title / abstract does not report prematurity
Sample $\geq$5	Sample <5
Title or abstract refers to categories associated with autism; Neuropsychiatric disorders, Psychiatric outcomes, Developmental disorders	Title or abstract does not refer to categories associated with autism; Neuropsychiatric disorders, Psychiatric outcomes, Developmental disorders

Table 2.3: Inclusion and exclusion criteria for full text screening

Inclusion Criteria	Exclusion Criteria
Reports the number of participants that meet clinical cut off for autism	Does not report the number of participants that meet clinical cut off for autism
Reports gestational week	Does not report gestational week
Data in study were extractable for meta-analysis	Not possible to extract data (means)
Tools used to assess autism are reported	Tools used to assess autism were not reported
Sample may have been reported on before, however paper evidences new information on the cohort	Multiple publications from the same sample that do not include new information
Participants recruited without specific bias	Participants were recruited because they had a formal diagnosis of autism

To eliminate the risk of researcher bias, an additional researcher screened a subsample of papers at both stage one and two outlined above (19%). They then completed quality ratings against the quality weighting framework for *all* included papers. A good level of

reliability for the independent quality weightings was obtained (weighted Cohen's Kappa 0.7). Where discrepancies were identified, agreement was made between the two raters.

2.3.3 Quality Criteria

The quality of all studies that progressed to stage three of the review process was assessed using standardised quality weighting criteria to control for threats to validity. These criteria were adapted from a previous meta-analytic study (Richards et al., 2015) for the current study. Three key areas were assessed: autism assessment, sample identification and study design (Table 2.4). A visual matrix of quality weighting is presented in Table 2.5, alongside study characteristics and outcome data. From each paper, data were then extracted and number of participants meeting cut off for an autism diagnosis or established cut offs on screening tools were taken.

Table 2.4: Quality criteria for autism assessment, sample identification and study design

	0 – Poor	**1 – Adequate**	**2 – Good**	**3 - Excellent**
Autism Assessment	Not specified / reported Clinical judgement only	Informant report / self-report instrument Screening instrument Clinical judgement against specified diagnostic criteria (DSM-5 or ICD 10)	Diagnostic instrument / interviews -	Consensus from multiple assessments, including at least one diagnostic instrument
Sample Identification	Not specified / reported	Single restricted or non-random sample (specialist clinic or previous research study)	Multiple restricted or non-random samples (multi-region specialist clinics)	Random or total population sample
Study Design	Not specified / reported	Case series	Historically identified cohort (e.g., via patient records)	Prospective cohort

Table 2.5: Sample characteristics and quality criteria for included papers

Author	Location	Gestational age of sample	Diagnostic tools used	Age at assessment	Sample Size	N preterm individuals scored over the autism threshold	Quality Criteria		
							Autism	Sample Identification	Design
Abolfotouh et al., 2018	Saudi Arabia	22-23wks (10) 24-25wks (43) 26-28wks (52) 29-30wks (12)	Denver developmental screening test	3yrs	63	4 (Hyperactive autistic)	1	1	3
Al-Hathlol et al., 2020	Saudi Arabia	<32 weeks or <1500g	Unspecified questionnaire	Mean 12.3yrs	158	3	1	1	2
Atladóttir et al., 2016	Denmark	24-43 weeks	Diagnosis was retrieved from the Danish Psychiatric Central Register	NR[i]	82911	1203	1	3	2
Bakian et al., 2018	Utah	<37 weeks	Registry of Autism and Developmental Disabilities	NR	4855	112 (ASD)	1	2	2
Boone et al., 2018	Columbus	<30 weeks	PDDST-II-DCS[1] ADOS-2[2]	18 – 36mths & 3yrs	528 555	190 24 (ASD)	3	2	3
Bröring et al., 2018	Amsterdam	Very preterm (30.2 mean)	SRS[3], Children's Communication Checklist, SCQ[4]	Mean 9.2yrs	57	0	1	1	3
Brumbaugh et al., 2020	Minnesota	<37 weeks	Medical and educational records	Mean 6.5yrs	7876	266	1	3	3
Chen et al., 2020	Taiwan	<32 weeks or <1500g	ADOS and ADI-R[5]	5yrs	324	30	3	2	3
De Groote et al., 2006	Belgium	<37 weeks	Autism Diagnostic Observation Schedule-Generic	24mths	25	2 (Autism)	2	1	3

[1] Pervasive Developmental Disorders Screening Test-II, [2] Autism Diagnostic Observation Schedule, Second Edition, [3] Social Responsiveness Scale, [4] Social Communication Questionnaire, [5] Autism Diagnostic Interview revised

[i]NR is used as an abbreviation for 'not recorded' throughout where data was not present or extractable

Author	Location	Gestational age of sample	Diagnostic tool used	Age at assessment	Sample Size	No. preterm individuals scored over the autism threshold	Quality Criteria		
							Autism	Sample Identification	Design
De Oliveira Holanda et al., 2020	Brazil	<37 weeks	MCHAT[6]	18 – 24mths	40	20	1	1	3
Dudova et al., 2014	Prague	Mean GA 28.4	MCHAT ADOS	24mths	157 33	28 15	3	2	3
Gray et al., 2015	Brisbane	very preterm	MCHAT, The CBCL[7] & DASS[8]	NR	97	13 (Autism)	1	1	3
Guy et al., 2015	East Midlands	32-36 weeks	MCHAT & follow up phone interview	24mths	634	92	1	2	3
Hack et al., 2009	America	26 weeks	Parent Child Symptom Inventory	NR	219	8	1	1	2
Harel-Gadassi et al., 2018	Jerusalem, Israel	31.16 (mean)	MCHAT ADOS-T[9]	18 – 36mths	93 101	25 8	3	1	3
Hubert et al., 2020	Poland	GA Mean 27.8	Childhood autism spectrum test	4yrs	89	5	1	1	3
Hvidtjørn et al., 2011	Denmark	<37	Public child mental health service	NR	37283	277	1	2	3
Hwang et al., 2013	Taiwan	Late preterm = 1078, Later preterm = 28947, Full-term = 1104071	Coded by doctors based on ICD-9-CM[10]	NR	Early preterm = 1078, Later preterm = 28947	Early preterm = 24, Later preterm = 387	1	2	3
Ikejiri et al., 2016	Juntendo	>33 Weeks	DSM-4-TR[11]	NR	59	9 (ASD)	1	1	3

[6] Modified Checklist for Autism in Toddlers, [7] The Child Behaviour Checklist, [8] Depression Anxiety Stress Scales, [9] The Autism Diagnostic Observation Schedule – Toddler Module, [10] The International Classification of Diseases, Clinical Modification [11] Diagnostic and Statistical Manual of Mental Disorders, text revision

Author	Location	Gestational age of sample	Diagnostic tool used	Age at assessment	Sample Size	No. preterm individuals scored over the autism threshold	Quality Criteria		
							Autism	Sample Identification	Design
Indredavik et al., 2004	Norway	GA mean: 28.8	Interviewed and conclusions drawn according to DSM	14yrs	56	1	1	2	3
Johnson et al., 2010	UK & Ireland	<26	SCQ	24mths	189	29 (ASD)	1	3	3
Johnson et al., 2018	England	32 wks= 38	MCHAT	24mths corrected age	638	92	1	2	3
Joo et al., 2015	Korea	24-36	CARS[12]	Mean 44.4mths	58	1	2	2	3
Kihara & Nakamura, 2015	Japan	GA mean: 27.4	Clinical assessments & DSM criteria	NR	321	35	1	2	3
Klimek et al., 2018	Poland	28 weeks (Mean)	The Childhood Autism Spectrum Test	4yrs	86	5	1	1	3
Kuban et al., 2009	US	before 28 weeks gestation[1]	MCHAT	24mths	988	212	1	2	3
Kuzniewicz et al., 2014	California	< 24 weeks	ASD evaluation centre	24mths	15696	280	3	2	3
Lærum et al., 2019	Norway	28.9 weeks (mean)	Autism Spectrum Quotient	Mean 26.4yrs	59	21	1	1	3
Lean et al., 2020	USA	<30 weeks	ADOS & Parent report	5yrs	85	11	3	1	3
Leavey et al., 2013	California		Diagnostic codes	NR	33121	213	1	2	2
Lederman et al., 2018	São Paulo, Brazil	29.5 (mean)	MCHAT & Autism Behaviour Checklist	NR	60	4	3	1	3

[12] Childhood Autism Rating Scale

Author	Location	Gestational age of sample	Diagnostic tool used	Age at assessment	Sample Size	No. preterm individuals scored over the autism threshold	Quality Criteria		
							Autism	Sample Identification	Design
Limperopoulos et al., 2008	Boston	23 – 30wks	MCHAT	Mean 21.9mths	91	23	1	1	3
Matheis et al., 2018	Louisiana	<37 Weeks	BISCUIT Part 1[13]	Birth to 36 months	687	213	1	2	2
Mir et al., 2021	Texas	< 28 weeks	MCHAT ADOS & CARS	24mths & 4yrs	218 218	31 16	2	1	2
Mohammed et al., 2016	Saudi Arabia	GA 27-33	Clinical assessments & DSM	36mths	107	5	1	1	3
Moore et al., 2012	England	<26wks	MCHAT	24mths	523	216 (Positive result on the MCHAT Autism)	1	3	3
Nagai et al., 2020	Japan	VLBW <1500	DSM-5 and ADOS	3yrs	38	10	3	1	3
Persson et al., 2020	Norway	<37 weeks	Medical records	NR	165845	3544	1	3	2
Pineda et al., 2014	USA	<30 weeks	MCHAT	24mths	77	19	1	2	2
Pinto-Martin et al., 2011	New Jersey	GA mean:31.2	ADI-R/ADOS SCQ	NR	623 623	14 117	2	2	3
Pritchard et al., 2016	Australia	<29 Weeks	ADOS-G[14] MCHAT	24mths	15 169	3 22	2	1	3
Rand et al., 2016	New Zealand	<32	DAWBA[15]	2 & 4yrs	102	3	1	2	3

[13] The Baby and Infant Screen for Children with autism Traits-Part 1, [14] The Autism Diagnostic Observation Schedule-Generic, [15] The developmental and well-being assessment

Author	Location	Gestational age of sample	Diagnostic tool used	Age at assessment	Sample Size	No. preterm individuals scored over the autism threshold	Quality Criteria		
							Autism	Sample Identification	Design
Rutkowska et al., 2018	Poland	<28 Weeks	Screening Tool for Autism in Toddlers & Young Children	2yrs	10	4	1	1	1
Sharp et al., 2018	Australia	22 – 24 wks	Multidisciplinary team assessment	NR	159	9	1	1	2
Stephens et al., 2012	NICHD Neonatal Research Network	<27 weeks	PDDST-II & adapted items from the ADOS	18 & 22mths	554	Positive screen - 113	2	2	3
Sumanasena et al., 2018	Sri Lanka	<34	DSM Criteria	NR	39	3	1	2	3
Treyvaud et al., 2013	Melbourne Australia,	<30 weeks	DAWBA	NR	177`	8 (ASD)	1	1	3
Twilhaar et al., 2019	Amsterdam, Netherlands	29.2 weeks (mean)	SRS	Mean 13.35yrs	60	18	1	1	3
Verhaeghe et al., 2016	Belgium	Before 27 weeks	SRS	36mths	47	21	3	2	3
			ADOS, and The ADI-R		43	14			
Vermeirsch et al., 2020	Belgium	< 30 weeks	SRS	NR	55	22	2	1	3
			ADOS, ADI-R & clinical information		55	7			
Yaari et al., 2016	Israel	24 – 34 weeks	The AOSI and ADOS-T	8 – 18mths	99	High ASD risk – 8, Low ASD risk - 91	-	-	-
Yang et al., 2014	Taiwan	Mean BW 1200g	Diagnostic tools, observations and parental reports	13.4yrs	61	2	1	2	3
You et al., 2019	China	35.5 weeks (mean)	MCHAT	24-30 months	102	9	1	2	3

[14] The Autism Diagnostic Observation Schedule-Generic, [15] The developmental and well-being assessment

2.3.4 Statistical analysis

All estimated prevalence rates for autism in preterm samples were extracted from papers remaining in the final stage of review (N=52). These estimates were collated based upon the type of assessment tool used, screening tools or diagnostic assessments. These data were analysed to generate two pooled prevalence estimates, with random and fixed effect models created for both. Fixed effects models assume equal weighting of studies, with any error attributed to sampling error, whereas random effect models allow the true effect to vary between studies, with weighting fluctuating between studies (Borenstein et al., 2010). To calculate the random effects model within the current study, the restricted maximum-likelihood estimator was used. This estimator is more robust than traditional DerSimonian-Laird estimates in non-normal distributions of effect, as the method restricts the likelihood estimates to control for underestimation and minimise bias (Cheung, 2013). This decision was supported from analysing the Quantile-Quantile plots (see Appendix 1), which suggested the fixed effects models did not conform to normal distribution. A quality effects model for each assessment method was also produced to assess the impact of methodological variation as defined and weighted by the quality framework outlined above, and this quality effects estimate was compared to the random effects estimate (see Appendix 2). In order to explore the prevalence of autism amongst individuals born preterm in comparison to rates amongst the general population, odds ratios (OR) with 95% CI were generated. This analysis compared the random effects pooled prevalence estimates from diagnostic assessment methods with the most recent total population surveillance prevalence estimate for autism diagnosis (one in 54; Maenner et al., 2020). This particular population surveillance was chosen given its use of gold standard assessments and diagnostic and statistical manual definitions to confirm diagnosis. Data from this paper were also referenced by the Centre for Disease Control and Prevention

and others widely support the conservative estimate of 1 in 54 as a representative and inclusive population estimate.

2.4 Results

Prevalence of autism characteristics in individuals born preterm

To address aim i), to calculate pooled prevalence estimates for autism characteristics in individuals born preterm, 52 studies were included in the final meta-analysis; 23 used screening tools only, 22 used direct assessment only and 7 studies used both types of assessment. Pooled prevalence estimates of autism using random and fixed effects models were generated for both screening tools (See Figure 2.2) and diagnostic assessment (see Figure 2.3).

Screening tools: The fixed-effects model generated a pooled prevalence estimate of 11% (z = 31.89 $p = <.001$; 95% CI: 0.1018; 0.1151%) for autism characteristics in individuals born preterm. The random-effects model generated a prevalence estimate of 20% (z = 7.97, $p = <.001$; 95% CI: 14.98; 24.75%). The random-effects model extended with a quality weighting estimated a prevalence of 21% (z = 8.39, $p = <.001$; 95% CI: 16.38; 26.37%).

Diagnostic assessments: The fixed-effects model generated a pooled prevalence estimate of 1% (z = 73.54 $p = <.001$; 95%, CI: 1.36; 1.43%) for autism characteristics in individuals born preterm. The random-effects model generated a prevalence estimate of 6% (z = 5.8, $p = <.001$; 95% CI: 3.74; 7.57%). The random-effects model extended with a quality weighting estimated a prevalence of 9% (z = 8.17, $p = <.001$; 95% CI: 7.19; 11.74%).

In summary, the prevalence of autism characteristics was explored in individuals born preterm for both screening tools and diagnostic assessments in turn, with estimates ranging across the models created. Both fixed-effects models revealed high levels of heterogeneity (I^2 = 97.3 – 97.8%) indicating that the fixed effects model is not appropriate given it could not be concluded that studies were conducted under similar conditions. The random and quality-effects models that account for variability between studies and quality respectively produced estimates between 6-21% (Screening tools; random-effects model - 20%; quality effects model -21%; Diagnostic assessments; random-effects model - 6%; quality effects model - 9%).

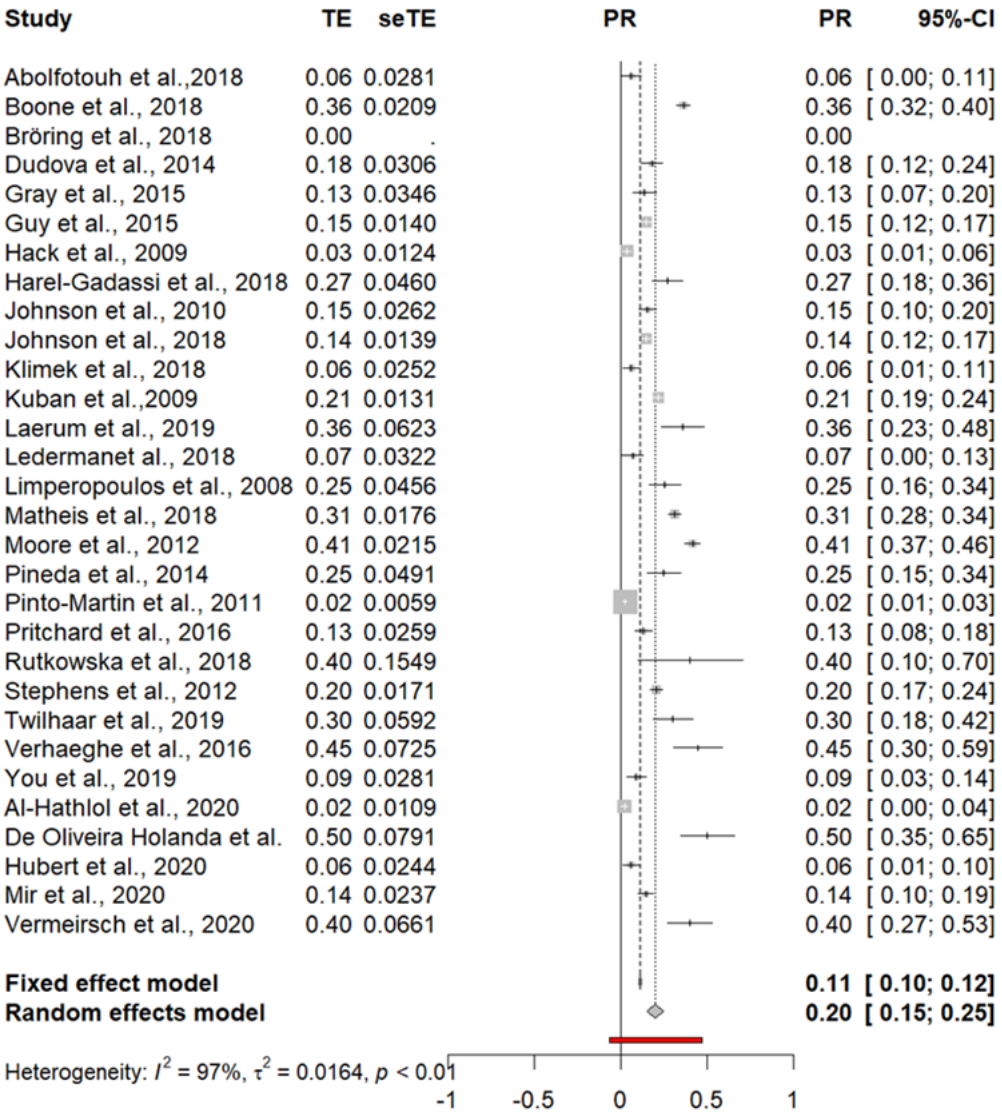


Figure 2.2: Fixed and random effects pooled prevalence estimates for autism characteristics in individuals born preterm using screening tools. Treatment effect (TE), standard error of the treatment (seTE), prevalence rate, confidence intervals and weighting by the random effects model are reported

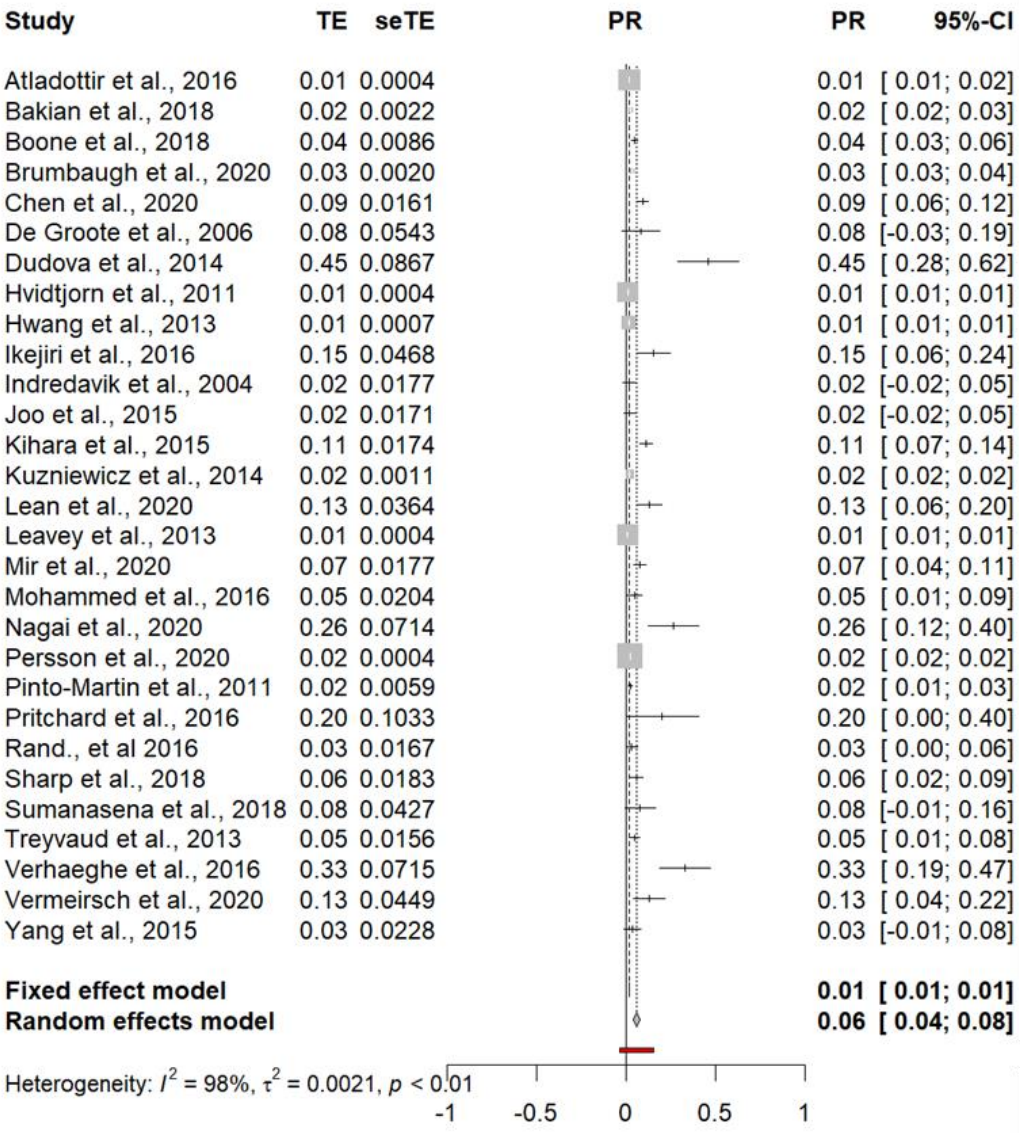


Figure 2.3: Fixed and random effects pooled prevalence estimates for autism characteristics in individuals born preterm using diagnostic tools. Treatment effect (TE), standard error of the treatment (seTE), prevalence rate, confidence intervals and weighting by the random effects model are reported

2.4.1 Sources of heterogeneity

To identify any studies that had significantly high impact on the overall effect, a 'leave one out' analysis was conducted (Figure 2.4). Where a study estimate fell outside of the 95% CI for the pooled prevalence estimate, it was considered to have disproportionate effect. Inclusion of such studies did not alter overall prevalence estimates and therefore no studies

were removed. To assess studies with large contributions to the overall heterogeneity of prevalence analysis, a Baujat Plot was created (Baujat, Mahé, Pignon, & Hill, 2002). No studies fell into the quartile of high heterogeneity and impact on effect and therefore no studies were removed.

2.4.2 Publication Bias

Visual inspection of funnel plots created to detect publication bias showed a broad asymmetrical distribution (Figure 2.5). Given the subjective nature of visual inspection, linear regression analysis was conducted to statistically test for asymmetry (Egger et al., 1997). A non-significant result (Screening tools – $p = 0.494$; Diagnostic assessments - $p = 0.057$) suggested no evidence of publication bias, exaggerated estimates of smaller studies or the inclusion of poor-quality studies.

Comparing pooled prevalence estimates in the preterm population with estimates of autism in the general population

To address aim ii), the prevalence of autism amongst individuals born preterm in comparison to rates amongst the general population, odds ratios (OR) with 95% CI were generated. In the case of diagnostic assessments, OR analysis suggested the odds of an autism diagnosis were 3.3 times higher in individuals born preterm than in the general population (95% CI 0.24 - 47.60).

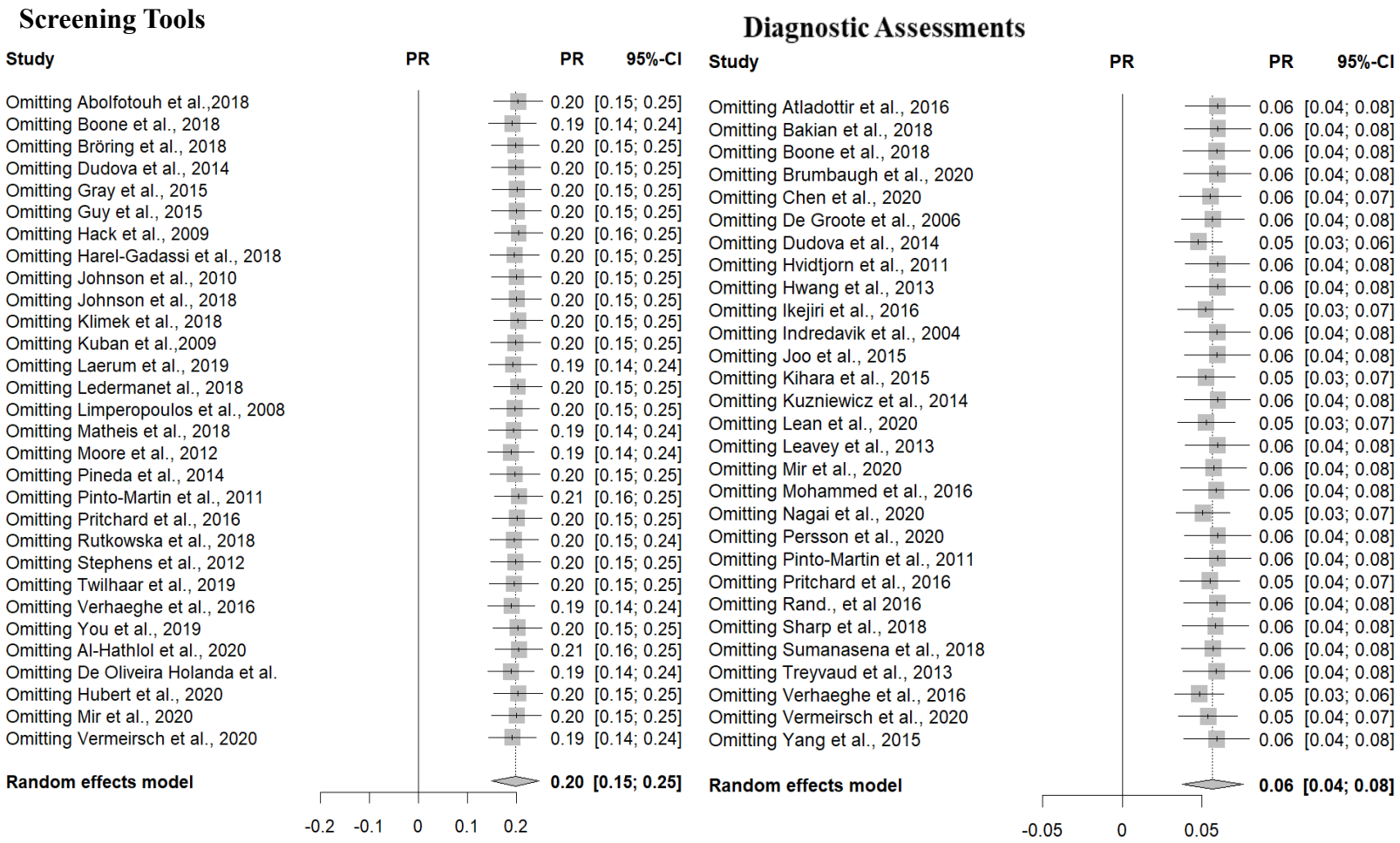


Figure 2.4: Pooled prevalence estimate for autism characteristics in individuals born preterm categorised by assessment type using a random-effects model with each study omitted

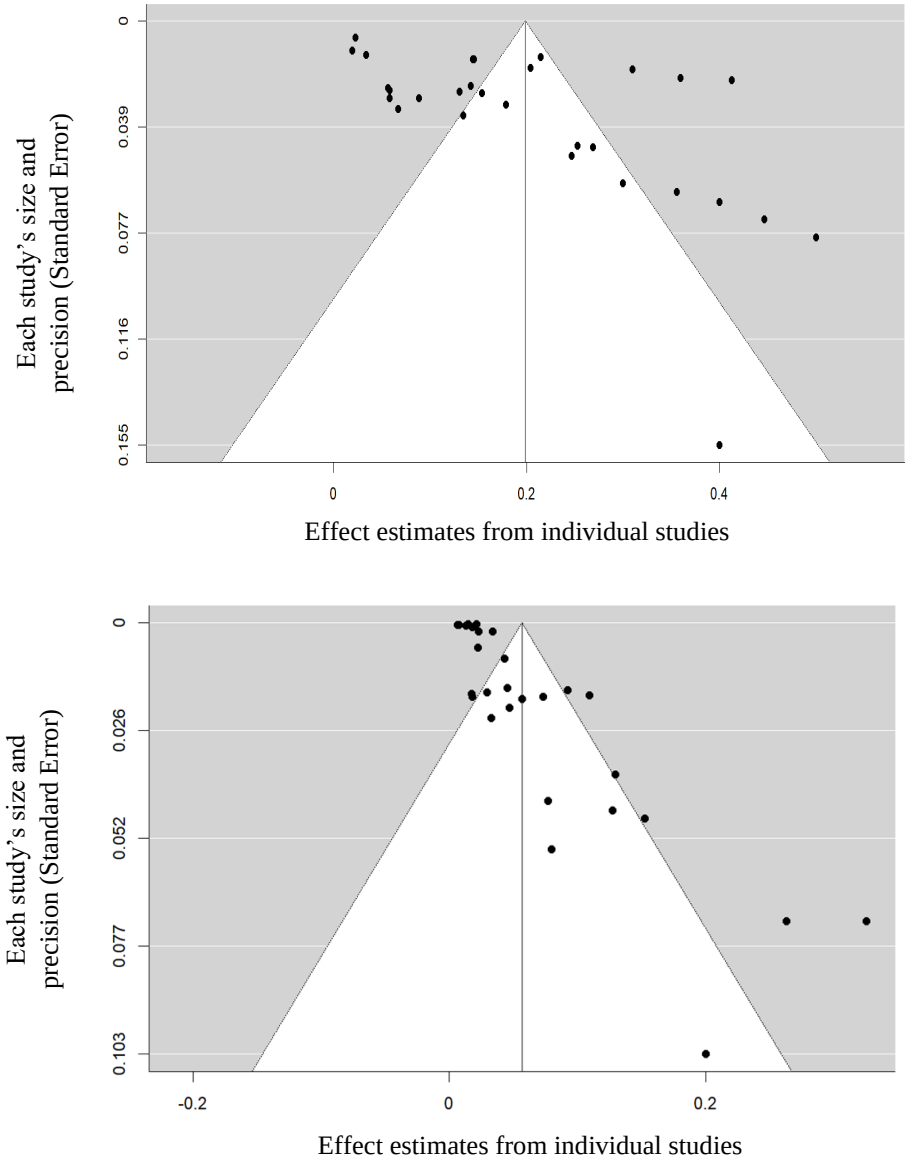


Figure 2.5: Two funnel plots presenting the effect estimates from individual studies against each study's size and precision. A separate funnel plot was created for each of the analyses run; screening tools (top) and diagnostic assessment (bottom)

Identifying the profile of and participant characteristics that may be associated with autism characteristics in preterm samples

To address the third aim of the study (iii), to explore participant characteristics associated with autism characteristics, the influence of participants' age at assessment and

gestational age on prevalence rates were assessed using a meta-regression (Table 2.6). Both meta-regressions revealed no significant associations between age at assessment (screening tools p =.118; diagnostic assessment p =.579) or mean gestational age (screening tools p =.192; diagnostic assessment p =.579) and prevalence of autism characteristics. Due to insufficient data, it was not possible to assess the profile of autism characteristics in individuals born preterm and consider how this differed from individuals born at term.

Table 2.6: Participant characteristics influencing prevalence of autism diagnosis in individuals born preterm.

Screening Tools

Covariate	Estimate	S.E.	Z	p	Lower 95%CI	Upper 95%CI
Age at assessment	-0.00010	0.0005	-1.9172	.055	-0.0021	0.0000
Gestational Age	-0.0080	0.0144	-0.5546	.579	-0.0362	0.0202

Diagnostic Assessments

Covariate	Estimate	S.E.	Z	p	Lower 95%CI	Upper 95%CI
Age at assessment	-0.00005	0.0004	-1.3022	.193	-0.0012	0.0002
Gestational Age	-0.0175	0.0112	-1.5602	.119	-0.0394	0.0045

2.5 Discussion

The prevalence of autism characteristics in individuals born preterm was systematically reviewed and meta-analysed. This was the first study to meta-analyse data across both diagnostic assessments and screening tools. Due to the inclusion bias present in studies using diagnostic assessments, this meta-analysis therefore provides novel estimates of prevalence across gestational age. The use of a robust and standardised search strategy improves the accuracy of estimates, with stringent inclusion and exclusion criteria considerably enhancing the internal validity of findings. Overall, autism characteristics were estimated to have a prevalence rate of between 6-20% for individuals born preterm, dependent upon assessment method used. The odds of an autism diagnosis were 3.3 times higher in individuals born preterm than in the general population. Both meta-regressions revealed no association between age at assessment or gestational age and autism characteristics in preterm samples. Results have significant clinical importance for both individuals born preterm and the provision of services.

Autism characteristics were present in 6-20% of preterm individuals in the current study. This is considerably higher than general population estimates (1.5%; Maenner et al., 2020) and consistent with a recent meta-analysis of autism in preterm individuals that included only diagnostic tools (7%; Agrawal et al., 2018). The current study confirms and extends the findings that preterm individuals are more likely to have presentations consistent with an autism diagnosis, and also show heightened rates of autism characteristics compared to the general population.

The inclusion of data from papers that used screening tools is a key strength of the current study, as these prevalence estimates capture a broader range of autism characteristics. One consideration when comparing screening measures to diagnostic assessments is that the differing tools are perhaps asking different questions; one surrounding the presence and levels

of autism characteristics whilst the other only identifies those that reach a predetermined cut off. It has previously been suggested that screening measures are not as valid as diagnostic assessments (Charman & Gotham, 2013), over-identifying the individual likelihood of autism (Kim et al., 2016). Nevertheless, screening measures are increasingly used to help reduce clinical waiting lists and enable earlier access to support, which has been shown to improve outcomes (Landa et al., 2007). The results from this meta-analysis suggest that 1 in 5 children born preterm warrant further assessment for autism. Future research should therefore quantify the extent to which screening tools within preterm samples generate prevalence estimates similar to diagnostic tools *and* explore the positive predictive power of screening tools in preterm samples through consideration of their psychometric properties.

High levels of heterogeneity were identified during analysis (I^2 = 97.3 – 97.8%), likely due to the the variability in both sample identification and populations studied. Studies have found that poorly identified samples (inclusive of all gestational ages) provided lower prevalence estimates of autism characteristics, while studies with well-defined samples consistently comprised individuals born very preterm, where rates of autism characteristics identified are notably higher (Soul & Spence, 2020). This has wide implications for future research; studies of neurodevelopmental outcomes should adhere to classifying groups using standard definitions of prematurity and consider these outcomes across all gestational ages. While samples are continuously use differing definitions of prematurity, the ability to robustly assess these groups decreases.

To explore the influence of gestational age on prevalence estimates of autism characteristics, meta-regressions were conducted on available data. No significant associations were found between gestational age of participants and autism characteristics. Previous research has highlighted an increase in autism prevalence amongst those born very preterm

when compared to those born closer to term (Johnson et al., 2010; Pritchard et al., 2016). Although the results of current analysis suggest no significant difference, caution must be taken when interpreting this result. A noteworthy limitation of this analysis was the lack of clarity in sample descriptions reporting effects across included studies. As mentioned previously, the most well-defined populations are often those born very preterm, with most of the current studies simply providing a mean gestational age. It is vital future research clearly defines participant groups so that outcomes can be rigorously stratified.

Further analysis was conducted to explore any mediating effect age of assessment had upon autism prevalence estimates, with no significant associations found. Research highlights the reliability of autism diagnosis as young as 24 months (Johnson et al., 2007), and the beneficial impact this can have upon service use and support (Daniels & Mandell, 2014). The current study did not identify a significant difference in prevalence based upon age of assessment, although more research would be needed to confidently rule out any effect of age. Whilst this could suggest the stability of autism across the lifespan, there was again a large amount of missing data surrounding the age of participants at assessments. Research has highlighted the importance of understanding the early behavioural phenotype of preterm infants, as early behaviours could result in a later diagnosis of autism (Yaari et al., 2016). In line with World Health Organisation (WHO) guidance on routine early medical and developmental follow up after preterm birth (WHO, 2015), and with evidence that poorer outcomes can be identified throughout the lifespan, it is important future research focuses on providing assessments and intervening at a younger age.

Due to insufficient data, it was not possible to assess the profile of autism characteristics in individuals born preterm and consider how this differed from autism characteristics in individuals born at term. This highlights a substantial gap in the current literature, as subscale

scores for social communication and restricted repetitive domains were consistently not reported, despite diagnostic and screening tools providing these outputs. While many studies utilised standardised assessment methods that are well validated, the omission of reported subscale scores significantly impacts any conclusions that can be drawn from them as literature highlights that individual characteristics and traits (often measured separately through subscales of measures) are often deemed more important than an overall 'autism severity' score (Robertson, 2009). Similarly, current interventions target specific social cognitive differences and or social behaviours evidenced in individuals with autism characteristics instead of intervening at a global level (Rogers & Williams, 2006; Wallace & Rogers, 2011; Whalen et al., 2006; Young et al., 2003). Yet, without the ability to delineate the profile of autism characteristics in those born preterm, we cannot explore the underpinning social cognitive mechanisms and establish links between cognition and behaviour. Further, without precise documentation of the profile of autism evidenced by individuals born preterm, it is not yet clear if interventions created for use in term populations with autism can be successfully used for individuals born preterm. As such, the utility of currently available autism interventions or packages of support is unknown for those born preterm.

To conclude, the results of this meta-analysis indicate that individuals born preterm are 3.3 times more likely to receive an autism diagnosis than individuals in the general population, with prevalence estimates ranging from 6-20% depending on the method of autism assessment. Following the publication of the WHO recommendations for improving outcomes of those born preterm, neurodevelopmental outcomes of preterm infants, such as those delineated in the current study, are considered to be of particular importance (WHO, 2015). Services offered to preterm individuals are lacking, with further support deemed necessary in areas such as infant neurodevelopment as well as more specific domains such as feeding and sleeping. Current data

show considerably elevated prevalence of autism characteristics in individuals born preterm; it is therefore vital that service providers reflect this increased likelihood in the support and professional follow up they offer.

CHAPTER THREE

THE BEHAVIOURAL PROFILE OF MODERATE TO LATE PRETERM INFANTS OVER TIME; A CROSS-SECTIONAL ONLINE SURVEY

3.1 Preface

The meta-analytic data in Chapter 2 revealed a heightened prevalence of autism characteristics in those born preterm. No evidence for gestational age-related difference in autism characteristics was found. However, there was limited evidence within the literature specific to those born MLPT, and limited description of the *profile* of the observed social differences beyond diagnostic cut offs. Therefore, the present chapter aims to extend these findings to fully characterise the profile of social abilities within a sample of children born MLPT (aim two of the thesis). The use of cross-sectional age-related analysis will provide some indication of how these abilities may manifest over childhood. Exploration of the associations between social abilities and executive functions contributes to the growing literature linking these abilities and extends research undertaken with term and very preterm children.

3.2 Introduction

Previous large scale surveillance studies, and the results of the meta-analysis in Chapter 2, highlight heightened rates of autism in the preterm population (Crump, Sundquist, & Sundquist, 2021; D'Onofrio et al., 2013; Section 2.4). The surveillance and meta-analytic approaches both document clinically meaningful differences in autism prevalence for individuals born before 37 weeks, yet population level prevalence estimates often fail to encapsulate individual differences in the underlying profile of social abilities. This is particularly relevant when considering both a clinically heterogeneous population, such as those born preterm, and a behaviourally heterogeneous diagnosis, such as autism. As such, two key questions remain unexplored. First, given the increased prevalence of social differences which translate into a formal autism diagnosis in children born preterm, what is the specific *profile* of these differences? Second, are these behaviours linked exclusively to being born preterm (forming a component of a wider preterm phenotype), *or* are they associated with broader differences in developmental skills? Given these remaining questions, a cumulative science approach would suggest researchers should explore in more detail these claims and challenge areas in which population level data collection has identified flaws (Sharpe & Goghari, 2020). Given the high proportion of preterm births that occur between $32^{+0/7}$ - $36^{+6/7}$ weeks gestation (Howson et al., 2013), and the lack of clarity regarding the profile of social abilities within this subgroup (see section 1.4.3 and 1.5.4), a comprehensive exploration of social differences in those born MLPT is therefore warranted.

When considering social differences, a popular method adopted within the literature is the use of screening tools. These are often brief questionnaire measures designed to document

social differences or the need for further neurodevelopmental assessment and can be delivered quickly at low cost (Sappok et al., 2015). Within clinical settings, it is widely accepted that screening tools assessing social skills are not sufficient for diagnosis, with both clinical expertise and additional neurodevelopmental assessment required to formally assess autism (Levy et al., 2020). Yet, within a research capacity the use of such measures has increased over the past decade and has potential utility providing appropriately cautious conclusions are drawn (Sasson & Bottema-Beute, 2021). The wider psychometric value of such screening tools often results from broad validation studies. Large datasets collected on a particular measure allows for sensitivity (a measure's ability to detect the number of true positives within a sample) and specificity (a measure's ability to detect the number of true negatives within a sample) to be calculated (Van Stralen et al., 2009). In the case of screening tools measuring social abilities, many argue sensitivity is more important than specificity given further neurodevelopmental exploration in the absence of need is not a detrimental outcome (Surén et al., 2019). An additional useful metric to consider is a measure's reliability or diagnostic validity; how consistent and accurate the measure is (Bolarinwa, 2015). Such metrics for measures of social differences and/or autism are complex when we consider the observed behavioural heterogeneity across autistic individuals and the evolution of the diagnostic classification system (Wolfers et al., 2019). Further understanding of the psychometrics of screening tools that explore social differences or autism is necessary. Such evidence would allow clinicians to consider their utility beyond traditional diagnostic metrics towards a more individualistic approach of documenting behaviours that may facilitate personalised support.

Screening tools used within a research context (often in the absence of concern) allow for further exploration of subtle but important differences across participants on areas of social differences and restrictive and repetitive behaviours (Sappok et al., 2015). Autism screening tools fall broadly into two categories, measures that aim to categorise participants scores on a *dichotomous* system paralleling the process of a diagnosis, such as the Modified Checklist for Autism in Toddlers – MCHAT; Robins & Fein., 2018, or the Social Communication Questionnaire - SCQ; Berument et al., 1999, and measures that document the profile of behaviours on a *continuum*, highlighting areas of relative strength or difficulty such as the Social Responsiveness Scale – SRS; Constantino & Gruber., 2012. Further to these differences in purpose, measures can also differ in the way they ask respondents to document behaviours with some, such as the MCHAT or SCQ, collating 'yes/no' responses and others, such as the SRS, asking respondents to quantify the frequency or impact of behaviours on a Likert scale of frequency. For these reasons, while all screening tools relating to social abilities or autism are often pooled into a singular category, there is a strong case for hypothesising that the likely measurement properties differ (for example using a cut off score of 15 – SCQ sensitivity = 0.85; SCQ specificity = 0.75; [Berument et al., 1999]; SRS Sensitivity = 0.78 – 0.80 [Bölte, Westerwald, Holtmann, Freitag, & Poustka, 2011; Charman et al., 2007; Constantino et al., 2004], specificity = 0.75, Constantino et al., 2004). Given screening tool thresholds are often derived from dated studies that employ a sensitivity-specificity trade off (Mottron, 2021), a recent move towards a subthreshold autistic traits model acknowledges there is value to considering traits on a continuum (Dell'Osso et al., 2016). In order to document the profile of autism in MLPT, it is therefore critical to include multiple measures that purport to describe autism characteristics in different ways.

Methods of considering screening tools for autism at a subthreshold level have been evidenced within larger studies of preterm populations, although thus far almost exclusively amongst those born at the earliest gestations. When comparing participants' scores on screening tools to categorisations on formal diagnostic assessments, a significantly higher proportion of children born very preterm scored above threshold for further neurodevelopmental assessments than received a diagnostic classification (Pritchard et al., 2016). In addition, for those whose scores on screening tools indicated the need for further neurodevelopmental diagnosis but did not reach a diagnostic classification on a direct assessment, there was an increase in social communication indicators of autism. This may suggest social communication difficulties occur commonly in preterm samples, but often sit below the diagnostic threshold. This is corroborated by evidence exploring subscale scores on the SCQ for adolescents born extremely preterm, which revealed social and communication domains as areas of particular difficulty in contrast to less difficulty with repetitive behaviours (Johnson et al., 2010). Elevated subthreshold scores across screening tools have also been evidenced in a sample of adults born extremely preterm (O'Reilly et al., 2021) suggesting the potential stability of these traits in adolescents and adults. These studies highlight that those born at the earliest gestations may display an alternate social profile that warrants further investigation but *did not* meet clinical cut off for formal diagnosis (Vermeirsch et al., 2021). Given these findings are reported exclusively for those born at the earliest gestations, exploration of these behaviours within those born MLPT is warranted. Corroborating findings of those born at the earliest gestations and obtaining comprehensive evidence of differences for those born across all gestations would allow for a timelier package of support.

Alongside precise documentation of the profile of social abilities, their association with other developmentally relevant areas of ability should also be considered in individuals born preterm. Closely linked to the development of social abilities are executive function abilities; a set of cognitive control processes that underpin self-regulatory and goal oriented behaviours (Taylor & Clark, 2016). One way these abilities can be fractioned is into the components of working memory, inhibitory control and cognitive flexibility (Diamond, 2013), with abilities developing rapidly throughout early childhood (Hughes, 2011). Whilst there is broad agreement that social abilities and executive functions are linked, the precise nature of this association remains unclear. Some argue executive functioning abilities underpin social skills, with it being necessary to be able to inhibit the behaviour of 'others' and hold perspectives in mind to be able to successfully carry out tasks requiring social cognition (Marcovitch et al., 2015). Conversely, longitudinal evidence would suggest an inverse relationship, with early social abilities predicting later executive functioning (Wade et al., 2016), more specifically early social attention behaviours as the foundation for later executive skills (Marciszko et al., 2020). A large scale synthesis exploring the relationship between broader social cognitive skills such as theory of mind and false belief understandings and executive functions in young children (aged 3-6 years) showed a moderate but significant association (Devine & Hughes, 2014), suggesting that these skills may develop together. Although the specific relationship between executive functioning and social abilities is complex, given these abilities are developmentally linked within their emergence during the early years, research further exploring the nature of this relationship in children born preterm is warranted.

Many studies have shown differences between preterm and full term populations when looking at the development of executive functions, with those born preterm appearing to show

a delay in both acquisition and development of executive functions (Aarnoudse-Moens et al., 2012 [GA ≤30wks]; Marlow et al., 2007 [GA ≤25wks]; Sandoval et al., 2021 [GA <37wks]). This is perhaps unsurprising given the frontal lobe is described as playing a crucial role in executive functioning (Anderson et al., 2011) and notably is the last area of the brain to develop, so is often affected by preterm birth (Vandewouw et al., 2020). These differences in executive functions have been shown to persist not only into adolescence (Aarnoudse-Moens et al., 2012 [GA ≤30wks]) but also to be closely associated with later academic outcomes (Taylor & Clark, 2016). Unlike social profiles, the development of executive functions have been well characterised within MLPT populations (Baron et al., 2009, 2012; Brumbaugh et al., 2014; Hodel et al., 2016, 2017). Late preterm children have been shown to score lower on direct measures of working memory when compared to full term children, with no significant differences on measures of inhibition (Baron et al., 2012). In addition, some evidence also highlights "hot" executive functions as a specific area of difficulty for children born between 32–36 weeks (Hodel et al., 2016). However, other research points towards broader differences that affect a range of executive functioning abilities, with attention, memory and inhibition all areas of notable difference for nine month old infants born between 30 – 36 weeks (Hodel et al., 2017). Despite contrasting findings, all studies provide evidence of executive functioning differences in preterm and MLPT children and documented higher prevalence rates of social differences. Future research should explore how executive functioning skills may be related to social abilities in this group.

Exploring the profile of skills and behaviours across preterm populations has given rise to the idea of a distinct 'preterm phenotype'. A phenotype approach suggests that within a population (often linked through a common genotype) there is a distinct profile of cognitive

abilities and behaviours unique to this population (Skuse, 2000). This approach towards understanding behaviour is argued to have value at both an individual and clinical level, assisting in understanding of expectations and service provision (Finegan, 1998). Currently, the preterm phenotype is said to be one characterised by an increase in cognitive impairments, attention differences and social-emotional differences with an absence of behavioural problems (Anderson, 2014; Johnson et al., 2018; Johnson & Marlow, 2011). Yet, in line with the emergence of a suggested preterm phenotype, questions can be raised about the utility of this approach. When comparing the described phenotype to a population of extremely preterm neonates, researchers highlight four separate qualitatively distinct profiles of behaviour rather than one (Burnett et al., 2019). At its core, the assumption of a phenotype also requires a population to have similar aetiology, yet preterm birth is continuously described as an incredibly heterogenous group (Church et al., 2018). Given the multiple aetiologies of preterm birth and heterogeneous developmental experiences of those born preterm, there may be limited construct validity in a phenotype when combining all individuals born <37 weeks. It is well documented those born MLPT present with fewer immediate health concerns and potentially a more nuanced profile of behavioural outcomes than those born at the earliest gestations (Shapiro-Mendoza & Lackritz, 2012). Consequently, describing the 'preterm phenotype' based upon the outcomes of those born at the earliest gestations may mean it is not entirely applicable to those born at later gestations, such as those born MLPT. More robust descriptions of subgroups that exist under the umbrella of 'preterm birth' are therefore warranted.

In addition to improving description of clinically relevant behaviours in social differences and executive function domains, it is equally important to consider the context and

method in which clinical data are collected. It is well understood that development should not be considered in isolation, and should instead be explored across time points either individually or between groups (Kraemer et al., 2000).While longitudinal studies are the gold standard in developmental data collection (Caruana et al., 2015), they are both time and cost intensive. Cross sectional research is an alternative method that allows for deeper exploration of a range of abilities and how they are associated in a timely and efficient manner (Kraemer et al., 2000). This study design allows for the employment of a developmental cascade framework of analysis (Masten & Cicchetti, 2010), broadening the questions such data can answer. Therefore, research that explores developmentally relevant abilities within a developmental trajectories framework considering change over time through contrasts between age groups *and* contrasts with appropriate reference groups is warranted (Knowland & Thomas, 2011). Such methods of data collection adopted within those born MLPT to explore profiles of social cognitive skills and executive functions would allow for the characterisation of these abilities across childhood in an efficient manner.

To conclude, those born preterm appear to display differences in social abilities, although the specific profile of differences in those born MLPT has not been characterised. Research demonstrates that domains of executive function are impaired in children born MLPT compared to term born children, but there has been limited exploration of how this may relate to social differences, and hence directionality and focus of interventions is unclear. Comparing such profiles of social abilities across age groups *and* to appropriate comparison groups is imperative when characterising the need for support and service provision.

The current study therefore aims;

i. To describe the profile of social abilities, executive functions and emotional and behavioural difficulties within a sample of children born MLPT.

ii. To explore how the profile of social abilities, executive functions and emotional and behavioural difficulties fluctuates with age within a sample of children born MLPT.

iii. To explore the similarities or differences between those born MPLT and their peers on a measure of social behaviours.

iv. To explore the association between executive functioning skills and social behaviours within children born MLPT.

3.3 Methods

3.3.1 Participants

The statistical power needed to create a simple structural equation model was predicted to be greater than for other statistical tests, therefore an a priori power analysis was conducted using G*Power 3.1 (Faul et al., 2013) to test the proportion of variance in relation to putative predictor variables. Results showed that a minimum sample of 80 participants was required to achieve a power of .8 based on $\alpha = .02$ with seven predictor parameters. Guidelines for structural equation modelling also suggested a 10:1 ratio for the number of participants per model component (Suhr, 2006). Given model components would not exceed 7, a sample size of 80 was considered appropriate. A total of 87 parents and caregivers of individuals born MLPT completed the online survey, exceeding the necessary sample size. Participants were excluded if; (a) their child was born outside of the specified gestational age (<32 or >36 gestational weeks), (b) their child had a sibling who had received a formal diagnosis of autism (N = 3)[4] or (c) participants had completed less than 75% of the total measures. Three participants were therefore excluded leaving a final sample of 84 (see section 3.5.1 for full demographic information).

3.4 Recruitment

Parents and caregivers were recruited both locally and internationally through social media sites (such as Facebook and Twitter), as well as global charities for those born preterm. Information was shared via a video and flyers. While initial pre-registered recruitment plans

[4] Participants were excluded from the current study if they had a sibling who had received a formal diagnosis of autism given the broader autism phenotype and prevalence of social cognitive differences within relatives of autistic people.

involved promoting the research within face-to-face settings such as schools, nurseries and play groups, recruitment was instead restricted to online strategies, due to the Covid-19 pandemic.

3.4.1 Procedure

Parents and caregivers were invited to complete a remote online survey. The survey was accessible through a public URL and could be completed on a computer, phone or other mobile device. The survey was also available in paper format upon request, although all participants chose to complete the survey via the public URL. Upon providing consent, parents and caregivers reported the current age of their child. Participants were then stratified into three age categories (1-3 years, 4-5 years, or 6-11 years old) and were presented with a set of age-appropriate validated measures to complete. Parents and caregivers were sent a comprehensive feedback report detailing their responses within the context of the wider sample when the study closed. Ethical approval for this study was obtained from the School of Psychology ethical review committee at the University of Birmingham (ERN_09-048AP9; see Appendix 3).

3.4.2 Measures

Parents and caregivers completed a range of validated questionnaires exploring autism related behaviours, executive functions and emotional and behavioural difficulties (see Appendix 4). Given the broad age range of participants, age-appropriate validated measures were completed (as outlined in Table 3.1) and are described in detail below. Validated measures were chosen to address the same constructs across age groups in a developmentally appropriate format.

Table 3.1: Measures completed by each parent or caregiver dependent upon their child's age

	1.5 – 3yrs (N = 36)	4 – 5yrs (N = 23)	6 – 11yrs (N = 25)
Background Questionnaire	✓	✓	✓
Autism related behaviours			
Modified Checklist For Autism in Toddlers Revised	✓		
Social Communication Questionnaire		✓	✓
The Social Responsiveness Scale, Second Edition (Preschool)	✓		
The Social Responsiveness Scale, Second Edition (School Age)		✓	✓
Executive Functions			
Behaviour Rating Inventory of Executive Function, Second Edition			✓
Behaviour Rating Inventory of Executive Function, Preschool Version	✓	✓	
Emotional and Behavioural Difficulties			
The Strengths and Difficulties Questionnaire	✓	✓	✓

Background questionnaire

Parents or caregivers first completed a background questionnaire which comprised three sections; contextual information relating to the Covid-19 pandemic, information about the parent or caregiver completing the questionnaire and information about their child. Providing information about individual experiences throughout the Covid-19 pandemic was optional. Questions such as changes to family routine, instances of isolation or positive household cases and children's educational experiences were considered. Household demographics and socioeconomic status were then collected from participants, as well as

maternal characteristics throughout pregnancy and birth (such as age and general health). Finally, medical information surrounding the birth of their child (such as location, complications, NICU admissions and health concerns) were collected.

Autism related behaviours:

Modified Checklist for Autism in Toddlers revised (MCHAT- R)

The Modified Checklist for Autism in Toddlers – Revised (M-CHAT-R) is a validated developmental screening tool for autism suitable for children aged between 16 – 30 months (Robins et al., 2014). The checklist comprises 20 items asking parents or caregivers to document the presence or absence of specific behaviours (e.g. 'When you smile at your child, does your child smile back at you?') through a 'yes' or 'no' response. Higher scores on the checklist indicate greater need for further developmental follow up, with a scoring algorithm generating 'risk' categories for an autism diagnosis and placing toddlers into appropriate groups. The checklist has an optional follow up that was not administered within the current study given the remote nature of data collected, the use of multiple tools to assess autism characteristics and the intended use of responses (the optional follow up was administered as part of direct assessments in Chapter 5). The MCHAT-R has good levels of reliability and validity (Robins et al., 2014), with sensitivity levels of the current measure improved compared to previous versions (Robins, Fein, & Barton, 1999).

Social Communication Questionnaire – Lifetime Version (SCQ)

The Social Communication Questionnaire - Lifetime Version (SCQ) is a screening tool for assessing autism characteristics validated for use in children 4 years or older (Rutter,

Bailey & Lord., 2003). The lifetime version of the SCQ asks parents or caregivers to consider their child's entire developmental history and was chosen within the current study as authors advise the lifetime version be used for the purpose of diagnostic screening, and the alternative 'current' version to be employed to explore change over time post diagnosis. The measure consists of 40 items (e.g. 'Has she/he ever seemed to be more interested in parts of a toy or an object (e.g. spinning the wheels of a car), rather than in using the object as it was intended?'), their content paralleling The Autism Diagnostic Interview-Revised (ADI-R; Lord et al., 1994). Parents or caregivers are asked to respond via a dichotomous 'yes' or 'no' answer, with responses subsequently receiving '1' or '0' dependent upon present or absent behaviours. The SCQ has been shown to have good internal consistency ($\alpha = .90$) and item level validity (Rutter, Bailey & Lord., 2003). Items are grouped into three subscales; 'Communication', 'Social Interaction' and 'Repetitive and Stereotyped patterns of behaviours', with higher scores indicating higher levels of behaviours associated with autism and thus greater need for further developmental follow up. Total scores can be generated for the measure and interpreted with reference to published cut-off scores (Berument et al., 1999). Researchers suggest scores ≥ 15 indicate possible autism spectrum disorder and ≥ 22 differentiates between those with autism and those with other pervasive developmental disorders; these cut-offs are widely accepted within clinical practice (Berument et al., 1999). Given the current research aims to explore the profile of social abilities rather than purely categorise children based on diagnostic cut-offs, both cut-offs will be considered. The SCQ has been shown to have good diagnostic validity and reliability within those born extremely preterm (Johnson et al., 2011).

The Social Responsiveness Scale, Second Edition (SRS-2)

The Social Responsiveness Scale, Second Edition (SRS-2) is a questionnaire measure exploring social differences commonly associated with a diagnosis of autism spectrum disorder (Constantino & Gruber., 2012). The 65-item measure asks respondents to consider a variety of behaviours (e.g. 'Is aware of what others are thinking or feeling') across a four point Likert scale. The SRS-2 is available in multiple formats to account for age and respondent variability. The two versions used within the current study were the SRS-Preschool and the SRS-School Age parent respondent forms. These two versions vary several times (14) whereby wording is adjusted to be age appropriate. Unlike screening measures (such as the SCQ and MCHAT previously described), the SRS-2 measures traits on a continuous distribution. Total scores as well as scores across five domains (Social Awareness, Social Cognition, Social Communication, Social Motivation and Restricted Interests and Repetitive Behaviour) can be calculated. Higher scores on the measure are indicative of higher levels of behaviours associated with a diagnosis of autism spectrum disorder. The SRS-2 allows professionals to use raw scores or generate *T* scores based upon gender and age of the individual. Authors recommend *T* scores are used in educational settings and clinical practice to assist ease of interpretation (Constantino & Gruber., 2012), therefore *T* scores were generated alongside raw scores within the current study. The SRS has been shown to have good construct and internal validity within the general population (Wigham et al., 2012).

Executive Functions

Behaviour Rating Inventory of Executive Function, Preschool Version (BRIEF-P)

The Behaviour Rating Inventory of Executive Function, Preschool Version (BRIEF-P) is a 63-item questionnaire that measures executive functioning in pre-school aged children aged between 2 – 5 years (Gioia, Espy, & Isquith, 2003). The measure is designed to be completed

by parents or caregivers and asks respondents to document the frequency of relevant behaviours (e.g. 'Has trouble concentrating on games, puzzles or activities') on a three point scale; 1 – 'never', 2 – 'sometimes', 3 – 'often'. An overall 'global executive composite' can be calculated alongside five scales of behaviours characterised by authors as falling under the broader umbrella term of executive functions; 'inhibition', 'shift', 'emotional control', 'working memory', and 'plan / organise'. Higher scores across these subscales suggest areas of clinical difficulties that warrant further exploration. Similarly to SRS-2, the availability of normative data means *T* scores can be generated based upon individuals gender and age and were used within the current study. The BRIEF-P has been shown to have high internal consistency ($\alpha = .80$), moderate interrater agreement (measured via correlations .06 - .28) and moderate test-retest stability (measured via coefficients .78 - .90) (Gioia, Espy, & Isquith, 2003).

Behaviour Rating Inventory of Executive Function, Second Edition (BRIEF-2)

Similarly to the BRIEF-P, the Behaviour Rating Inventory of Executive Function, Second Edition (BRIEF-2) is a 63-item questionnaire that measures executive functioning specifically in school aged children aged 5 – 18 years (Hendrickson & McCrimmon, 2019). The measure is designed to be completed by parents or caregivers and asks respondents to document the frequency of relevant behaviours (e.g. 'Does not plan ahead for school assignments') on a three point scale; 1 – 'never', 2 – 'sometimes', 3 – 'often'. Using scores collated from the BRIEF-2 an overall 'global executive composite' can be calculated, as well as the five scales present within the BRIEF-P ('inhibition', 'shift', 'emotional control', 'working memory', and ''plan / organise') and four additional subscales; 'self-monitor',

'initiate', 'task-monitor' and 'organisation of materials'. Higher scores across these subscales suggest areas of clinical difficulties that warrant further exploration. As with the BRIEF-P, *T* scores can be generated based upon individuals gender and age and were used within the current study. The BRIEF-2 has good internal and construct validity (Gioia, Isquith, Retzlaff, & Espy, 2002).

Emotional and Behavioural Difficulties;

The Strengths and Difficulties Questionnaire (SDQ)

The Strengths and Difficulties Questionnaire (SDQ) is a behavioural screening questionnaire consisting of 25 items suitable for children and adolescents ages 3 – 18 years (Goodman, 1997). These items describe emotional and behavioural differences (e.g. 'Considerate of other people's feelings') and are answered on a three point scale; 'not true', 'somewhat true' or 'certainly true'. Scores are generated across 5 subscales: 'emotional symptoms', 'conduct problems', 'hyperactivity-inattention', 'peer problems', and 'prosocial behaviour'. 'Externalising' and 'internalising' scores can also be generated by combining relevant subscales, and a 'total difficulty score' can also be calculated. The SDQ is used widely across research and clinical settings, and was used within the current study to explore behavioural and emotional difficulties. The 'impact supplement' was not used within the current study to reduce participant burden given the breadth of questions used across the online survey. An adapted version is recommended for 3 and 4 year olds (whereby the phrasing differs on 3 items), and was used where appropriate within the current study. The SDQ has been shown to have good internal reliability within the general population (Niclasen et al., 2012).

3.4.3 Data Analysis

Data were assessed using a combination of Statistical Package for Social Sciences (SPSS) 26.0 software and STATA 17.0 statistical software packages. Normality statistics of data were first assessed using Shapiro-Wilk tests. Due to the dataset significantly deviating from normal distributions ($p < .05$), non-parametric alternatives were employed. Where appropriate, data were corrected for multiple comparisons.

Throughout this study, age will be considered as a categorical variable for multiple reasons. Firstly, it is recommended that in clinical and public health contexts data should be grouped into meaningful categories of age (rather than treated as a continuous variable) to provide meaningful and actionable outcomes (Sigelman and Rider, 2014). Within the current study, age groups were formed based upon categories within the UK national curriculum to facilitate efficient translation from research into practice.

Secondly, though alternate age-appropriate measures of similar constructs were used, these remain alternate measures. Combining these in a statistical sense (as well as in a descriptive sense) is not a validated method of handling data. Therefore, both the measures used, and age group of focus will be appropriately detailed at each stage of the results section. While at points for clarity participant data will be presented next to each other, this is purely to provide a descriptive comparison.

To address aim i) and describe the profile of social abilities, executive functions and emotional behaviours within a sample of children born MLPT, the percentage of participants scoring above threshold on screening measures were first explored. For participants who

completed the BRIEF-P, scores could be classified into a singular category indicating *T* scores are elevated past 1.5 standard deviations when compared to normative scores. For participants who completed the BRIEF-2, scores could be classified into three categories indicating *T* scores are elevated past one standard deviation when compared to normative scores.

To address aim ii) and explore how the profile of social abilities, executive functions and emotional and behavioural difficulties differ across the developmental trajectory within a sample of children born MLPT, participants were divided into three age categories to explore emotional and behavioural profiles throughout early childhood. Age groups were derived based upon United Kingdom national curriculum key stages as a method of comparison; 1-3 years (N=36), 4-6 years (N=32) and 7-11 years (N=16). Kruskal Wallis tests were used to compare data between age groups on measures collected. Significant differences were explored through non-parametric Mann Whitney post hoc analyses, with significance values adjusted to account for multiple comparisons using the Bonferroni correction (Dunn, 1961).

To address aim iii) and explore the similarities or differences between those born MPLT and their peers on a measures of social behaviours, normative data collated as part of the SRS-2 standardisation study were used (Constantino & Gruber., 2012). Within the reference study, data were divided into three categories; those that completed the pre-school age parent form (N = 227), those that completed the school age parent form whose child was male (N = 493) and those who completed the school age parent form whose child was female (N = 518). The current sample was therefore categorised accordingly to assist comparisons: pre-school (N = 36), school age male (N = 16) and school age female (N = 32). Welch's unpaired t-tests were employed to explore differences between the current sample and normative data collected as part of the SRS validation study.

To address aim iv) and explore the association between executive functioning skills and social behaviours within children born MLPT, Spearman rank-order correlation coefficients were first conducted to explore the potential relationship between executive functions and subscales of the SRS. A conservative p value of $p<.001$ was adopted to interpret significance given multiple comparisons. The SRS was chosen for these analyses as unlike the MCHAT or SCQ, the SRS documents social behaviours on a continuous scale.

A structural equation model exploring the association between BRIEF 'global executive composite' scores and a latent variable 'social communication and interaction' was created to further explore this relationship. The latent variable 'social communication and interaction' was comprised of the subscales 'social awareness', 'social cognition', 'social communication' and 'social motivation', and is drawn from studies using normative SRS-2 data (Constantino & Gruber., 2012)[5]. Goodness of fit for the proposed model was first considered through the inspection of various model fit indices (chi-squared, RMSEA, pclose test, TLI / CFI and SRMR value), before the proposed model was explored.

[5] The SRS has been shown to fraction in a stable way, with a factor analysis using normative population level data indicating a good fit for combining observed constructs into the latent factor of 'social communication and interaction' (Constantino & Gruber., 2012), hence its use in this way within the current study.

3.5 Results

3.5.1 Demographic characteristics of the sample

Prior to hypothesis testing, the demographic characteristics of the sample and respondents who completed the online survey were explored. Participants were given the option to document their experiences of the Covid-19 pandemic in the form of an additional questionnaire.

Distribution of country of residence of parents is outlined in Table 3.2, with 71% of respondents based in the United Kingdom. All informants were mothers, and the mean number of adults (2.0) and children (1.9) within households did not significantly differ across countries.

Table 3.2: Household characteristics of sample (N = 84)

Country of residence % (N)	
England	57 (48)
Northern Ireland	2.4 (2)
Scotland	7.1 (6)
Wales	4.8 (4)
Guernsey	1.2 (1)
Finland	1.2 (1)
Norway	1.2 (1)
United States	2.4 (2)
Australia	1.2 (1)
New Zealand	21.4 (18)
Relationship to child % (N)	
Mother	100 (84)
Household Mean *(SD)*	
Adults in household	2.0 (*0.3*)
Children in household	1.9 (*0.7*)

Parents and caregivers self-described education and household income, detailed in Table 3.3. Over half of respondents (57.1%) had completed 3 or more 'A' Levels, NVQ 3, BTEC National, or equivalent with a proportion of respondents (34.4%) living within a household with a combined income of £65,001 or more.

Table 3.3: Educational and financial characteristics of parents & caregivers of those who participated (N = 84)

No formal educational qualifications	2.3 (2)[1]
Fewer than 5 GCSE's or O Level's (grades A-C), NVQ 1, or BTEC First Diploma	1.2 (1)
5 or more GCSE's or O Level's (grades A-C), NVQ 2, or equivalent	8.3 (7)
3 or more 'A' Levels, NVQ 3, BTEC National, or equivalent	14.3 (12)
Polytechnic/University degree, NVQ 4, or equivalent	57.1 (48)
Masters/Doctoral degree, NVQ 5, or equivalent	16.7 (14)
Less than £15,000	3.6 (3)
£15,001 to £25,000	6 (5)
£25,001 to £35,000	7.1 (6)
£35,001 to £45,000	10.7 (9)
£45,001 to £55,000	13.1 (11)
£55,001 to £65,000	13.1 (11)
£65,001 or more	34.5 (29)
Prefer not to say	11.9 (10)

[1]All results displayed as % (N)

Moderate or Late Preterm Children

Demographic characteristics of the 84 children included in the final sample are summarised in Table 3.4. Participants were primarily female (60%) and from singleton

pregnancies (80%). Mean APGAR scores for the cohort at each time point fell within the 'reassuring' category (≥7) indicating little immediate concern regarding physical health (Casey, McIntire, & Leveno., 2001). Contrary to this, 86.9% of the cohort were admitted to neonatal intensive care facilities with 38.1% requiring the use of a ventilator to assist breathing. A small proportion had intracranial haemorrhages (4.8%) or required surgeries within the first year of life (8.3%). Breastfeeding was more common amongst the sample than formulae feeding (75% and 23.8% respectively).

Table 3.4: Participant and family characteristics of the 84 participants in the final sample

Participant Characteristics	
Male % (N)	40.5 (34)
Gestational Age at birth Mean (*SD*)	33.4 (*1.3*)
Birth weight (kg) Mean (*SD*)	2.01 (*0.5*)
Head Circumference Mean (*SD*)	28.74 (*5*)
Part of a multiple pregnancy % (N)	20.2 (17)
Twins	100.0 (17)
Maternal age at birth (years) Mean (*SD*)	31.3 (*4.5*)
APGAR Score Mean (*SD*)	
1 minute	8.0 (*1.5*)
5 minutes	9.3 (*1*)
10 minutes	9.9 (*0.4*)
NICU Stay % (N)	86.9 (73)
Ventilator % (N)	38.1 (32)
Neonatal Surfactants % (N)	25.0 (21)
Intracranial haemorrhages % (N)	4.8 (4)
Surgeries within first year % (N)	8.3 (7)
Breastfed % (N)	75.0 (63)
Formula % (N)	23.8 (20)

Covid-19

55 participants (65.5%) detailed their experiences of the Covid-19 pandemic as outlined in Table 3.5. Changes in educational activities, daily routines and electronic device use were common. Families reported more time spent together, potentially linked with a 42% increase in home working. A considerable proportion of respondents reported members of their household experiencing symptoms (37%) with a smaller number reporting positive cases of Covid-19 within the household (14.1%).

Table 3.5: The impact of Covid-19 on participants within the current study (N = 55)

Education	
Changes to nursery or school attendance	24.1 (13)[1]
Children still participating in educational activities at home	75.2 (41)
Daily Routines	
Parents or caregiver is now working from home	42.6 (23)
Loss of employment as a result of the pandemic	7.4 (4)
Spending more time together as a family	70.4 (38)
Electronic Device Usage	
Children spending more time on devices for educational purposes	16.7 (9)
Children spending more time on devices for leisure	44.4 (24)
Health	
Members of household have experienced symptoms	37.0 (20)
Members of household have tested positive	14.1 (8)
Family have experienced bereavements (family or friends)	9.3 (5)
Changes in children's typical sleep pattern	14.1 (8)

[1]All results displayed as % (N)

3.5.2 Profile of Behaviours

In order to address hypothesis i), the profile of social and emotional behaviours within a sample of children born MLPT was explored.

Prevalence of social differences according to published cut-offs

Participants were split into two categories based on their age and subsequent age-appropriate screening tool[6] completed (MCHAT, SCQ, SRS-P or SRS-2). The percentage of individuals that either fell into clinical 'at risk' categories or scored above clinical thresholds for autism are presented in Table 3.6. For participants that completed the MCHAT, the majority of participants scores indicated they were 'low risk' (77.8%) with 16.7% being categorised as 'moderate risk' and 5.5% as 'high risk'. For participants who completed the SCQ, 97.9% of participants scored below 15 with one participant scoring above 15 ('autism spectrum disorder' cut off) and no participants scoring 22 or above ('autism' cut off). Calculated *T* scores on the SRS-2 revealed for those who completed the pre-school questionnaires, 8.3% showed moderate but clinically significant differences in social skills and 2.8% showed severe differences that were clinically significant and highly impactful within everyday life. For participants who completed the school aged version of the SRS-2, 8.3% showed mild differences in social skills, 16.6% showed moderate but clinically significant differences in social skills and 2.0% showed severe differences that were clinically significant and highly impactful within everyday life.

[6] The SRS-2 is a descriptive profiling tool that aims to capture variability between profiles of behaviour and does not provide clinical cur-off scores for 'autism' in the same way as the MCHAT / SCQ. Given validated cut off scores that direct clinicians to those who may benefit from further assessment are presented within the current study, the SRS-2 is presented alongside the MCHAT / SCQ and described as a 'screening tool' for brevity.

Table 3.6: Participants scores on age-appropriate screening measures for autism characteristics[1]

	Aged 1.5 – 3yrs (N = 36)	Aged 4 – 11yrs (N = 48)
MCHAT %		
Low Risk	77.8 (28) *14:14*	-
Moderate Risk	16.7 (6) *2:4*	-
High Risk	5.5 (2) *2:0*	-
SCQ %		
Below threshold (<15)	-	97.9 (47) *16:31*
'autism spectrum disorder' (≥ 15)	-	2.0 (1) *0:1*
'autism' (≥ 22)	-	-
SRS -2[2]		
'Within normal limits' (<60T)	88.9 (32) *15:17*	72.9 (35) *13:22*
'Mild range' (≥ 60T to <65T)	0	8.3 (4) *0:4*
'Moderate range' (≥ 66T to <75T)	8.3 (3) *3:0*	16.6 (8) *2:6*
'Severe range' (≥ 76T)	2.8 (1) *0:1*	2.0 (1) *0:1*

[1]All results displayed as % (N) *Male: Female*

[2]*T* scores calculated from the age-appropriate SRS completed

Prevalence of executive functioning differences and emotional and behavioural difficulties according to published cut-offs

Participants' standardised scores for each of the five comparable subscales and the global executive complex of the BRIEF can be seen in Table 3.7. *T* scores are presented

alongside standardised published categories based upon participant's age (and therefore version of the BRIEF they completed).

For the 59 participants that completed the BRIEF-P, a proportion of participants scores fell into the 'abnormally elevated' category (shift – 20.3%; plan / organise – 16.9%; emotional control – 18.6%; working memory – 30.5%; inhibition – 15.3%), with 22% of participants having global executive scores that were 'abnormally elevated', indicating an increased likelihood of executive dysfunction.

For the 25 participants that completed the BRIEF-2 a minority scored in the 'potentially clinically elevated' (inhibit – 12%; shift – 16%; emotional control – 16%; working memory – 4%; plan / organise – 16%) or 'clinically elevated' range (emotional control – 28%; shift – 20%; inhibit – 12%; working memory – 16%; plan / organise – 16%). A proportion of participants (16%) had global executive complex scores that fell into the 'clinically elevated' category indicating an increased likelihood of clinical executive dysfunction.

Table 3.7: Participants scores on age-appropriate measures of executive functioning abilities[1]

	Inhibit	Shift	Emotional Control	Working memory	Plan / Organise	Global Executive Complex
Aged 1.5 – 5yrs						
≥65, 'abnormally elevated'	15.3 (9), *2:7*	20.3 (12) *2:10*	18.6 (11) *4:7*	30.5 (18) *6:12*	16.9 (10) *3:7*	22.0 (13) *4:9*
Aged 6 – 11yrs						
>60 - ≤64 'mildly elevated'	4.0 (1) *0:1*	-	-	8.0 (2) *1:1*	8.0 (2) *0:2*	8.0 (2) *0:2*
>65 - ≤69 'potentially clinically elevated'	12.0 (3) *2:1*	16.0 (4) *1:3*	16.0 (4) *3:1*	4.0 (1) *0:1*	8.0 (2) *2:0*	16.0 (4) *0:4*
≥70 'clinically elevated'	12.0 (3) *1:2*	20.0 (5) *1:4*	28.0 (7) *1:6*	16.0 (4) *2:2*	16.0 (4) *1:3*	16.0 (4) *3:1*

[1]All results displayed as % (N) *Male: Female*

The percentage of participants that fell into each of the four categories for their overall and standardised subscale scores of the SDQ are presented in Table 3.8. The majority of participants overall SDQ score fell into the 'close to average' category (69%), with some participants scores being 'slightly raised' (13.1%), high (8.3%), or very high (9.5%). For all subscales, scores were evenly distributed across the four categories with the majority of participants scores falling into the 'close to average' category (emotional problems – 75.0%; conduct problems – 53.6%; hyperactivity – 67.9%; peer problems – 72.6%). For the conduct problem subscale, participants scores were more evenly dispersed across the higher three categories; 'slightly raised' – 15.5%; 'high' – 29.8% very high – 1.2%. The prosocial subscale is negatively scored and thus is categorised differently. The majority of participants' scores on the prosocial scale were categorised as 'close to average' (53.6%), with the remaining participants scores dispersed across the remaining three categories; 'slightly lowered' (14.3%), 'low' (8.3%) and 'very low' (23.8%).

Table 3.8: Participants scores on measure of strengths and difficulties according to published cut offs[1]

	Close To Average	***Slightly Raised***	***High***	***Very High***
SDQ Total difficulties score[1]	69.0 (58) *21:37*	13.1 (11) *6:5*	8.3 (7) *2:5*	9.5 (8) *5:3*
SDQ Emotional problems score	75.0 (63) *25:38*	10.7 (9) *4:5*	10.7 (9) *4:5*	3.6 (3) *1:2*
SDQ Conduct problems score	53.6 (45) *16:29*	15.5 (13) *7:6*	29.8 (25) *11:14*	1.2 (1) *0:1*
SDQ Hyperactivity score	67.9 (57) *22:35*	16.7 (14) *4:10*	6.0 (5) *2:3*	9.5 (8) *6:2*
SDQ Peer problems score	72.6 (61) *22:39*	14.3 (12) *5:7*	2.4 (2) *2:0*	9.5 (8) *6:2*
	Close To Average	***Slightly Lowered***	***Low***	***Very Low***
SDQ Prosocial score	53.6 (45) *16:29*	14.3 (12) *6:6*	8.3 (7) *3:4*	23.8 (20) *9:11*

[1]All results displayed as % (N) *Male: Female*

To summarise, MLPT participants' scores on autism screening tools (the SCQ, MCHAT and SRS) fell broadly within the 'lower risk' / 'below threshold' ranges. Scores on measures of executive function indicated the 'shift' and 'emotional control' subscales as an area of potential clinical difficulty for MLPT participants across all age groups. 'Working memory' was a particular difficulty for children in the younger age category (age 1.5 – 5yrs). While total scores on the SDQ fell into close to average categories, conduct problems and hyperactivity appeared to be two areas of relative difficulty for those born MLPT.

3.5.3 Cross sectional exploration of the change in social abilities, executive functions and emotional and behavioural difficulties with age

In order to address aim ii) and explore social abilities, executive functions and emotional and behavioural profiles throughout early childhood within a sample of children born MLPT, participants were divided into three age categories (Table 3.9) and standardised scores across measures compared. Kruskal Wallis analyses identified significant differences between groups on all measures of executive functioning; inhibition ($\chi 2$ (2) = 28.97, p <.*001*) and working memory ($\chi 2$ (2) = 26.27, p = <.*001*). Significant differences were also found on three subdomains of the SDQ; peer problems ($\chi 2$ (2) = 10.56, p = *.005*) and prosocial behaviour ($\chi 2$ (2) = 20.07, p <.*001*). Further significant differences were also found on the subscales of the SRS; social cognition ($\chi 2$ (2) = 7.3, p = *.0026*) and social awareness ($\chi 2$ (2) = 8.6, p = *.014*).

Pairwise post hoc analysis corrected for multiple comparisons revealed significant differences between scores. For the two subscales of executive functions, two subscales of the SDQ and the social awareness subscale of the SRS significant differences were found between the 1-3yrs group and the 7-11yrs group, with those within the 1-3yrs group scoring

significantly higher across measures (indicating greater difficulty). Further significant differences were also found between the 1-3yrs group and the 4-6yrs group with two subscales of the SDQ (peer problems and prosocial behaviour) and the social cognition subscale of the SRS, significantly higher within the 1-3yrs group. Finally, across two subscales of the BRIEF (inhibition and working memory) significant differences were identified between the 4-6yrs and 7-11yrs group, with those within the 4-6yrs group scoring significantly higher across measures.

To summarise, exploration of broader behaviours such as social abilities, executive functions and social emotional behaviours show while some behaviours are more common across early childhood, others did differ between age groups, with scores frequently higher within the younger years.

Table 3.9: Behavioural profile of EF and social abilities of sample organised by age (based on UK KS) median (IQR)

	1-3yrs N = 36	4-6yrs N = 32	7-11yrs N = 16	Kruskal-Wallis H	*p* value	Post hoc[1]
BRIEF Total Global Executive Score	101.5 (30.5)	95.0 (39.0)	95.0 (57.5)	0.174	0.917	
Inhibition	26.0 (7.8)	21.0 (7.0)	12.0 (5.3)	28.965	*<.001*	1-3, 4-6 >7-11
Shift	15.5 (6.0)	15.0 (7.0)	13.5 (8.8)	3.393	0.183	
Working Memory	27.0 (11.8)	20.0 (13.0)	13.0 (9.5)	26.273	*<.001*	1-3, 4-6 >7-11
Emotional Control	15.5 (8.8)	18.0 (6.0)	15.0 (8.8)	1.014	0.602	
Plan / Organise	16.5 (7.0)	15.0 (7.0)	11.5 (9.3)	3.107	0.211	
SDQ Total Difficulties Score	10.0 (7.8)	10.0 (10.0)	9.5 (11.3)	0.073	0.964	
Emotional Problems	2.0 (2.0)	2.0 (2.8)	3.5 (5.8)	2.910	0.233	
Conduct Problems	2.0 (2.0)	2.5 (3.8)	3.0 (2.8)	2.728	0.256	
Peer Problems	2.0 (2.0)	1.0 (1.8)	0.0 (1.0)	10.555	*0.005*	1-3>4-6,7-11
Hyperactivity Scale	4.0 (4.8)	3.5 (4.0)	3.5 (5.5)	0.330	0.848	
Prosocial Behaviour	6.0 (3.0)	9.0 (3.0)	9.5 (3.0)	20.070	*<.001*	1-3<4-6,7-11
Internalising	4.0 (4.0)	3.0 (3.8)	3.5 (6.5)	1.922	0.383	
Externalising	6.0 (4.8)	6.0 (8.3)	5.0 (3.0)	0.093	0.954	
SRS Total Score	45.0 (29.3)	38.0 (34.0)	6.0 (8.0)	3.637	0.162	
Social Communication and Interaction	41.5 (23.8)	35.0 (23.0)	27.5 (47.5)	4.801	0.091	
Restricted interests and Repetitive Behaviours	4.5 (5.0)	3.0 (8.0)	4.5 (8.5)	0.457	0.796	
Social Communication	14.0 (8.8)	13.0 (13)	8.5 (18.8)	2.890	0.236	
Social Cognition	9.5 (5.8)	6.0 (7.0)	6.5 (11.5)	7.263	*0.026*	1-3>4-6
Social Motivation	8.5 (6.0)	8.0 (4.0)	4.5 (8.5)	2.704	0.259	
Social Awareness	8.5 (5.0)	7.0 (5.0)	6.0 (6.3)	8.566	*0.014*	1-3 >7-11

[1]Mann Whitney U Tests – between group differences presented that remained significant after correcting for multiple comparisons

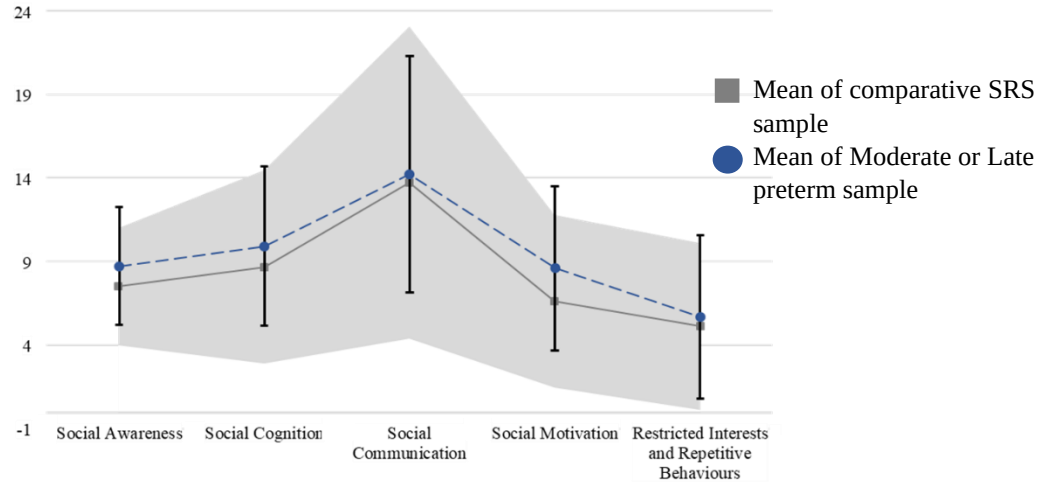
3.5.4 Comparing MLPT Children's Social Abilities to those within the general population

To address aim iii) the profile of social skills for individuals born MLPT was compared to those within the general population on a continuous measure of social abilities (SRS). Methods of comparison to the general population as described in the data analyses section were employed.

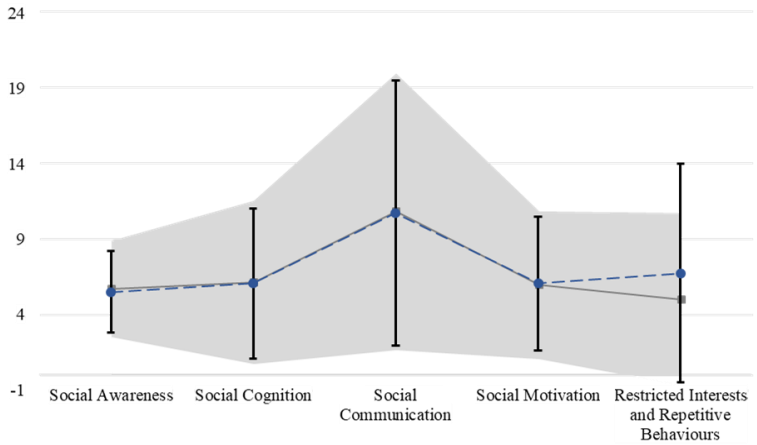
Figure 3.1 presents the means and standard deviations of the current sample across subscales of the SRS in contrast to the means and standard deviations of the normative sample and shows no evidence of difference according to visual inspection. In the preschool category, those born MLPT appear to have higher scores across all domains of the SRS except the 'social cognition' subscale where mean scores are similar to general population scores. School aged males born MLPT show similar mean scores across all subscales when compared to the normative sample apart from on the 'restricted interests and repetitive behaviour' subscale where scores within the preterm group appear elevated. School age females born MLPT show an inverse pattern to their male peers, with elevated mean scores across all domains apart from on the restricted interests and repetitive behaviour subscale.

To account for varying sample sizes and distributions, Welch's unpaired t-tests were used. Each of the means and standard deviations were statistically compared to the means and standard deviations of the normative sample across subscale domains. No significant differences across any subscale of any of the three groups showed a significant difference.

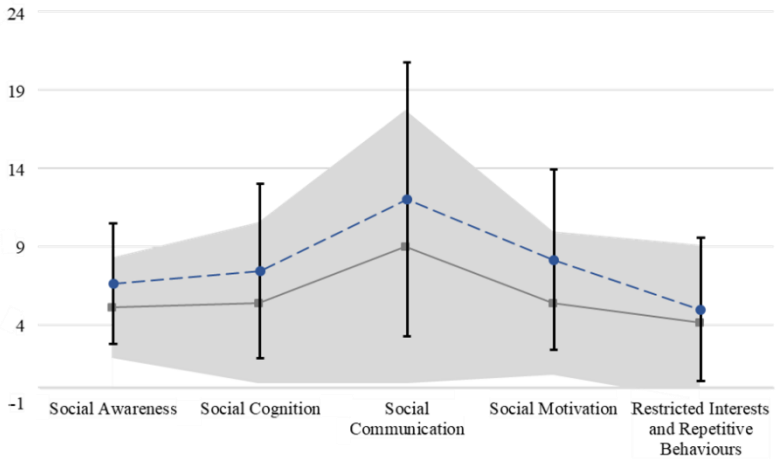
To summarise, there were no apparent differences identified through visual inspection or inferential analysis between those born MLPT and a normative population sample on the SRS.



a) SRS Preschool comparing current sample (N = 36) to normative sample (N=227)



b) SRS School Age comparing current sample of males (N = 16) to normative sample (N=493)



c) SRS School Age comparing current sample of females (N = 32) to normative sample (N=518)

Figure 3.1: Mean and standard deviation scores for subscale domains of the SRS. Grey area and line represent the standard deviation of the normative sample. Blue circles represent the MLPT means and black lines represent the MLPT standard deviations.

3.5.5 Exploring the Association Between Executive Functions and Social Abilities

To address aim iv), the association between executive functioning skills and social behaviours was explored.

Table 3.10 presents correlations between the total domain score on executive function and subscale scores across domains collected through the SRS. When considering the age range and prematurity of the current sample, chronological and gestational age were also included in these analyses. Missing data for five participants on the BRIEF scales resulted in 79 participants' data being used in this analysis.

Participants' age or gestational age was not significantly correlated with any of the SRS domains. BRIEF 'Global Executive scores' (GEC) and all subscales significantly correlated ($p<.001$) with the 'Social Communication and Interaction' and 'Social Communication' subscales of the SRS. 'Inhibition', 'Working Memory' and 'Plan / Organise' were significantly positively correlated ($p<.001$) with all subscales of the SRS. 'Shift' and 'emotional control' were significantly positively correlated ($p<.001$) with all subscales of the SRS apart from 'Social Awareness'.

To evaluate aim iii) further and the association between executive and social functioning, a structural equation analysis was performed (Figure 3.4). On the basis of multiple significant correlations identified using Spearman rank analysis, the BRIEF 'global executive complex' was entered into the model as an observed variable. The latent factor 'social communication and interaction' was derived from the SRS manual whereby a factor analysis indicated a good fit for combining observed constructs in this way when using normative population level data (Constantino & Gruber., 2012).

Table 3.10: Correlations of executive function global and subscale scores with SRS total and subscale scores

	SRS Total Score	Social Communication and Interaction	Restricted interests and Repetitive Behaviours	Social Communication	Social Cognition	Social Motivation	Social Awareness
Age Exact	-.02	-.03	-.05	-.21	-.28	-.19	-.33
Gestational Age	-.03	.02	-.13	-.01	-.02	-.02	.02
BRIEF Total Global Executive Score	**.76***	**.76***	**.67***	**.71***	**.66***	**.54***	**.59***
Inhibition	**.50***	**.50***	**.48***	**.50***	**.49***	**.37***	**.49***
Shift	**.47***	**.47***	**.43***	**.44***	**.43***	**.51***	.24
Working Memory	**.55***	**.54***	**.49***	**.54***	**.58***	**.41***	**.58***
Emotional Control	**.47***	**.46***	**.45***	**.38***	**.39***	**.38***	.28
Plan / Organise	**.55***	**.56***	**.49***	**.50***	**.58***	**.42***	**.52***

* $p<.001$

Calculated for 79 participants, N=5 missing BRIEF data

Model inspection across all five measurement estimates showed a high goodness of fit. Chi-squared goodness of fit tests were non-significant, $\chi 2(5)= 0.93$, $p=.968$, suggesting good model fit of the model to the data. Inspection of the RMSEA indicates a small value (<.001) that is considerably under accepted estimates of fit (Pituch et al., 2016: RMSEA <.08). The pclose test was non-significant (0.979) indicating the model did not deviate significantly from one that is a close fit to the data. The TLI (1.034) and CFI (1.00) indicated very good fit relative to thresholds of an acceptable model (Weston & Gore, 2006). SRMR values were low (0.010) again indicating good fit (Pituch et al., 2016: SRMR <.05).

BREIF GEC was a significant positive predictor of 'social communication and interaction' (β =.78, SE= .042, $p<.001$). 'Social communication' (β =.87, SE= .032, $p<.01$) and 'social cognition' (β =.89, SE= .030, $p<.01$) significantly loaded onto the latent factor of 'social communication and interaction'. Contrastingly, 'social awareness' (β =.80, SE= .043, $p=.08$), and 'social motivation' (β =.68, SE= .062, $p=.06$) did not significantly load onto the latent factor of 'social communication and interaction' as presented within the SRS manual.

To summarise, the association between executive functioning skills and behaviours for a sample of MLPT participants was presented. There were multiple significant correlations between subscales of the BRIEF and SRS. A further structural equation model highlighted that BRIEF 'GEC' was a significant positive predictor of 'social communication', with 'social awareness' and 'social motivation' not significantly loading onto the latent factor of 'social communication and interaction' as expected.

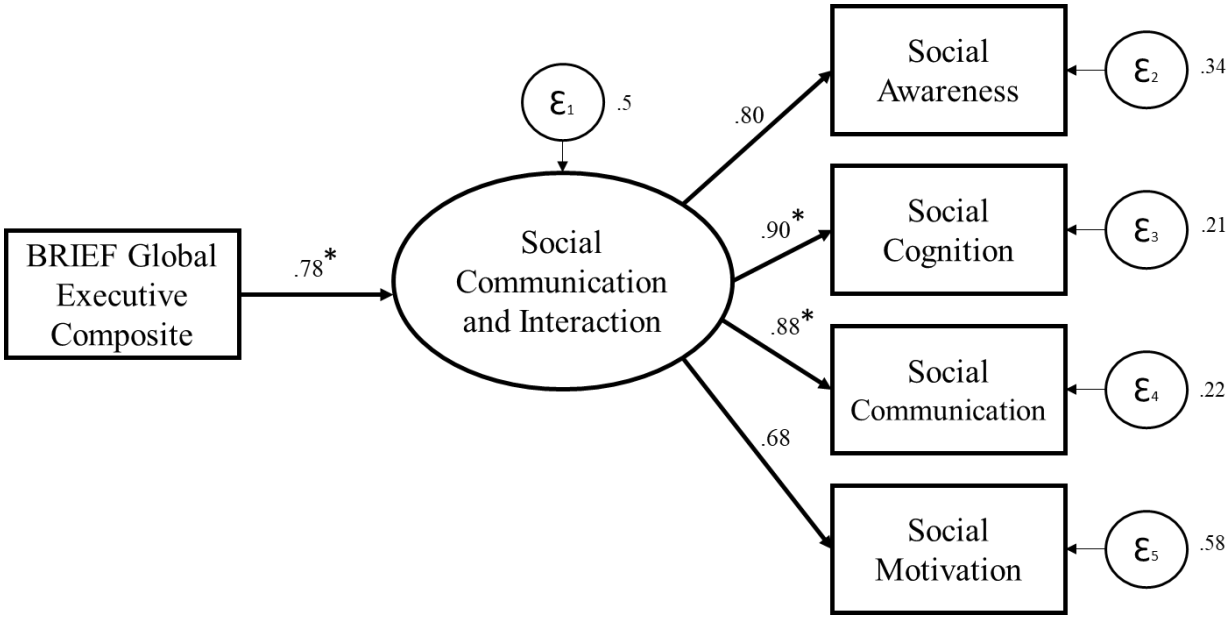


Figure 3.2: Structural equation model exploring the association between BRIEF global executive composite scores and the latent factor 'social communication and interaction' derived from the SRS-2 manual (Constantino & Gruber., 2012)

To summarise, results delineate the prevalence and profile of a range of behavioural differences in a sample of children born moderately or late preterm. Figure 3.3 provides a visual summary of group level profiles discussed in depth within this section, each of which are considered in turn within the discussion.

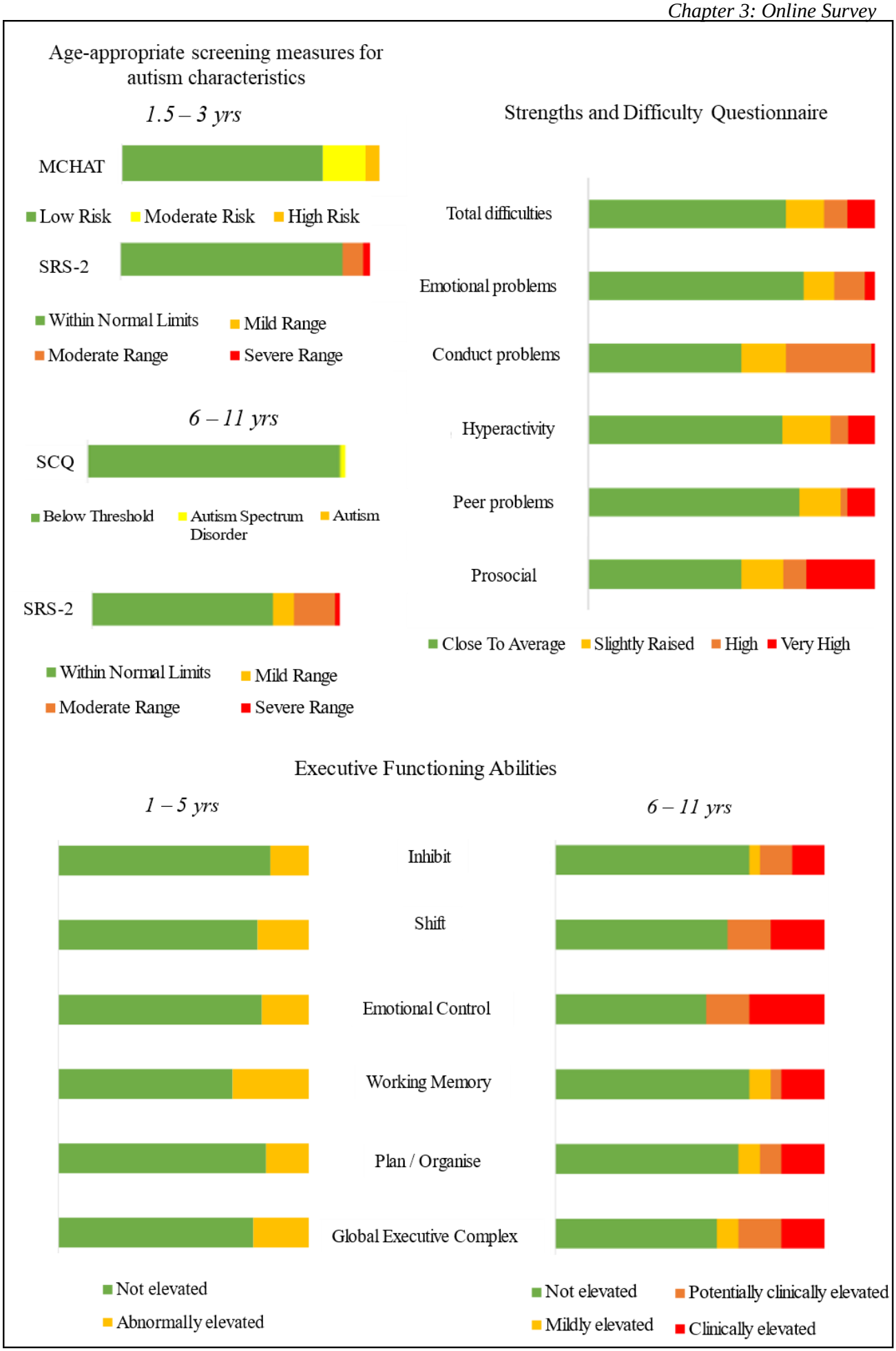


Figure 3.3: Visual summary of the behavioural profile of moderate and late preterm children. Each bar represents the percentage of the MLPT scoring in each domain of each measure. Every measure is split into subgroups of children that scored within validated categories (all totalling 100% together). These subcategories are represented by a colour defined in the associated key.

3.6 Discussion

This study detailed the prevalence and profile of a range of social differences, executive functioning and emotional and behavioural difficulties in a sample of children born MLPT. The use of carefully selected age-appropriate measures to explore such behaviours facilitated documentation of a comprehensive profile of the strengths and difficulties of a sample of MPLT participants for the first time (see figure 3.3 for visual summary). Social behaviours were considered at an individual time point and in contrast to an appropriate reference group allowing for a complete developmental trajectory to be considered. Multiple validated measures were used to assess social skills, with comparisons made to a published normative population sample. A comprehensive profile of behaviours is therefore presented, with clinical and theoretical considerations discussed in turn.

A key aim of the current study was to explore the prevalence of autism characteristics using the three validated measures. Within this sample of MLPT children, only a small proportion reached published cut-offs on age-appropriate screening tools (MCHAT – 'high risk' = 5.5%; SCQ - $\geq$15 = 2%). An increased number of participants met threshold for displaying clinical differences that impact daily social interactions (SRS - 'moderate or severe clinical differences' = 15.5%), although this still only represented a small proportion of the overall sample. Findings offer important clinical insight into the utility of screening programmes and potential subthreshold difficulties for those born MLPT. Current findings support the feasibility of widespread screening programmes to identify individuals for whom advanced neurodevelopmental follow up may be warranted. These questionnaire measures are quick to administer and would provide meaningful information for clinicians to tailor further neurodevelopmental assessment and support. Ultimately, the MCHAT, SCQ and SRS are all

indirect measures of behaviour. Future research should endeavour to combine these measures with direct observations (Bruni., 2014), to provide further information about both their performance across preterm groups *and* their validity towards describing a profile of behaviours. Clinical services should consider adopting routine population level screening for populations that may display greater need for neurodevelopmental follow up (such as those born preterm [Chapter 2]), to help identify individuals and provide support in a timely manner.

In direct contrast with the apparent utility of routine clinical follow up is the structure of clinical services and neonatal follow up in the UK. Current provision almost exclusively focusses on those born at the earliest gestations rather than at a population level. NICE guidelines indicate children born ≤28 weeks are at increased risk for a later diagnosis of autism with enhanced developmental surveillance therefore recommended *only* for those born ≤30 weeks (McKinnon & Huertas-Ceballos, 2019). Whilst a large proportion of the current sample did not meet threshold for additional neurodevelopmental follow up, the use of validated screening measures with high levels of sensitivity identified the handful of children that may warrant further support. The proposal for population-based screening for children born preterm (inclusive of gestational ages >30 weeks), is made within the consideration of the current findings *and* the current global context. Throughout the Covid-19 pandemic, while some services report successful adaptation ensuring digitally driven service provision (Reddy & Brumpton, 2021), emerging evidence highlights the *negative* impact the Covid-19 pandemic has had on access to timely services provision, support and clinical waiting lists (Topriceanu et al., 2021). Given the growing need to stratify those that are in greatest need of further neurodevelopmental assessment efficiently, screening tools such as those used within

the current study offer a solution to facilitate early identification. It is important that screening tools used in clinical practice should be augmented by a range of behavioural evaluations to determine what is most beneficial for each individual MLPT child. However, the use of widespread neurodevelopmental screening to facilitate early identification within the current global context is warranted.

Further exploration of the social cognitive profile of MLPT children compared to the general population showed no apparent differences through visual inspection or inferential analysis on subscales of the SRS. This parallels the previously held narrative that often described MLPT children as presenting similarly to their full term peers (Shah, Robbins, Coelho, & Poehlmann, 2013). Yet, when compared with dichotomous screening tools (MCHAT and SCQ), a higher proportion of those born MLPT displayed clinical differences that impact daily social interactions. This raises an important consideration surrounding the identification of and support for subthreshold behaviour differences that impact daily living for individuals without meeting criteria for a formal diagnosis. Evidence of an increase in subthreshold differences has been shown for adolescents born extremely preterm whereby a greater number of individuals score on autism screening tools than receive a formal autism diagnosis (O'Reilly et al., 2021). Those born very preterm are also at an increased likelihood to score highly on measures assessing ADHD characteristics (Montagna et al., 2020). Current findings may offer insight and support towards a more transdiagnostic model of understanding differences. Clinically meaningful behaviours that impact daily living may warrant support, regardless of formal diagnosis. The proportion of the current sample scoring on a broader measure of individual social differences warrants further research that moves beyond parental report measures. Future research should use objective behavioural

assessments to compare those born preterm with those born full term to gain a comprehensive understanding of differences that warrant further clinical support.

In addition to delineating the profile of social behaviours, the profile and fluctuation with age of executive, emotional and behavioural differences was explored through the BRIEF and SDQ. When looking broadly at executive difficulties (as measured by the BRIEF-P and BRIEF-2), a handful of participants scored within the abnormally or clinically elevated categories for each of the calculated sub scales. Though statistically a distribution of scores is to be expected when sampling, T scores for those born MLPT in the current sample appear slightly elevated in comparison to previously reported samples of school aged children (Dekker et al., 2017). In particular, for participants that completed the BRIEF-P, 'working memory' presents as a particular area of difficulty, whereas 'emotional control' and 'shift' were areas of difficulty for slightly older children (as measured by the BRIEF-2). Contrastingly, when looking broadly at emotional and behavioural difficulties (as measured by the SDQ) the distribution of scores for those born MLPT in the current sample appears consistent with general population school aged children with the exception of the 'conduct problems' subscale which was elevated compared to the general population (Wright et al., 2020). Taken together, these findings support wider research with extremely preterm children that links difficulties in executive function with problem behaviours (Scott et al., 2012), although it is not immediately evident if this profile is unique to children born MLPT or displays variation that would be expected among full term children of similar ages. Given the putative links between executive functioning, emotional and behavioural differences and social functioning, possible explanations and implications will be discussed in turn.

First, the pattern of observed scores in the present study could reflect broader developmental differences for those born MLPT. Age related executive functioning abilities were significantly higher in older children compared to younger participants both in terms of global and subscale scores, with younger participants presenting higher scores, indicative of greater difficulty, than older participants. This contributes towards a growing body of evidence in the wider preterm literature demonstrating a delay rather than deficit in executive functioning abilities (Ritter et al., 2013). Similar patterns are seen on two of the seven subscales of the SDQ, with peer problems and prosocial behaviour scores significantly decreasing over time. Similarly, regarding SRS scores, there were significant decreases on two of the six subscales with social cognition and social motivation scores significantly decreasing over time. These findings potentially indicate that there are aspects of abilities, namely executive functions and areas of social and emotional behaviours, which progressively fluctuate with age. Although these findings are drawn from cross-sectional rather than longitudinal analysis, they provide a clear snapshot of areas in which service provision or support could be warranted and provides a stable foundation for longitudinal research to replicate findings. While many behaviours remain low and stable across childhood within our sample, internalising and externalising behaviours are areas of concern with no natural decline noted across the cross-sectional groups. Such behaviours have been shown to predict both later peer problems and use of antidepressants within preterm cohorts (Carlson et al., 2004). These difficulties seemed to co-occur with stable yet high scores of social communication and interaction and social motivation differences as evidenced in other MLPT cohorts (Cheong et al., 2017). Taken together, these findings highlight both areas in which MLPT children appear to show a delay rather than a deficit in executive functioning abilities, as well as some behavioural abilities for which targeted intervention may be beneficial. The

prevalence and stability of internalising and externalising behaviours measured within this cohort of MLPT challenge the traditional approach to neonatal follow-up and, evidence the necessity of routine follow up provision for children born between $32^{+0/7}$ - $36^{+6/7}$ weeks gestation.

Additionally, given the disparity noted between younger and older MLPT children within the current study, the context that data collection took place during the Covid-19 pandemic is important. Given the early years are formative in terms of social development, the differing experiences of younger children specifically should be considered. The degree to which the Covid-19 pandemic impacted the social and behavioural outcomes of those whose early years were characterised by mask wearing and disrupted social interactions and routines will only become apparent with time (Charney et al., 2021; Green et al., 2021). The sample of participants presented here, the majority of which were based in the UK and collated at the height of UK national lockdowns, present a unique and important starting point for further longitudinal research.

A final consideration when interpreting the profile and fluctuation of executive and emotional behaviours within the current sample relates directly to the practicalities of measuring these abilities. Universally, younger participants within the current sample scored higher on measures than older participants. This may represent a particular challenge in the use of parent report measures to specify difficulties within the early years. For executive functioning abilities, two age-appropriate versions of the BRIEF were administered with calculated T scores providing a means for comparison. The BRIEF-P (suitable for pre-school aged children) was developed specifically in acknowledgement of the varying development and presentation of these abilities in the early years and the benefit of assessing such skills through informant report measures that capture behaviour across contexts (Gioia et al., 2003).

Although an entirely separate version of the SDQ for younger participants does not exist, an adapted version with a handful of age-appropriate modifications was used within the current study. Early development is complex, and as such the identification of behavioural difficulties solely through a parent report measure is challenging. It is also acknowledged that informant report of executive function does not always converge with direct measures of executive function (Ten Eycke & Dewey., 2016). As such, it is widely recommended that developmental screeners and developmental monitoring are adopted *together* to best identify and support children for whom early intervention may be beneficial (Hirai et al., 2018). Given interpretations solely from parent report measures are limited and subjective, future research should combine the use of such measures with direct behavioural assessments. This would provide a more conclusive understanding of both the profile of MLPT children's behaviour *and* the way in which these measures generalise to wider behavioural functioning.

Additional analysis of the potential association between executive functioning skills and social communication showed high positive correlations; higher scores on the BRIEF with the exception of inhibition, were significantly correlated with higher scores on the SRS. Uncovering this association for those born MLPT is important as it suggests these abilities may have a large influence on social differences within this group. Findings within the current study are consistent with longitudinal evidence from preterm populations. Research demonstrates that impairments in executive functioning abilities persist into adolescence with the exception of inhibition difficulties which appear more transient (Aarnoudse-Moens et al., 2012). Interestingly, within the MLPT sample presented here, inhibition significantly correlated with the restricted and repetitive behaviours and social motivations subscales of the SRS. Poor inhibition has been associated with brain abnormalities as a result of preterm birth

(for example cerebral lesions; [Katz et al., 1996] and white matter abnormalities; [Edgin et al., 2021]). These medical consequences are notably less frequent amongst MLPT born neonates than their earlier born peers. Further longitudinal research that employs direct assessment of executive function, in combination with additional direct neurocognitive measures such as EEG or MRI would be valuable to explore links between early brain development and later executive functions and social abilities to improve causal models.

The creation of a simple structural equation model to explore the direct association between global executive function skill and social communication revealed that these abilities were directly and significantly associated. 'Global executive composite' scores were used to account for both a smaller sample size and in acknowledgement of the fact that executive functioning abilities are rarely measured in isolation (Van Eylen et al., 2015). A significant positive association highlights that these abilities are important in relation to social communicative abilities. Yet, the strength of the association suggests there are clearly other non-measured factors that could be contributing to the latent variable of 'social communication and interaction'. This finding is supported by direct measures of such skills, with differences regarding social cognitive skills consistent even after controlling for the effects of executive functioning (Marleau et al., 2021). The latent variable 'social communication and interaction' was taken directly from normative data derived from the SRS (Constantino & Gruber, 2012). Interestingly within the MLPT sample, the model presented an alternate loading of variables onto the latent factor 'social communication and interaction' such that 'social awareness' and 'social motivation' did not load significantly onto the latent factor. This suggests that these behaviours may cluster in a different pattern in the MLPT sample compared to the normative population data. For those born MLPT, social awareness

and social motivation capabilities may be weaker drivers of social communication than in the general population. Given that these analyses within the current study allude to nuanced differences in the association between executive functions and social abilities, further direct behavioural assessments of these skills is necessary to corroborate and expand upon the emerging profile first characterised in this study.

There are some important limitations to consider when interpreting the results presented. Firstly, the high proportion of females within the current MLPT sample which could in part explain findings such as social awareness and social motivation not loading onto the latent variable of social communication and interaction in the structural equation model in a predictable way. Females have been shown to receive scores indicative of less difficulty on measures of social awareness than their male peers in the general population (Lai et al., 2015). Further research using direct observational data is required to determine whether the modelling outcomes in this study were driven by the specific measures used or the high proportion of females within the current sample.

The MLPT children included in the current study sample and normative sample gathered within the SRS validation study were not matched, which introduces some additional limitations (Constantino & Gruber, 2012). From a population perspective we might also anticipate that roughly 106 of the 1238 participants within the normative population cohort were born MLPT given current population estimates (Shapiro-Mendoza & Lackritz, 2012). Since this was not controlled for, comparisons to the broader population inclusive of all gestations would have diminished observed differences. If, as the current findings suggest, the

presentation of social differences in those born MLPT when directly compared to those within the general population is subtle, the potential for social differences should be highlighted and adequate support made available that is suitable to even the most nuanced presentations.

To conclude, this study described the prevalence of social abilities, emotional and behavioural difficulties and executive functions within a sample of MLPT children. Though a small proportion of participants reached threshold for clinical difficulties on validated measures of social differences, some discrepancies across measures warrant further behavioural investigation of these abilities. The association between social skills and executive function abilities specifically within this under researched group warrants further detailed exploration.

CHAPTER FOUR

A QUALITATIVE INTERVIEW WITH PARENTS AND CAREGIVERS OF MODERATELY OR LATE PRETERM INFANTS

4.1 Preface

Using a methodologically robust meta-analysis (Chapter 2) and cross-sectional questionnaires (Chapter 3), an emerging profile of social behaviours and putative correlates has been documented. Yet so far, the broader family context has not been explored. Quantitative data presented thus far should not be considered in isolation and instead must be grounded in the qualitative experiences of families of children born preterm. Therefore, this chapter addresses aim three of the thesis, through a qualitative interview exploring mothers' experiences, thoughts and emotions around having a MLPT born infant. The entire journey of pregnancy through to coming home and starting school is explored, with parents detailing areas in which they feel future service provision could be targeted.

4.2 Introduction

The neurodevelopmental and behavioural impact of preterm birth has been well explored so far within this thesis. Data in previous chapters demonstrates a higher prevalence of autism characteristics within those born preterm (Chapter 2), yet only a small proportion of those born MLPT reach formal cut offs on validated measures (Chapter 3). Whilst exploring 'outcomes' in terms of behavioural assessments and informant report measures provides a useful starting point from which to compare MLPT children to other groups, these approaches can be somewhat reductive and a focus on group means precludes an exploration of individual experiences. The consideration of parents' experiences is vital to ensure that research findings are relevant to the lives of families with a child born MLPT (Heneghan et al., 2017). Clinicians and policy makers have increasingly found value in the viewpoint of individuals engaging with services, with women accessing maternity care now being considered 'consumers' rather than 'patients' (Redshaw, 2008). NICE guidelines highlight the importance of the family construct in relation to preterm birth, with exploration of support services for parents and caregivers a key area where future research is recommended (Kallioinen et al., 2017). Given the intertwined nature of preterm birth and parental experience, further understanding is not only warranted but vital when considering suggestions to improve outcomes.

Despite the prevalence of preterm birth, no singular screening measure exists to identify women who may experience birth before 40 weeks (Oskovi Kaplan & Ozgu-Erdinc, 2018). Whilst medical monitoring of cervical length, foetal fibronectin testing, maternal history and health conditions can give prior indication, clinical judgement and balancing risk of medical interventions is still heavily relied upon (Suff et al., 2019). Research highlights

that families who experience a preterm birth are more likely to view their birth and postnatal experience negatively (Trumello et al., 2018) and suffer from post-traumatic stress (Karatzias et al., 2007); experiences that persist years after the preterm birth (Latva et al., 2008). The unexpected nature of early birth, coupled with anxiety surrounding maternal and/or infant health *and* a shift in expectations of parental roles mean many preterm births meet criteria for 'traumatic births' (Beck & Watson, 2008).

Even before birth, parents of preterm born babies have an experience that is atypical and potentially distressing, with increased uncertainty and elevated probability of negative experiences. There is misalignment in knowledge of preterm birth between parents and clinicians. Despite many parents noting a desire to have had prior conversations about preterm birth, clinicians disclose the outcomes of preterm birth only selectively, citing fear of reaction as one of numerous reasons to withhold information (Tesfalul et al., 2021). Given a high proportion of preterm births are both spontaneous and unpredictable, this unexpectedness alone could increase parental anxiety or distress. It is vital that more is understood about both maternal experiences of preterm birth *and* maternal understanding about outcomes following preterm birth. Such understanding would facilitate open communication and knowledge of mothers' experience of preterm birth and their child's early development to help clinicians be more confident in what is helpful to share with families.

One downstream consequence of preterm birth is a potential disruption to the process of bonding with a new-born (Guillaume et al., 2013). Within the current study, the term 'bonding' is used to denote an umbrella term encapsulating many wider psychological constructs such as 'attachment' (Wittkowski et al., 2020) and 'familiarity' (Achterhof et al.,

2022). This umbrella term has considerable utility when aiming to capture parental perspectives, and is particularly pertinent within the current study given the bonding process between a mother and baby is suggested to begin in the first trimester and extend past the baby's birth (Twohig et al., 2016). The development of bonding has been theorised to be extremely heterogenic and context dependant; some parents initially feel a strong connection with their infant and others develop a bond through a gradual process that deepens with time (Figueiredo et al., 2007). In turn, disrupted bonding has been shown to impact many areas of a child's later cognitive development, including later executive functioning skills, a consequence that extends into toddlerhood (De Cock et al., 2017). Earlier findings highlighted the distinct profile of social cognitive differences in those born MLPT alongside the association between executive functioning and social cognitive skills (see sections 3.4.4 and 3.4.5). Further understanding of mothers' experiences may help to contextualise these observations, in this instance also made by mothers, of MLPT children.

Self-efficacy, defined as the perception of ones ability to execute behaviours, is noted to heavily affect the process of bonding (Bandura et al., 1999). Within the context of development, self-efficacy may reflect a parent's ability to facilitate a child's development through control of their environment (Jones & Prinz, 2005), and is influenced by infant characteristics, educational status and maternal depression (Azmoude et al., 2015). Spending periods of time away from a new-born infant for reasons such as an extended stay in neonatal care facilities (Craig et al., 2015) or restrictions on parental visiting in hospital settings as seen during the Covid-19 pandemic (Xue et al., 2021) can impact self-efficacy and the development of bonding. For parents of preterm born infants, the spontaneity of the experience coupled with the increased likelihood of periods of time away from their new-born may reduce self-efficacy. Systems that support the development of self-efficacy and in turn

the process of bonding may be necessary as standard practice in postnatal clinical care, although more research is necessary to understand parental perspectives and to explore the utility of this approach.

Combining early birth with the context of the neonatal intensive care unit (NICU) environment is shown to significantly limit the development of initial bonding for parents of very preterm infants (Fernández Medina et al., 2018). As a clear example of environmental contexts spreading beyond the infant themselves, the hospitalisation of a preterm born baby is noted to have a detrimental impact on the health and wellbeing of an entire family unit (Ramezani et al., 2014). At a patient level, the NICU environment is characterised by excessive levels of light and sound that are in stark contrast the in-utero environment (Lasky & Williams, 2009) and are noted to impair growth and development of new-borns (Miller et al., 1974). As our understanding of the needs of both parents and new-borns have increased over the past decade, so have clinical practice recommendations in the NICU environment. It is now suggested that alongside prioritising the immediate medical need of new-borns, the NICU should be a neuroprotective environment that minimises parental separation and is developmentally supportive in areas such as feeding, sleeping, skin to skin contact and stress management (Griffiths et al., 2019). While these are considered recommendations, the rate at which these suggestions positively impact new-born NICU graduates will only be clear with time as new-borns grow into childhood and adolescence (Lockridge, 2018). Recommendations that are parent focussed however have immediately assessable impact. Much research thus far focusses on the need for parents to have ample opportunities to participate actively in their childcare (Cleveland, 2008), as well as the adoption of a family-centred individualised care approach to increase the confidence of parents (Govindaswamy et

al., 2019). Although there have been numerous advances in NICU care for the immediate medical needs of infants, further research is needed to understand how best to support parents within this context. While prioritising clinical set up to facilitate positive infant development is undoubtedly important, so is the emotional protection and preparation for parents who will provide care well past neonatal stays.

Although much research focusses on outcomes at a behavioural level following preterm birth, there has also been some qualitative exploration on parental perspectives of having a preterm new-born. Through qualitative interviews conducted with parents of preterm born children, detailed descriptions of satisfaction of care (Sawyer et al., 2013), first moments with a preterm new-born (Arnold et al., 2013) and feeding behaviours (Mörelius et al., 2020) have been carefully documented. Yet, the above studies focused solely on those born extremely or very preterm, at the expense of those born MLPT. Similarly to the bias noted in quantitative preterm research, the depth of qualitative investigation in parents of those born MLPT is severely limited. The small pool of qualitative research that exists highlights that parents of late preterm infants feel unprepared to take their new-borns home and liken their medical treatment to that of term-born babies (Premji et al., 2017). Wider exploration of research priorities for parents of preterm children highlights the requirement for additional information throughout pregnancy (Franck et al., 2020) and regarding later cognitive and developmental outcomes (Ginnell et al., 2021). Similarly, when collating interviews with parents of individuals born extremely and moderately preterm, research highlights some broad similarities in parental experiences, yet clinical differences in treatment as staff fail to recognise the need for support amongst those born closer to term (Widding et al., 2020). Despite the perceived similarity between those born closer to term and at full term, further

research surrounding parental experience is warranted to ensure concerns are not being missed. A clear documentation of the context of MLPT birth *and* the experiences of parents is vital to allow for the provision of adequate support.

One conclusion from earlier chapters in this thesis is that early intervention may be helpful to facilitate a supportive environment where those born MLPT can thrive (section 2.5 and 3.6). There are two forms support may take; interventions primarily focussed on the mother delivered immediately after birth (such as kangeroo care, mother infant transactional program or creating oppurtunities program; Puthussery, Chutiyami, Tseng, Kilby, & Kapadia, 2018), or behavioural interventions delivered directly to the preterm born infant in late toddlerhood (Trickett et al., 2020). This is a seemingly positive split of resources to focus on both parental and infant wellbeing in the early years, with behavioural interventions moving beyond the 'preterm' label and towards individualised targeted areas of support such as physical health and disabilities, cognitive development or social emotional development. Those born at the earliest gestations in the United Kingdom are 'likely' to be offered a package of enhanced support and surveillance upon meeting gestational age and medical criteria (McKinnon & Huertas-Ceballos, 2019). Thus far, it is clear there may be additional neurodevelopmental consequences for those born MLPT (see Section 2.5) and potential social differences for some MLPT children (as evidenced through informant report measures – see Section 3.5). Combined, these findings may indicate that parents would support further neurodevelopmental interventions. However, no research has yet explored parents' perceived needs and no additional guidance, support or surveillance is currently offered to this group. The reliance on parents and caregivers to pursue pathways in primary care seems highly

imbalanced and warrants further investigation from a service user perspective, to explore whether care needs and offered support are aligned.

To summarise, further understanding of parental experiences and opinions regarding MLPT birth is necessary to ensure that the needs of parents and infants are being met. While some parental experiences have thus far been well documented, evidence is drawn from those born at the earliest of gestations. Alongside this, early intervention and surveillance programmes are also targeted towards those born at the earliest gestations, despite the emerging need of those born MLPT.

The current study therefore aims to;

i. Describe the experiences of mothers of children born MLPT.
ii. Explore support experiences and consider whether these are adequate in relation to mothers' perceived needs.

4.3 Study Design

4.3.1 Setting

Ethical approval was obtained for this research study as part of a wider research programme investigating social communication in infants born between $32^{+0/7}$ – $36^{+6/7}$ weeks (STEM UoB committee - ERN_09-048AP9; NHS ethical board IRAS - 265040, RG_19-146; see Appendix 3 & 5 for approvals). A subsequent amendment was approved in response to the Covid-19 pandemic and a transition to remote working to allow the interviews to be conducted online over video conference software. This amendment also removed the requirement to participate in face-to-face research (direct assessment study described later in Chapter 5) allowing the interviews to be conducted independently of the play-based assessments. This qualitative study was conducted between April 2021 and November 2021. Participants were recruited via social media, as well as through the online survey described in Chapter 3, where participants had consented for their details to be added to a recruitment database.

4.3.2 Participants

Participants were parents or caregivers of infants born MLPT. Infants were currently aged between 18 – 36 months old and were living in the UK. Table 4.1 details the characteristics of participants and their children. A total of six mothers took part in the qualitative interview study. Half of mothers had vaginal deliveries of their MLPT infant, with five out of six participants reporting needing NICU or specialist care equivalents immediately after birth. The mean age of mothers at the birth of their child was 32.4 years (standard deviation 4.8).

Table 4.1: Maternal and infant characteristics

	Child Age at interview	Maternal Age at Birth (years)	Gestational Age (weeks)	Siblings	NICU Stay	Delivery Type
1	29 mths 16 days	39	33.6	2 (older)	No	Vaginal
2	23 mths 24 days	35	34.4	0	Yes	Caesarean
3	20 mths 8 days	Withheld	34.4	0	Yes	Vaginal
4	36 mths 6 days	27	34.7	0	Yes	Caesarean
5	23 mths 22 days	29	32	0	Yes	Caesarean
6	21 mths 20 days	32	36.3	1 (older)	Yes	Vaginal

4.3.3 Interview and data collection

All interviews were conducted remotely using Zoom video conference software. Interviews lasted between 30 – 60 minutes and followed a semi-structured interview schedule (see Appendix 6), with participants encouraged to include any information that they felt relevant given the exploratory nature of the research. The schedule was generated from inspection of qualitative research conducted with parents of children born at earlier gestations, and consideration of aspects of NICE guideline recommendations (McKinnon & Huertas-Ceballos, 2019). Field notes were taken throughout the interviews and considered when collating data across interviews to assist understanding. Automatic zoom transcripts were generated and then corrected for any errors before being anonymised. An independent researcher who was not present during the interviews listened to half of the recorded interviews and checked the anonymised transcripts for accuracy.

4.3.4 Data analysis

Reflexive thematic analysis was employed to explore the data (Braun & Clarke, 2006). Anonymised interview transcripts were first coded by hand using NVIVO software. Codes

captured both the context and the content of the data and were combined at intervals to help begin to identify preliminary themes. These themes were then conceptualised through a process of inductive reasoning to identify patterns of meaning. The final framework of themes and subthemes was discussed and evaluated with an independent researcher involved in the wider project.

4.4 Results

4.4.1 Themes

Five themes are presented that are conceptualised from the data; (1) the moderate or later preterm 'label'- does it matter?, (2) vulnerability within a new role, (3) coming home and wanting to start 'normal' life, (4) comparisons to provide a reference to experiences, (5) experience of professionals throughout the pregnancy, new-born and early years journey.

Subthemes provide further insight into specific elements of broader themes and are presented below.

1. The Moderate or Late Preterm Label – does it matter?

A milestone focussed first year. Mothers reflected on their first experiences of considering the 'preterm label' in reference to developmental milestones "I was a little bit more anxious about him in the sense of milestones and things" (6). Some parents had been given prior warning of the potential impact preterm birth could have on milestones "for the first year you're always looking at their corrected age versus their actual age that can get very confusing. You're also waiting for milestones to hit later, so we were told 'oh a baby smiles anywhere from let's say six to eight weeks, [child name] is looking at let's say 10 to 12 weeks'

or what have you" (3). These milestones were used as a reference point to seek comfort "he seems to me to be developing really well and you know, along a kind of normal trajectory of milestones" (1), "for the first year waiting to see is he meeting milestones we expect? Is he developing okay? Yes he is, okay fine that's fine….He was meeting all the targets and so I thought well….yeah it doesn't really affect me much anymore" (6).

Growing out of the preterm label. After a milestone focussed first year many felt the preterm label began to diminish with time "I think it's only really important in that first year but that's my understanding" (2). Mothers note a gradual dissolving of the preterm label with no specific end date "I feel like he'll get to a certain age, maybe four or five, where it won't matter so much" (5). Participant 6 summarised this idea;

> "My experience is that it was fairly front loaded in terms of awareness of him being prematurely born in the sense that certainly the first week and first year I was more aware of it because obviously the hospital are very aware of it.… I don't really think of him as being prematurely born anymore in the sense it doesn't really make a difference to who he is and what he does not that that's the only reason you should think about it but you know it doesn't really affect me much anymore."

The relevance of the preterm label within the context of educational settings. Looking ahead towards educational settings that participants' preterm children would attend (nursery and school) mothers considered the relevance of the 'preterm' label. One mother whose child currently attended nursery noted she was "pleased they [nursery] asked" within initial enrolment "because I think it's really important" (1). This mother who had previously had twins born at earlier gestations noted her disappointment in her elder children's school

not considering prematurity "It's a bit of a worry isn't it because you'd hope that educational settings would understand the potential difficulties premature children are facing you know."

Contrastingly, other mothers presented alternative opinions on the relevance of such information "I don't think it would be necessary for a primary school to know that she was premature….It shouldn't really put her at any disadvantage so they've no reason to know other than out of interest." (2). Mothers were not surprised when "they [nursery] didn't ask on their application forms or anything like that" (4) perhaps related to the perceived lack of relevance regarding the 'preterm' label discussed earlier "I don't think it occurred to me to mention it, or for anyone to ask about it"(6).

2. Vulnerability within a new role

Initial moments after birth. Mothers reflected on the initial moments after birth as being incredibly lonely, particularly when separated from their new-born "I was left completely on my own, probably for about an hour which was really distressing actually. Probably because if you've been pregnant for that long and then suddenly you're all on your own it's very lonely" (1). This was echoed by other mothers, who noted a sudden shift in staff's perception of mothers immediately after birth "I felt as though I was kind of like a vessel and I was looked after while I was pregnant until he was out" (5). These early moments, often heavily described when preparing for the birth of a child, look characteristically different for some mothers who are then left to process their situation "A big thing they talk about in neonatal things is the importance of skin to skin and then I was like 'oh yeah that didn't really happen'. I assume when there are important things going on, things like that don't happen" (6).

NICU. The neonatal intensive care environment was described as a place that led many to question their role as a mother to a new-born. Having other medical professionals be the primary source of care was challenging "I often felt that the nursing team having to do their thing made me redundant and just sort of I didn't need to do anything" (5), "My overall feeling was not knowing what I was allowed to do and not to do" (6). Although the memory of mothers' time in the NICU was raw and vivid, the emotions associated with this context did not appear to persist "I feel really happy and secure now, whereas when he was younger and particularly this time in hospital I felt quite insecure about my role" (5). Provision of care was not the only situation that appeared to cause feelings of vulnerability and uncertainty, practical barriers unique to parents with children in NICU had lasting effects;

> "You know not being able to decide what he wore every day, I wasn't able to do that because I wasn't there every morning when he got up or there every time he was sick or his nappy needed changing. Other people were making these decisions and I found that really hard and kind of disempowering….for four months of my baby's life I had to ring a doorbell to see him"(5).

Breastfeeding. The experience of breastfeeding a new-born was continuously described as a tool to both bond with a new-born and remain necessary within their new-borns care;

> "I desperately wanted to breastfeed and it wasn't because of the actual breastfeeding process…it was just feeling like I had a purpose, that was the only thing I could give him….he's got all of these nurses looking after him and it doesn't matter if I'm at home or if I go at eight in the morning he's been looked after. And that was quite

difficult because that's my job as a mum, and so I desperately wanted to breastfeed" (4).

The desire to take responsibility for a decision within their new-borns care, such as feeding, was described by one mother to be detrimental to their discharge "She was being tube fed and I had expressed my desire to breastfeed and I think that probably put me in there [hospital] for another week more than I needed to be in if truth be told" (2). Nevertheless, another mother describes how this desire perseverated past her family's time in the NICU "I kept going [breastfeeding] for months because it gave me purpose" (5).

3. Coming home and beginning a 'normal' life

Something to strive for. Being discharged from hospital and returning home was a milestone all mothers spoke about regardless of their individual experiences and variation in immediate medical or health concerns. Going home was commonly positioned as the beginning of 'normal' life and subsequently something to strive for "I was just desperate to go home and start normal life with her" (2). For mothers whose new-borns had higher levels of immediate medical need, this was a particularly difficult expectation to manage, "I had to wait until he was well enough to come home obviously, and that was kind of the goalpost but it just kept moving because he got jaundice and then got better and then got jaundice again!" (1). One mother who reported an extended and particularly challenging time in NICU presented mixed feelings about the gravity of finally being able to take their new-born home "It was quite obviously a monumental occasion but also just wasn't it was just normal right, he was just here" (6).

Perception of normality. The societal perception of bringing a new-born home and 'normal' life beginning form this point was present in all mothers' responses. Marking this moment was important to mothers. One mother reflected on their experiences, noting an unspoken pressure to wait until their baby was home to share pictures with other people; "I've got a photo of both partner and I separately holding her little car seat outside the front door like waving, I'll never forget that day"(2).

> "I wouldn't share sort of any pictures from when he was really little until you know he came out and he didn't have the nasal tube and all that kind of stuff And I realized actually that's part of his story that's really important… the pictures that you have of your child in an incubator are no less incredible and beautiful than the really cute wrapped up ones in your arms at home, that's still the start of their life. It's almost as though we want to as a society want to kind of erase that part of their existence yeah and then them coming home is normality and that was where that sort of life began" (5).

4. Comparisons to provide reference to experiences

Comparisons to those born at earlier gestations. When reflecting on early birth experiences, mothers frequently compared their own personal journeys to those of mothers with babies born at earlier gestations as a frame of reference, "But again, the whole time is like this positioning against people having it worse" (1). These comparisons were in relation to both immediate contextual experiences such as the NICU, "I was very very aware that there were lots of mums around me who had been there for a lot longer that sort of kept me in check a bit that come on actually…in comparison this is nothing" (2) and longer term contexts

such as nursery "Like if I had a 25 weeker going to nursery that you know, was a lot smaller than other children and maybe a lot behind developmentally like I'd be really feeling like I had to justify myself all the time" (4). When seeking a reference point for experience, mothers considered new-borns' physical health in relation to those born at the earliest gestations.

The 'magical full-term baby'. As well as comparing to babies born at earlier gestations, mothers also made comparisons to babies born at full term. For some mothers, this provided a benchmark of 'normality' "I mean he came home, he wasn't on any kind of medication, he didn't need any extra stuff or have his NG [Nasogastric tube] tube. I think really it was quite comparable to having a full-term baby I think" (1), "I still got the whole coming home experience and it was still all brand new for me just like it would be for a full-term baby…I think it's just the initial after birth that's different personally" (3).

Participant 5 presented this comparison through a negative lens "I felt quite resentful when I saw heavily pregnant women, because I never was….I felt envious of the little things…having to have that relationship [with a new-born] in public". They further note the experiences they missed out on, "It felt more out of control…other parents whose pregnancies go to full term, they can have those meltdowns in private like we all do."

Other mothers reflected on being unable to consider the experiences of a full-term parent "yeah I think it was comparable. But then I don't know I've never had a full-term baby so this magical full-term baby, I don't know!" (1). One mother even sought out the comparison to be made by educational staff, although was aware this was not common practice, "I'm not allowed in the nursery setting but I'd love to go and compare her to other children, I'd love if normal talk was 'she does this, someone her age should be doing this' no one's ever going to say that but I'm dying to know!" (2).

5. Experience of professionals throughout the pregnancy, new-born and early years journey

Throughout pregnancy. The lack of prior information regarding preterm birth throughout pregnancy was voiced by all mothers interviewed within this study, "I definitely didn't contemplate that [being born preterm] being something that might happen without any prior warning…it certainly wasn't a conversation that was ever had that it might be a possibility" (2). One mother noted that even after a medical procedure, preterm birth was not discussed by healthcare professionals, "They did the steroid injections but never said to me 'right you're having these and this means we are anticipating he's going to come in a week'." (4).

Some mothers contemplated why information was withheld throughout pregnancy, "No one really talked about that [NICU] in our sort of journey so far, I don't know if it's not wanting to scare people and wanting to present the best case scenarios, there's a lot of talk in like NCT and stuff about avoiding fear"(6), with others reflecting that it would be been helpful "They kind of want to tell you enough but they don't want to overcomplicate things….but I feel like it would have been reassuring to know more in advance" (4). One mother who was aware her baby may be born earlier because of medical concerns spoke about seeking her own information as a result of a lack of communication from healthcare professionals and the challenges this posed, "Towards the end of pregnancy I was still reading these books that have got the typical journey and thinking right I don't know at what point this is going to stop applying to me" (5).

Early Years professionals. Mothers also reflected on their experiences of professionals throughout their new-born's first years of life, with particular reference to health

visitors and GPs. There appeared to be some discrepancies in relation to how informed health visitors were on preterm birth "It depends who's weighing them, but sometimes if you've got a prem baby they'll be like 'Oh, you know I'm not sure if I'm supposed to fill the charts with their current or actual age' or whatever it's called…that can be a bit disconcerting if you're like well if you don't know I'm not sure I know kind of thing" (1). Notably, one mother sought to bridge the knowledge gap outside of health visitors all together; "The health visitor is just a broad person to give you little snippets of advice…maybe there needs to be more support groups like independent ones that you can go to" (2). These broader concerns were carefully summarised by one mother;

> "We got sent home and at no point has anyone ever said we're going to do a follow up…no one's really checked his growth other than a health visitor with a tape measure…I feel like you need a bit of an MOT for preterm babies to have a bit of reassurance that everything's developing as it should be…I felt like I needed a debrief, you need someone to run through with you and say 'oh right so because of all this everything's fine now, and this is what you want to look out for going forward and if you've got any concerns' "(4).

4.5 Discussion

This is the first qualitative interview study solely to explore in detail the experiences of mothers of MLPT born infants. Findings offer in-depth evidence surrounding mothers' experiences of healthcare throughout pregnancy and immediately after birth, perceptions of the 'preterm' label, and thoughts on how mothers reflect on their experiences.

Aim i; The experiences of mothers of children born moderately or late preterm

Mothers of MLPT born children described a loose affiliation with the 'preterm' label, explaining this is something that diminished as their child grew older. This is in contrast to qualitative research with parents of children born at earlier gestations who describe a stronger affinity with the preterm label (Bright et al., 2020). While their participation within the current study denotes a degree of recognition that their child was born <37 weeks gestation, the belief that prematurity is something that would no longer be relevant to their family's lives was repeated across interviews. Social identity theory states that to be a member of a group, one's self-concept must align with others' experiences, knowledge, values and emotional significance (Tajfel, 1974). Mothers of MLPT new-borns share a biological context that their baby was born before 37 gestational weeks, but experiences from this point onwards can differ dramatically. This could explain a potential identity shift as the postnatal experience for those of MLPT born babies becomes more similar to those born at full term, and less similar to those born at earlier gestations. While socially the identification as a member of a 'preterm' group is an inherently personal preference, there may be some clinical utility in preserving the preterm label for those with new-borns born MLPT. Families of preterm new-borns are less likely to access routine postnatal services and support than parents

of full-term new-borns (Henderson et al., 2016), suggesting that those in need of timely support for their preterm new-born may not readily seek support. Providing specialist postnatal support tailored to the experiences of parents of MLPT born infants could assist in preserving the preterm label for those who would benefit from continued care. However, it is important that these strategies are aligned to parental priorities.

Related to uncertainty about a preterm identity, mothers made comparisons to both those born at earlier and later gestations throughout their reflections. Strategies such as this are commonly used to provide clarity, understanding and reference within a context as outlined in early descriptions of social comparison theory (Festinger, 1954). This method of self-evaluation is noted to be particularly common where concrete information is lacking (Buunk, Schaufeli, & Ybema, 1994) and is suggested to play a key role within the cognitive vulnerability model of depression (Swallow & Kuiper, 1988). The use of both upwards (to parents of 'full term' new-borns) and downwards (to parents of those born at earlier gestations) comparisons throughout the early birth context indicates mothers of MLPT new-borns could be at an increased risk for feelings of low self-concepts and low self-esteem (Buunk & Gibbons, 2007). This is corroborated by higher incidences of depression and anxiety in mothers following a child being born MLPT (Voegtline & Stifter, 2010). A recent meta-synthesis highlighted the continued importance of maternal care in the postnatal period (Finlayson et al., 2020), which is even more pertinent for mothers whose birth is earlier than expected. To reduce downstream emotional consequences of early social comparisons, concrete information for those born MLPT should be provided so the necessity to both upwardly and downwardly compare is removed. Conversations that validate the experiences

of parents of MLPT born babies could contribute to reducing any negative impact drawing comparisons may have.

All mothers interviewed within the current study spoke in detail about bringing their new-born home, irrespective of differences within the postnatal experience. This milestone was noted as something to strive for, with mothers associating bringing their baby home with 'normal' life beginning. This transitional period has been associated with regaining control through being within a familiar environment, with an explicit need for professional reassurance during this transition period highlighted for parents of preterm children (Breivold et al., 2019). Adequate and timely information provided at discharge to parents of new-borns about the individual needs of their child is said to increase parental psychosocial wellbeing and reduce readmission to hospital in new-borns (Weiss & Lokken, 2009). For families whose new-borns experienced an extended period of time within NICU, going home is a monumental occasion often accompanied with extensive parent focussed information around continuation of care (Aydon et al., 2018). However, only one of the five mothers in the current study whose new-borns were admitted to the NICU highlighted information provided by healthcare professionals as being relevant to their transition home. This suggests healthcare professionals, both at the point of discharge and in the immediate aftermath of the new-born coming home, should be aware of the nuanced needs of families of MLPT born infants and how their experiences may differ from 'normal'. This will equip professionals to provide support throughout this transition.

Aim ii; Explore support experiences and consider whether these are adequate in relation to perceived need

Despite the vulnerability noted by mothers in reference to the transition to motherhood and early postnatal experiences (Theme 2), interactions with professionals appeared to be a rare and targeted occurrence. Interestingly, many mothers noted the lack of information regarding preterm birth during pregnancy and suggested this would have been a useful conversation to have had with medical professionals. The NICE guidelines detail the extent to which parents of children born preterm receive information and support *after* the birth of their child; surrounding immediate postnatal care, at discharge home and across the early years (McKinnon & Huertas-Ceballos, 2019). However, there are currently no guidelines surrounding information provided throughout pregnancy, despite 15 million births worldwide being before 37 weeks completed gestation each year (Walani, 2020). Recent exploration of parental priorities of preterm children aligns with ideas highlighted within the current study, suggesting presenting parents with literature that they can read and discuss in their own time might be helpful (Ginnell et al., 2021). Further evidence suggests a more directed midwife-led model of antenatal care as another solution to bridge the gap (Fernandez Turienzo, Sandall, & Peacock, 2016). These two putative solutions directly address one of the 15 research priorities related to preterm birth, regarding what should be included in packages of support given to families (Duley et al., 2014). Yet the current study dramatically highlights parents' need for information and support *prior* to the birth of their child as well as after. Future research and service provision should explore how best to address this need for information throughout pregnancy as well as postnatally in a timely manner.

All mothers within the current study described their interactions with health visitors, with differing levels of perceived support regarding their child's prematurity. Whilst one mother noted an incredibly positive interaction with a local health visitor, who was very well informed regarding preterm birth, many noted uncertainty and confusion in relation to the practical adjustments such as timing of follow ups or adjusting age. This is in line with evidence highlighting a particular knowledge gap and training need for health visitor professionals with regards to preterm birth (Ginnell et al., 2021). The Covid-19 pandemic was reported to have a detrimental impact on interviewee's experiences with health visitors. A nationwide survey documented that redeployment, staff shortages and an increase in caseload during the Covid-19 pandemic led to considerable pressure on health visitors and the service they were able to provide (Conti & Dow, 2020). Conclusions from the current study combined with those mentioned within previous research emphasise the need for further information being provided to parents of preterm new-borns through health visitors alongside other developmental checks routinely given. Taking into consideration the overwhelming pressure noted throughout the context of the global pandemic that persists today, a timely solution may be the creation of information pamphlets detailing the unique experiences and challenges for parents of MLPT born children that could be distributed with no additional resource need for Health Visitors.

Given the age of infants within the current study (18 – 36 months) opinions around school and other educational settings were purely speculative. Despite this, the overarching opinion was that a child being MLPT was not something parents would automatically share with a school as it was considered to be unrelated to their wider growth and development. This opinion goes hand in hand with the lack of professional information or support provided

to parents for their MLPT born child (Theme 5). This opinion contradicts research highlighting the specific needs of preterm pupils within the classroom (Cheong et al., 2020; O'Reilly et al., 2020; Twilhaar et al., 2018) and the success of a recently launched psychoeducational programme for schools relating to preterm birth 'Preterm Birth Information for Education Professionals' (Johnson, Clayton, Cragg, Gilmore, Griffiths & Marlow, 2019). This finding is also in tension with the higher prevalence of autism characteristics reported in those born preterm (see Section 2.4). The paucity of information regarding the potential downstream effects of MLPT birth (Theme 5), combined with educational professionals feeling ill-equipped to support preterm children within the educational context (Johnson, Gilmore, et al., 2015), indicates a concerning environment in which the needs of those born MLPT are not being recognised. The creation of training resources (such as those previously mentioned) and awards such as the 'Prem Aware' programme (The Smallest Things Premature Baby Charity, 2017) to assist schools in providing support is incredibly encouraging. Greater awareness and information provided to parents would further bridge this gap as without this, schools-based programmes may have little effect. Providing a system that offers an all-round model of support for those that need it must be the priority for those born MLPT.

In conclusion, the current study detailed the experiences of mothers of MLPT born infants. The findings offer unique insights into the ways in which parents of moderate or late new-borns classify themselves as having a 'preterm' child, and how this appears to diminish with age. A paucity of information provided by healthcare professionals both throughout pregnancy and postnatal care provides some explanation as to why parents believe the implications of preterm birth are no longer relevant past the period of health visitor follow up.

Future research should explore to what extent prior knowledge and discussion of preterm birth during pregnancy is helpful. Being mindful of the current circumstances health visitors are operating in and in the interest of more timely change in support, clinical services should explore the use of educational information that can be distributed alongside current developmental follow ups. Arguments made around 'early intervention' by the research community (such as those in Chapter 2 and 3) should perhaps shift to be discussions around more timely support for those identified as being most vulnerable to the effects of MLPT birth.

CHAPTER FIVE

AN EXPERIMENTAL STUDY OF EARLY SOCIAL SKILLS IN INFANTS BORN MODERATELY OR LATE PRETERM

5.1 Preface

Data presented thus far within this thesis highlights that individuals born preterm are more likely to receive a diagnosis of autism than those in the general population (Chapter 2), yet only a small proportion of MLPT children meet formal cut offs when relying on validated informant report questionnaire measures (Chapter 3). Chapter 5 attempts to build upon this through the use of informant report measures, eye-tracking methodologies and direct measures of spontaneous helping behaviours to explore nuanced social cognitive behaviours within a group of MLPT *and* term born infants (Aim four of thesis). Covid-19 significantly impacted on data collection within this chapter meaning completion of planned analysis was not possible. Preliminary data exploration in relation to key hypotheses are discussed in detail, alongside consideration of the feasibility of this approach to understand social cognition in those born MLPT.

5.2 Introduction

Preterm birth (<37 weeks) is associated with a multitude of outcomes including an increased risk of infant mortality (Callaghan et al., 2006), poorer physical health (Luu et al., 2017) and increased likelihood of downstream neurodevelopmental consequences (Younge et al., 2017). Survival rates of those born at the earliest gestations have increased dramatically over the past decade as a consequence of advances in perinatal intensive care and further understanding of positive immediate medical intervention to promote positive outcomes (Norman et al., 2019). Despite this, less is understood about neurodevelopmental and behavioural outcomes as a result of early birth (Cheong et al., 2020). While there is growing understanding of outcomes that are implicated by being born earlier, little is understood about the mechanisms behind these outcomes, which can limit clinical precision when determining provision of support. Future research that moves beyond broad statements of outcome and towards a more nuanced understanding of mechanisms that drive outcomes is vital to ensure adequate support and service provision and in turn more positive outcomes for those born preterm.

One such area where there is a particular lack of specificity and understanding is in relation to outcomes for those born at different gestational ages *within* the broader 'preterm' label of <37 weeks. Sub categories have long been used as a method of further detailing preterm birth (Kramer et al., 2012). Four broad sub categories of preterm birth are typically used in both medical and research settings; extremely preterm birth (<28 weeks), very preterm birth ($28^{+0/7}$ – $32^{+6/7}$ weeks), moderately preterm birth ($32^{+0/7}$ – $33^{+6/7}$ weeks) and late preterm birth ($34^{+0/7}$ – $36^{+6/7}$ weeks) (WHO, 2015). Yet, inconsistencies associated with alternate methods of gestational aging used clinically may further complicate this attempt at

categorisation, with initial gestational ages that are calculated later within the pregnancy thought to be less accurate (Lynch & Zhang, 2007). The development of such categorisations now adopted widely within clinical and research settings represents a subtle shift in the acceptance of nuanced differences between those born within the broader preterm umbrella definition.

Of particular note, given that they represent around 85% of all cases of preterm birth, are those born MLPT (Frey & Klebanoff, 2016). When compared to the experiences of those born very preterm, MLPT born individuals appear to show more favourable outcomes with evidence for higher intellectual functioning and cognitive performance (Hirvonen et al., 2017; Putnick et al., 2017; Shah et al., 2013). While comparisons such as these are logical given any explored outcome might not be limited to those born extremely or very preterm, there is growing concern that this method of comparison may underestimate levels of need and therefore subsequent support MLPT individuals receive (Engle, 2006). In response to this, there has been a shift towards comparing MLPT individuals to their full term peers, revealing those born MLPT are at increased risk of mortality, morbidity, and short *and* long-term neurodevelopmental outcomes (Woythaler, 2019). Such shifts in research focus are consistent with growing recognition of the heterogeneity within preterm populations and further supports research that takes this into account. A move away from comparing those born MLPT to their extremely or very preterm peers, towards comparisons to those born at the 'optimal' full term gestation is vital to gather a more conclusive picture of outcomes.

Neurodevelopmental outcomes are some of those most often reported across the prematurity literature, with research from across the world supporting the idea that those born

earlier or with a lower birth weight are at an increased likelihood of receiving a diagnosis of autism later in life (Persson et al., 2020; Talmi et al., 2020). The results from the previous meta-analysis (see Section 2.4) corroborate this idea, highlighting that the odds of an autism diagnosis were 3.3 times higher in individuals born preterm than in the general population. While broader likelihood estimates and odds ratio statistics are of value when advocating for group level service provision, their utility at an individual level is more limited. In the peripheries between those that meet clinical cut off and those that do not lies a group of individuals that may present with subtle, but important sub-threshold differences. Research beginning to explore this idea highlights that those born extremely preterm often present with specific sub-clinical social difficulties that fall outside the diagnostic threshold for autism (Johnson et al., 2010), with a larger number of preterm born individuals presenting with difficulties associated with autism than have received formal diagnoses (O'Reilly et al., 2021). The downstream effect of those with subthreshold difficulties *not* receiving a timely diagnosis of autism or subsequent support and intervention could be widespread. Those who do not meet diagnostic threshold are unable to access effective early intervention known to promote positive outcomes (Nahmias et al., 2019). Only considering those who meet diagnostic threshold also inhibits advances in research synthesis regarding the broader autism phenotype (Rubenstein & Chawla, 2018) and is a perspective that is entirely unreflective of the dynamic nature of autism diagnoses in early life (Tunç et al., 2021). Taken together, evidence suggests the widespread benefits of a more flexible approach to autism diagnosis and classification. Adoption of a perspective that is more akin to a continuum rather than categorical cut offs would allow for meaningful intervention and support that cuts across clinically imposed boundaries and is dynamic and responsive to alternate and/or sub-threshold profiles of autism characteristics.

Two key skills that may be affected by preterm birth and are possible correlates of sub-clinical differences or later autism diagnoses are social cognition (Ritchie et al., 2015) and social attention (Dawson et al., 2012). Early social cognitive skills that develop throughout infancy provide an important foundation for later social interactions and relationships (Striano & Reid, 2006). 'Social cognition' is often used as an umbrella term encompassing a variety of broader interrelated psychological constructs such as Social Understanding, Theory of Mind and Social Motivation (as discussed in section 1.5.1). Considering these fractional constructs allows for a comprehensive profile of abilities to be explored, an important first step when aiming to document behaviours. Many of these cognitive skills (social preference, helping behaviours, theory of mind) can be further divided into operationalizable tasks. Skills such as joint attention (Tomasello et al., 2005), imitation (Meltzoff & Marshall, 2018) and goal understanding (Liu et al., 2017), develop rapidly in the first few years of life (Sirois & Jackson, 2007). The emergence of these skills are initially characterised by dyadic interactions with others, whereby new-borns show an attentional preference for social stimuli (Lavelli & Fogel, 2002). These interactions later become triadic and are shown to influence future language and communicative abilities (Brooks & Meltzoff, 2005). Multiple explanations have been proposed to account for why the development of early social cognitive skills may be affected as a result of preterm birth. Atypical brain development noted by structural differences in both cortical and grey matter volume have been shown to correlate with later neurodevelopmental impairment in those born early (Brown et al., 2009). Similarly, parental stress and subsequent differing maternal attachment is suggested to also impact initial dyadic interactions (Forcada-Guex et al., 2011). Taken together, these factors provide a strong rationale for predicting that the development of early social cognitive skills will be affected following preterm birth. While this may go some way in explaining the links

highlighted between preterm birth and increased likelihood of later autism diagnoses, further research is necessary to explore this relationship and allow for further understanding of the early development of clinically relevant behaviours.

Early gaze patterns and social attention have similarly been shown to be directly related to later autism characteristics (Dawson et al., 2012). Notably, there is a growing body of evidence documenting that preterm children have reduced preference for dynamic human images along with atypical gaze patterns (Imafuku et al., 2017; Telford et al., 2016). Longitudinal analysis of attentional preferences corroborates these findings among preterm infants at 6, 12 and 18 months (Imafuku et al., 2021). A recent synthesis of the literature concluded that while there does appear to be a reduction in social attention for preterm infants under 12 months, current literature does not conclusively support a distinctive preterm phenotype of skills, with various external factors seeming to affect later skill development (Dean et al., 2021). This heterogeneity of skills is further supported by work exploring attention in six year olds where children born MLPT were over-represented in four identified 'suboptimal' attentional profiles when compared to their full term peers (Bogičević et al., 2020). Together these findings suggest that while an association between autism characteristics, social attention, social cognition and preterm birth is present, it is not well defined or understood.

One key consideration when exploring early behaviours across infancy is the appropriateness and tolerability of methods used. While developmental research has recently been subject to a replicability crisis, advances in collaborative efforts, developmental

technology and theoretical understanding suggest we can have confidence in methods broadly adopted (Frank et al., 2017). One method that has perhaps received more attention than others in the last decade is eye-tracking; a method of gaze detection that is practical in individuals as young as a few days old (Hessels & Hooge, 2019). Subtle differences in gaze patterns offer the potential to understand more about the cognitive processes and attentional preferences of infants with minimal participant burden and language requirements (Eckstein et al., 2017). Such measures are also suggested to be useful components of wider outcome measures in response to interventions, allowing for more detailed analysis of efficacy and utility (Fletcher-Watson & Hampton, 2018). Eye-tracking therefore provides an optimal paradigm to investigate implicit social cognition and social attention in infants born preterm.

A further, perhaps more traditional method of assessing early developmentally relevant behaviours, is through direct observations of administered tasks. Methods of behavioural observation have been shown to be both generalisable and reliable when delivered correctly by a trained administrator (Hintze & Matthews, 2004) and should not be overlooked with advancements in more novel approaches. Many tasks of early social cognition involve participants 'helping' by picking up an object dropped by an examiner (Warneken & Tomasello, 2007), responding appropriately following agents cues (Schulze & Tomasello, 2015) and working together with an agent to achieve a joint goal (Warneken et al., 2006). These methods have provided broad insights into the field of early social cognitive development, with seminal theories suggesting cognitive abilities develop in a predictable sequence (Wellman & Liu, 2004). This identification allows for wider understanding and support to be tailored towards those not progressing through such tasks in a developmentally predictably way (Ellis et al., 2020). Combining measures that assess subtle differences in gaze

pattern with explicit responses to 'real life' situations allows for a comprehensive understanding of infants development (Wass, 2016). Therefore, a more robust approach to answering developmentally relevant questions for infants born MLPT, would be combining eye tracking measures of social cognition with behavioural assessments of social cognitive skills. This multi-modal approach would allow exploration of the shared and divergent patterns of ability across different assessment modalities, which in turn could be explored in relation to autism characteristics.

A limitation noted across current research was that popular theory of mind tasks rarely ask for participants to act upon another person's mental state. The combination of eye-tracking measures and direct measures of spontaneous behaviours would allow for further understanding of the intricacies involved in broader constructs such as theory of mind. Models of social motivation suggest that early differences in social orienting are linked to early and later social behaviours (Chevallier et al., 2012). Intrinsic to this is the concept that there is a base level of seeking or enjoyment within interactions and that perhaps these two concepts could be separate. In line with this, a hypothesised model of what might be expected across a larger sample of MLPT or term born participants if social motivation and attention, and early social behaviours are separate components can be drawn up (Appendix 7). Perhaps some participants may display high levels of orienting to social stimuli on eye-tracking tasks (thus high levels of social attention and motivation) yet present lower scores on direct measures of spontaneous behaviours (thus showing less socially motivated behaviours or 'theory of mind use'). Distinguishing these concepts within the social motivation model would allow for further exploration of skills moving on from a dichotomous 'pass' or 'fail' perspective on tasks towards an understanding of what is sufficiently motivating or enjoyable for groups that present with differences.

To summarise, those born preterm appear to present diverging developmental trajectories across multiple behavioural, cognitive and attentional domains (Johnson & Marlow, 2017). Much within-participant heterogeneity of skills is noted, potentially being associated with gestational age. While there is a growing body of evidence surrounding those born at the earliest of gestations, less is known about those born MLPT despite these individuals comprising the majority of all preterm births (Bogičević et al., 2020; Raju, 2017). Evidence implies that larger between group designs spanning multiple gestational ages are not appropriate in identifying subtle differences *within* groups of preterm children. As looking narrowly at group differences on a singular measure may miss key differences, research should instead use multi-modal assessment across attentional, cognitive and behavioural aspects that would allow for more conclusive evidence among a notably heterogeneous group.

Therefore, through a carefully designed experimental paradigm, the current study aimed:

i. To identify the behavioural profiles (comprised of gold standard autism assessment and robust scales of early learning) of infants born MLPT when directly compared to age and ability matched term born infants.
ii. To explore the profile of autism related characteristics within infants born MLPT.
iii. To explore the relationship between social attention and social behaviours in term born infants

5.3 Design and Timeline

The current study used a novel experimental research strategy to undertake detailed phenotyping of social cognition in children born MLPT. This research received ethical approval from both the Science, Technology, Engineering and Mathematics Ethical Review Committee at the University of Birmingham (ERN_09-048AP9) and NHS ethical board (IRAS 265040, RG_19-146; see Appendix 3 & 5 for approvals). This study was also pre-registered prior to data collection and can be accessed here https://osf.io/8e3wy.

A strategic method of data collection was planned to ensure the optimal sample size was recruited and thus sufficient power was reached for the analysis approach (Figure 5.1).

Stage One involved approaching known contacts through databases and advertising on social media. It was anticipated that participants born MLPT may be fewer in numbers than those born at term recruited this way. It was therefore planned that in April 2020, Stage Two of recruitment would begin. In Stage Two, using obtained NHS ethical approval, contact would be made directly with parents or caregivers of MLPT children through health visitors and attending well-child clinics. All aspects of this two-stage recruitment plan were significantly impacted by the pandemic and subsequent government restrictions.

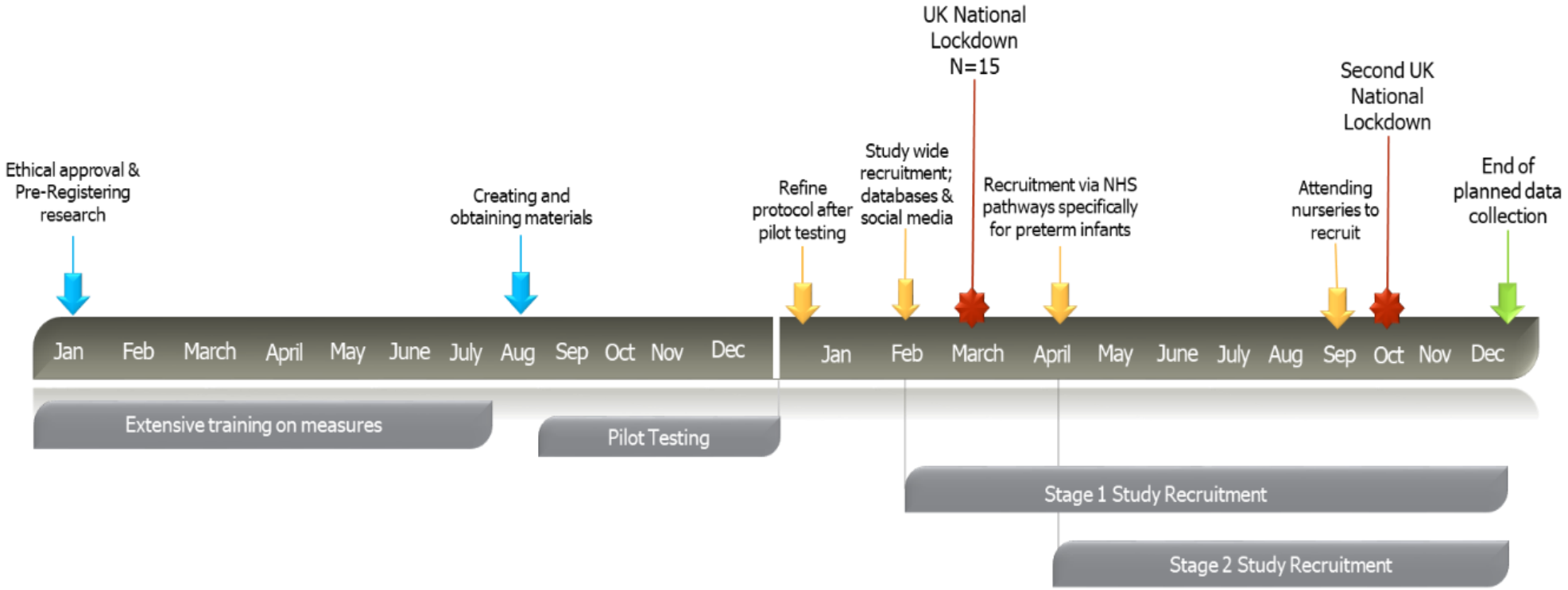


Figure 5.1: Planned methods of data collection and subsequent impact of national restrictions within the context of the Covid-19 pandemic

5.4 Participants

Participant recruitment estimates were based on a priori power analysis conducted using G*Power 3.1 (Faul et al., 2013). Effect sizes from a seminal paper on action anticipation in two year olds using eye tracking methods were used to inform the power analysis, given no exact replica study for direct effect size estimation existed (Southgate et al., 2007). Analysis suggested 18 participants were needed in each of the term and preterm groups to detect a moderate to large effect size ($\eta 2 \geq .14$). To allow for participant dropout, it was planned that a minimum of 20 children would be recruited to each of the following two groups.

Preterm group (N = ≥20);

Aged 18-36 months

Born mid-late preterm ($32^{+0/6}$ - $36^{+6/7}$ weeks gestation)

No siblings with idiopathic autism as genetic risk for social-cognitive differences are heightened in siblings of individuals with autism.

Comparison group (N = ≥20);

18- 36 months old age-matched (corrected for gestational age of preterm cohort)

Born 37^{+0} - $41^{+6/7}$ weeks gestation

No siblings with idiopathic autism

At the time of the UK National Lockdown on March 23rd 2020, recruitment for the current study had been open for two months. During this time, 15 participants had attended the University of Birmingham to participate in 30 separate research visits (two visits per

infant). Four participants (eight visits) were subsequently cancelled in line with government guidelines and it was not possible to restart recruitment during the PhD timeline, given continued restrictions and University of Birmingham risk assessments for participant testing.

5.5 Measures

5.5.1 Informant Report Measures

The following measures were completed at a single time point by the parent or caregiver responsible for the infant.

Health questionnaire

A health questionnaire created specifically for the needs of the current project was completed by a parent or caregiver. The questionnaire was developed with input received from clinical psychologists and experts in early development, and consisted of three broad sections; maternal history, birth & baby information and broader socioeconomic questions (see appendix 4 for a full copy of this measure). The questionnaire was completed during a visit to the University of Birmingham to partake in direct assessments outlined below, with some parents or caregivers returning the measure at a later date to confirm the accuracy of their response with medical records.

Modified Checklist for Autism in Toddlers – Revised (M-CHAT-R)

The M-CHAT-R is a robust screening tool for autism in young children (Robins & Fein, 2018). The measure is a 20-item questionnaire that is administered in two stages. After initial completion by the parent or caregiver, a member of the research team scored the item

and administered the second stage (a set of follow up questions) to those who scored within the 'medium risk' category. This process was important given the high levels of sensitivity noted for the measure (Robins et al., 2014). A total score falling into the high-risk category after initial scoring or falling into the medium *or* high-risk post follow up indicates a child should be referred for further diagnostic assessments. The MCHAT-R has been shown to be reliable within preterm populations when administered in full (Kim et al., 2016).

5.5.2 Direct Measures

The following measures were completed by infants as part of a two-day visit to the University of Birmingham and are presented in order of administration.

The Autism Diagnostic Observational Scale (ADOS-2)

The ADOS-2 (Lord et al., 2012) is a widely accepted "gold standard" play-based diagnostic instrument that is administered by trained professionals in a semi-structured manner and scored against a pre-defined robust algorithm (Gotham et al., 2007). Although not in the original set of modules available, the Toddler Module was later introduced to be suitable for children under the age of 30 months, with age and ability appropriate activities and presses (Luyster et al., 2009). This module was therefore deemed appropriate for the majority of participants within the current study. In this study, all ADOS-2 assessments were completed by the trained personal that had achieved both administrative and researcher reliability (see appendix 8). For the purpose of answering current research questions, ADOS-2 scores (rather than outcomes on diagnostic thresholds) would be used.

Eye tracking

Apparatus: The EyeLink Portable Duo (SR Research LTD) was used to collect all eye tracking data, using stimuli that had previously demonstrated good discriminative validity between autistic and non-autistic samples. Participants were seated on their parent or caregiver's lap in a dark room roughly 30cm away from a 19 LED monitor (screen resolution 1280 x 1024). The tracker was set to sample at a rate of 2000 Hz and each participant completed a five-point calibration, with drift correction where necessary, before proceeding to view the stimuli. Calibration targets were looming circles that grew in size to capture infants' attention.

Stimuli: All stimuli were programmed and run through Experiment Builder (software licence from SR Research) and are presented in order of administration (see Figure 5.2). Each participant completed a successful calibration and stimuli one, some participants did not complete stimuli two due to fatigue.

Infants were first presented with The Complex Social GeoPref test (Pierce et al., 2011). The GroPref test is a 60 second video comprising two components and subsequent areas of interest displayed side by side; a dynamic social image (DSI) and a dynamic geometric image (DGI). In the creation of the GeoPref stimuli, the authors produced DGI from recordings of screen savers and DSI from available clips of children doing yoga and therefore moving in a dynamic way. Single scene duration varied from two to four seconds and were presented at 24 frames per second. The side in which the DSI and DGI appeared on was counterbalanced between participants. Task data presented in the original article suggests looking time scores on the GeoPref task are appropriate at identifying those with higher levels

of autism characteristics, with longer dwell time on DGI (>69%) indicative of the need for further neurodevelopmental follow up (Pierce et al., 2011).

After an interim drift check and correction if necessary, infants were presented with point-light display stimuli (Johansson, 1973). This stimuli depicted alternate forms of biological motion and were taken directly from previous research with authors' approval (Annaz et al., 2012). During the first phase of this task, participants viewed a black screen with two point light walkers presented side by side. One walker illustrated biological motion, depicting thirteen points representing joints of an invisible human figure moving in the same position. The second phase scrambled walker was created by taking the same thirteen points and playing them temporally out of phase. During a final set of trials, the phase scrambled walker was *replaced* with a non-biological alternative. Using the same procedure of displaying stimuli side by side, a thirteen-point depiction of a spinning top leaning and turning (thus representing non-biological motion) was displayed alongside the biological motion walker. Data in the original paper suggest that autistic children do not preferentially look at biological stimuli when compared to phase scrambled or non-biological motion (Annaz et al., 2012).

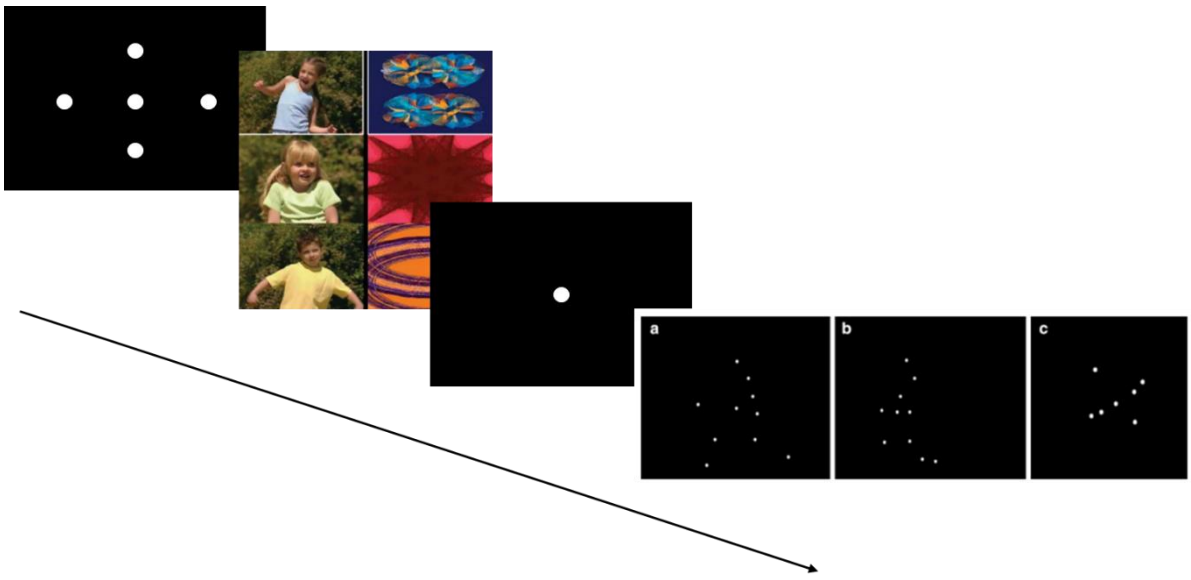


Figure 5.2: Order of presented stimuli used with the EyeLink portable duo to collect data. Stills from the GeoPref task and examples of biological walkers (a & b) and spinning top (c) point light displays are shown

The Early Social Cognition Scale (ESCogS)

The ESCogS is a scaled, play-based assessment that is a direct measure of spontaneous behaviour (Ellis et al., 2020, 2021). The battery includes six tasks of social cognition, drawn from the existing child development literature to assess diverse social cognitive skills (see Table 5.1 for outline of tasks). For each task, infant responses are coded as either a 'pass' or 'fail'.

In line with the authors' guidance on administration, participants completed the tasks in one of six potential orders (outlined in Table 5.2). To generate these orders, the six tasks were split into two groups that were then counterbalanced with the easiest three tasks presented to participants first and the latter three considered more difficult.

Table 5.1: Description and passing criteria for the six tasks in the Early Social Cognition Scale (ESCogS) (as described in Ellis et al., 2020, 2021)

Task	Description	Passing Criteria
Helping	The helping task was derived from the 'out of reach' tasks designed to explore infants' understanding of others' intentions (Warneken & Tomasello, 2006, 2007). There were two trials presented to participants in their appropriate order. 1. A researcher 'accidentally' drops their pen. The experimenter either does not reach for it in the control condition or reaches for it unsuccessfully in the experimental condition. 2. A researcher places six polystyrene cones on a table and picks them up with large tongs. After picking up and placing three cones in a separate box, they then either do not attempt to gather the final three cones in the control condition or reach unsuccessfully for the final three cones in the experimental condition.	Infants were scored a 'pass' if they completed the target behaviour (passing pen *or* cones back to examiner) in either one of the trials.
Re-enactment of Intended Acts	The re-enactment of intended acts task assesses infants ability to infer others' intentions based on goal-oriented actions (Bellagamba & Tomasello, 1999). The task is made up of three experimental trials where participants are presented with an 'object pair'. All trials are administered using the same procedure. 1. A researcher presents the infant with a string of beads and a plastic cup. The researcher then modelled the intention to place the beads in the cup on three occasions but failed all three times with the beads falling to the right, left and in front of the cup. The researcher then handed the object pair to the infant. 2. A researcher presents the infant with a loop that could be hung over a peg on a board. The researcher then modelled the intention to place the loop on the peg on three occasions but failed all three times with the loop falling to the right, left and in front of the peg. The researcher then handed the object pair to the infant. 3. A researcher presents the infant with a square with a hole in it that could be hung over a peg on a board. The researcher then modelled the intention to place the square on the peg on three occasions but failed all three times with the square falling to the right, left and in front of the peg. The researcher then handed the object pair to the infant.	Infants were coded as 'passing' the task if they successfully performed the target action on at least two out of the three trials.
Gestures Pointing	The gestures pointing task was based on 'Communication: Point' trials from previous literature that explored how well infants could follow communicative cues in reference to an object (Behne et al., 2005). This task involved two researchers, a set of matching containers (three pairs were varying in shape and colour), a moveable screen and a small toy.	Infants were coded as having 'passed' the gestures pointing task if they correctly

	1. Researchers introduced infants to the task by administering a 'warm up' first showing the infant all equipment. They then placed a matching pair of open containers in front of the infant and covered their view with a screen. The first researcher then showed the infant the small toy over the screen stating, 'Look I'll hide it!' and placing it in one of the containers. The researcher then moved the screen and asked the infant 'where's the toy?' 2. Two control trials were performed. In these trials, the first researcher administered the task in an identical procedure to the warm up. When the screen was removed, researcher two delivered a 'distracted point' to the container that the toy was hidden in. 3. Two experimental trials were also performed. In these trials, the first researcher administered the task in an identical procedure to the warm up. When the screen was removed, researcher two delivered a 'extended point' to the container that the toy was hidden in, expressing their intent with raised eyebrows.	found the hidden toy on *both* of the experimental point trials.
Gestures Gaze	The gestures gaze task was based on 'Communication: Gaze' trials from previous literature (Behne et al., 2005). This task was integrated into the administration of 'Gesture pointing' given its similarity and followed an identical procedure. 1. Two control trials were performed. In these trials, the first researcher administered the task in an identical procedure to the warm up. When the screen was removed, researcher two delivered an 'absent gaze' to the container that the toy was hidden in. 2. Two experimental trials were also performed. In these trials, the first research administered the task in an identical procedure to the warm up. When the screen was removed, researcher two delivered a 'ostensive gaze' to the container that the toy was hidden in, expressing their intent with raised eyebrows.	Infants were coded as having 'passed' the gestures gaze task if they correctly found the hidden toy on *both* of the experimental gaze trials.
Cooperation Tubes	The cooperation tubes task is a problem solving task that assesses infants ability to develop shared intentionality to achieve a joint goal (Warneken et al., 2006). Infants are required to both coordinate their actions and communicate their intentions during this task. This task involved two researchers, a large cardboard tube with handles that could be pulled apart and a small toy. A familiarisation demonstration was first administered, before four separate experimental trials.	Co-ordination and engagement were coded for the 15 second period of interruption. These were then scored against a predefined

	1. During the familiarisation demonstration, both researchers pulled the tube apart and placed a small toy inside before joining the toy back together. The researchers then pulled the tube apart using the handles to retrieve the toy. The researchers then repeated this once more with a second small toy. 2. After the familiarisation demonstration, the infant was encouraged to hold one handle themselves. The researcher then placed a small toy within the tube and prompted the infant to participate in the task. This experimental trial was performed twice. 3. Following the two experimental trials whereby the infant and researcher worked together to retrieve the small toy, experimental trials three and four were administered. These trials began like the first two, however as the infant began to pull the tubes apart the researcher dropped their handle placing their hands flat on the floor and looking towards the ground. The researcher remained like this for a period of 15 seconds, only continuing the task if the infant interrupted this time to re-engage or once the time period had passed.	coding schema from original authors, and then a median score was calculated across trials. Infants were deemed to have 'passed' this task if they re-engaged with the researcher at least once *and* their median cooperation score was three.
Cooperation Trampoline	The cooperation trampoline task (Warneken et al., 2006) is a social game that assessed shared intentionality to achieve a joint goal in an almost identical way to the cooperation tubes task. This task involved two researchers, a handheld fabric trampoline and a small toy. A familiarisation demonstration was first administered, before four separate experimental trials. 1. During the familiarisation demonstration, both researchers held a side of the fabric trampoline and bounced a small toy in the centre of it. The researchers then repeated this once more with a second small toy. 2. After the familiarisation demonstration, the infant was encouraged to hold the trampoline themselves. The researcher then held the other side of the fabric trampoline, placed a small toy in the centre and prompted the infant to participate in the task. This experimental trial was performed twice. 3. Following the two experimental trials whereby the infant and researcher worked together to bounce the small toy, experimental trials three and four were administered. These trials began like the first two, however as the infant began to bounce the toy the researcher dropped their handle placing their hands flat on the floor and looking towards the ground. The researcher remained like this for a period of 15 seconds, only continuing the task if the infant interrupted this time to re-engage or once the time period had passed.	Passing criteria is as described above for cooperation tubes task.

Table 5.2: Counterbalanced order of tasks in the Early Social Cognition Scale (ESCogS)

Order 1	Order 2	Order 3	Order 4	Order 5	Order 6
Re-enactment of Intended Acts	Helping (control)	Helping (control)	Re-enactment of intended acts	Gestures	Gestures
Helping Task (control)	Re-enactment of intended acts	Gestures	Gestures	Re-enactment of Intended Acts	Helping (control)
Gestures	Gestures	Re-enactment of intended acts	Helping (control)	Helping (control)	Re-enactment of intended acts
Tubes	Trampoline	Helping (experimental)	Tubes	Trampoline	Helping (experimental)
Trampoline	Tubes	Trampoline	Helping (experimental)	Helping (experimental)	Tubes
Helping (experimental)	Helping (experimental)	Tubes	Trampoline	Tubes	Trampoline

The Mullen Scales of Early Learning (MSEL)

The MSEL is an intellectual quotient (IQ) based assessment for children aged 0-68 months and provides standardised scores across five domains pertaining to gross motor, visual reception, fine motor, expressive language, and receptive language (Mullen, 1995). The scale is widely used in experimental and developmental psychology in young children, with standard scores, percentile ranking and age equivalent scores all able to be calculated. Composite scores are considered a proxy measure of IQ in particularly young individuals.

5.6 Procedure

Participants attended the University of Birmingham for two separate sessions within a seven-day period. The separate research visits allowed for a high level of flexibility given

participant's age, with numerous opportunities for breaks. During the research visits, parents or caregivers completed all informant-based measures and infants participated in all direct assessments previously outlined. All assessments were video recorded to allow for later analysis.

5.7 Final sample of participants

Fifteen infants aged between 18 and 36 months old took part. One participant was removed from the sample as a result of insufficient data due to mild distress during data collection. Maternal and participant characteristics (see Table 5.3) as well as individual participant scores (see Table 5.4) are reported below. A total of 14 participants completed the study before the UK national lockdown; 12 full term and two moderate/late preterm infants (MLPT participants were twins).

Table 5.3: Participant and family characteristics of the 14 participants in the final sample

Participant & Family Characteristics	
Birth weight (kg) Mean (*SD*)	3.6 (*5.4*)
Maternal age (years) Mean (*SD*)	33 (*3.1*)
Delivery Mode N (%)	
Vaginal	10 (71)
Caesarean section (scheduled)	2 (14)
Caesarean section (emergency)	2 (14)
NICU Stay	3 (21)
Feeding	
Breastfed	12
Formula	2 (14)
Maternal education N (%)	
5 + GCSE's, NVQ 2	1 (7)
3 + 'A' Levels, NVQ 3, BTEC National	1 (7)
Polytechnic/University degree, NVQ 4	7 (50)
Masters/Doctoral degree, NVQ 5	5 (36)
Family Income N (%)	
<£25,000	1 (7)
£25,001 to £35,000	3 (21)
£35,001 to £45,000	2 (14)
£45,001 to £55,000	2 (14)
£55,001 to £65,000	3 (21)
£65,001 or more	3 (21)

Table 5.4: Individual participant characteristics and subsequent scores across measures

Participant	Sex	Chronological Age (months)	Corrected Age	Gestational Age	Mullen Composite Score	ADOS Total Score	MCHAT Total Score
1	Male	32.26	32.03	39.00	69	1	0
2	Male	29.69	29.75	40.29	89	6	0
3	Male	24.55	24.59	40.14	125	0	0
4	Female	22.23	21.65	37.43	111	2	0
5	Male	26.32	26.36	40.14	133	0	0
6	Female	22.06	22.32	41.14	117	4	1
7	Female	20.78	21.03	41.14	101	6	0
8	Male	21.36	21.06	38.86	108	7	2
9	Male	24.29	24.36	40.29	124	7	0
10	Male	18.42	18.16	38.86	122	1	0
11	Female	28.75	28.69	39.71	141	4	0
12	Male	33.30	34.40	40.40	117	1	0[1]
13[2]	*Male*	*26.46*	*25.65*	*36.71*	*73*	*7*	*1*
14	*Male*	*26.13*	*25.39*	*36.71*	*63*	*3*	*0*

[1] Follow up MCHAT administered and presented

[2]Italics represent MLPT infants

5.8 Data Exploration

Due to small sample size, subsequent lack of power and lack of MLPT participants, running planned statistical analysis was not appropriate. Instead, data comprising 12 full term and 2 preterm participants were explored through a combination of visualisation and preliminary statistical tests as outlined below. Available data did not allow for originally presented aims to be addressed. Instead, the following alternative aims were explored:

i. To explore the differences between MLPT and full-term groups on the Mullen Scales of Early Learning and the Autism Diagnostic Observational Scale.

ii. To explore the profile of social attention on eye tracking measures for full term and MLPT participants.

iii. To explore the relationship between attending to social stimuli (as measured through eye tracking paradigms) and social behaviours (as measured through ESCogS) for all participants.

In order to explore group differences between preterm and full-term groups, data were visualised in two ways and performance on the MSEL and ADOS-2 explored. Firstly, Z scores for all participants were calculated in order to provide a comparable base between different subscales. Z scores provide a numerical representation of how many standard deviations away from the mean each individual score is. Scores were generated using the equation below whereby χ = observed measurement, μ = population mean and σ = standard deviation.

$$Z = \frac{\chi - \mu}{\sigma}$$

Secondly, mean scores were calculated for the full-term group along with upper and lower error bands generated using the group standard deviation. These data were plotted against the raw scores of the two preterm participants. Finally, participant characteristics and assessment scores were correlated to explore the strength and direction of any present relationships that might be indicative of a stronger statistical relation in a fully powered data set.

In order to explore the profile of autism related characteristics within infants born MLPT, eye tracking data for the full term (N=9[7]) and preterm group (N=2) were aggregated in turn and explored. Mean dwell time was first calculated for all interest areas using the summation of the duration across all fixations on the interest area divided by the number of trials using the given interest area. Dwell time percentage was then calculated using the sum of all fixation duration into the interest areas divided by the total fixation dwell time of those trials using this interest area. Static heat maps were also generated for each group across each of the three presented stimuli.

In order to explore the relationship between attending to social stimuli and social behaviours, trial data from the GeoPref eye tracking tasks was compared to scores obtained on the ESCogS. The ESCogS was first scored, taking into account control trials as instructed in the original protocol (Ellis et al., 2020), leaving each participant with a total number of 'tasks passed' score. Trail data from the GeoPref task was then aggregated for all 11 participants and mean dwell time for the social interest area calculated. Participants were then placed into two groups 'above group mean' and 'below group mean' dependant on their own dwell time in the social interest area. ESCogS scores for these two groups were than visualised to explore any potential relationship between longer dwell times in social interest areas and total number of task passes on the social cognitive assessment.

[7] Three participants were unable to tolerate the eye tracking tasks

5.9 Results

Behavioural profiles of full term and MLPT infants

In order to address aim i), data were first visualised in two ways to explore patterns of behaviours for full term and preterm infants.

Figure 5.2 shows Z scores for all participants across domains of the MSEL and ADOS-2. Visual inspection highlights that preterm participants are among those that scored lower on the MSEL. There is some indication that preterm participants score higher on ADOS-2 domains of social affect and total score than on the repetitive behaviour domain, although falling within the term participants mean scores.

Figure 5.3 shows mean scores for full term participants plotted with upper and lower error bands with preterm participants highlighted in blue. Both preterm participants appeared to differ from the broader group on the MSEL according to visual inspection, with infant's scores not overlapping into the error bands of full-term infants.

To consider these behavioural profiles further, behavioural characteristics and scores across measures were preliminarily correlated to explore any potential relationships (Figure 5.5). While sample size restricted any statistical analysis, having a higher gestational age appears to be positively related to all MSEL subdomain scores and lower ADOS-2 scores with the exception of the restricted and repetitive behaviour subscale.

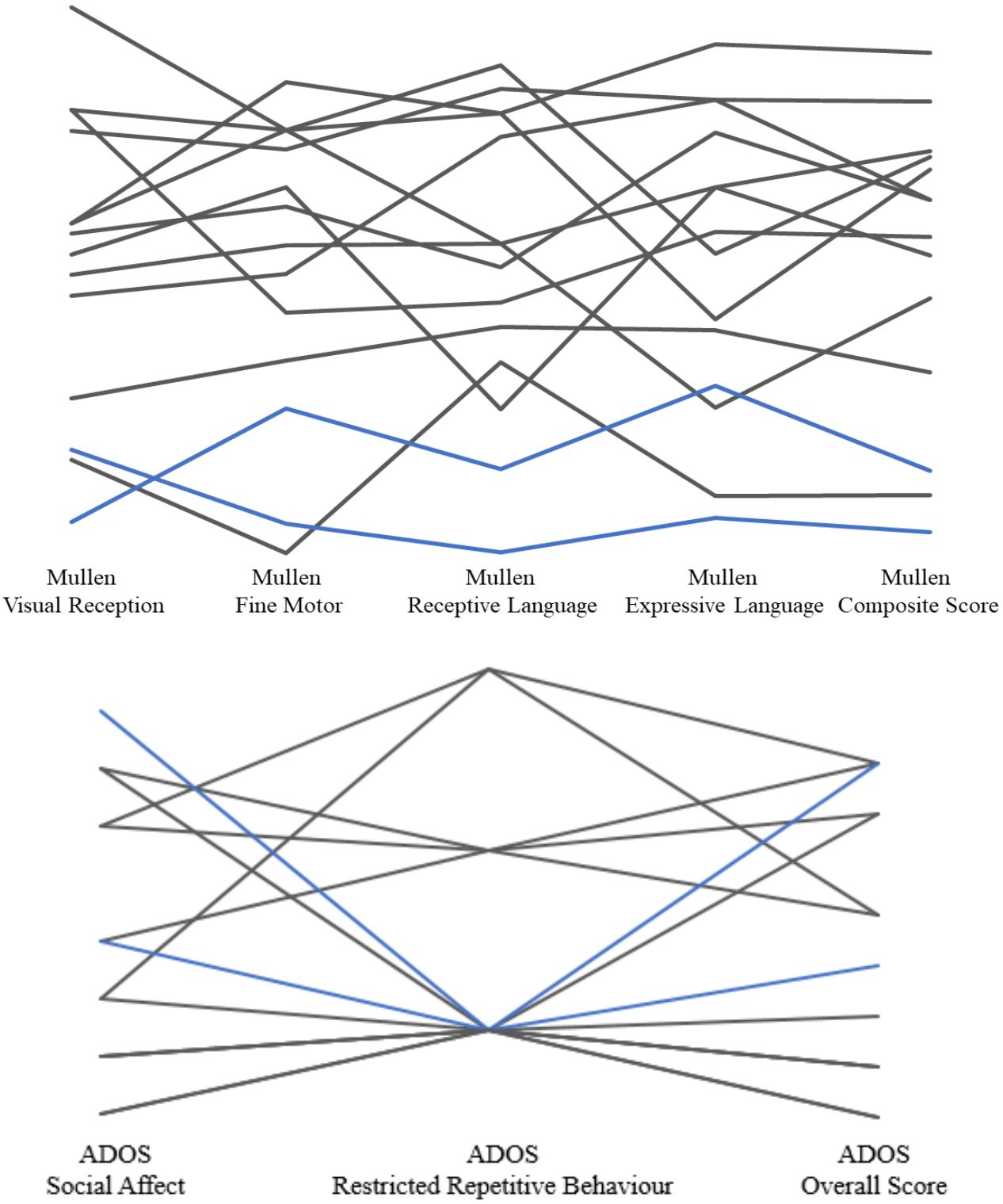


Figure 5.3: MSEL and ADOS subscale and total scores presented as Z scores. Grey lines represent 12 full term participants, blue lines represent 2 preterm participants

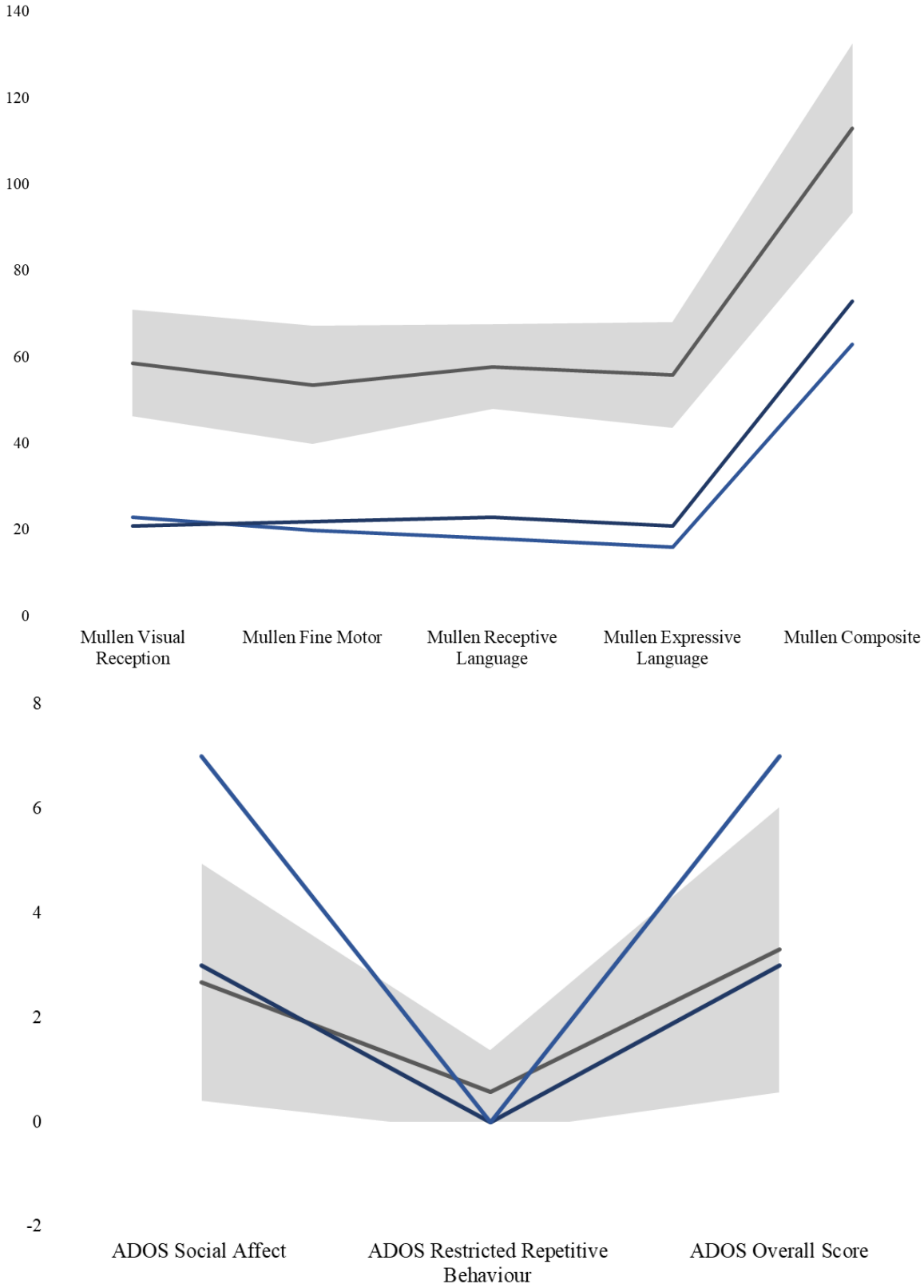


Figure 5.4: Mean MSEL and ADOS subscale and scores for full term participants (black lines) with upper and lower error bands (grey area). Preterm participant raw scores plotted in blue

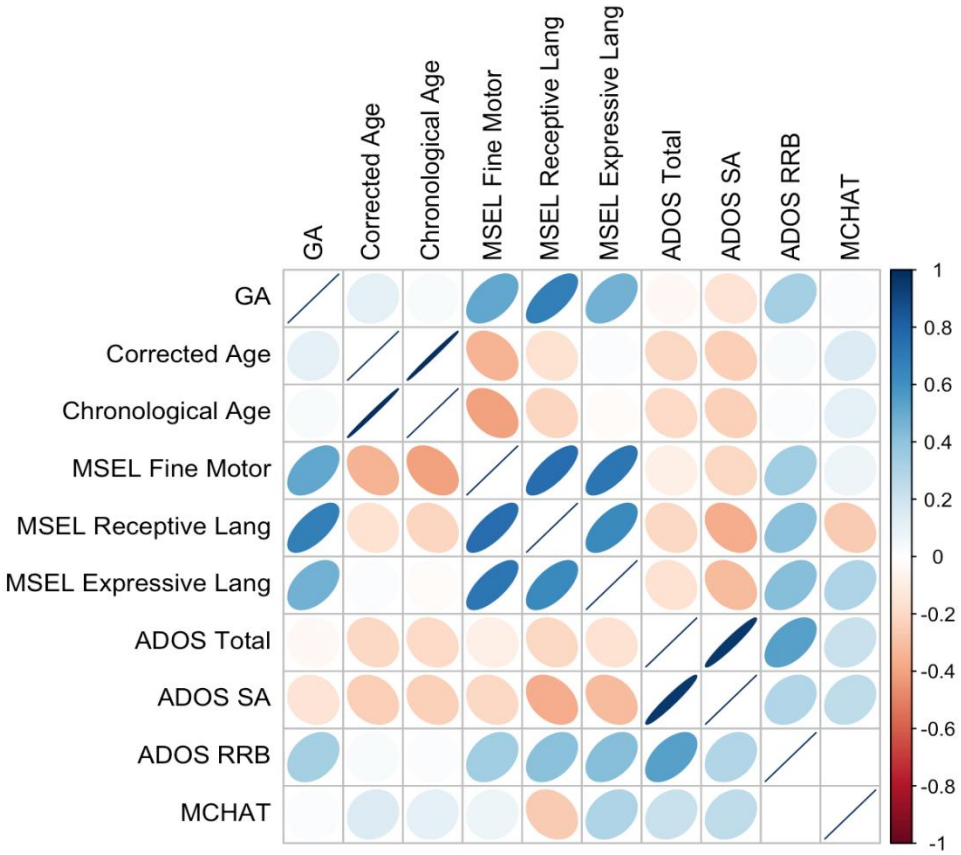


Figure 5.5: Correlation matrix of participant characteristics, MSEL, ADOS and MCHAT scores with strength and direction represented. Red indicates negative correlations and blue positive correlations. The direction of the correlation is indicated by the cells contents pointing up or down, with a thinner semicircle indicating stronger associations

The profile of social attention within infants born MLPT

In order to address aim ii), participants were again separated into term and MLPT born infants and between group differences inspected across all eye tracking tasks.

Table 5.5 presents mean dwell time and dwell time % data for both full term and MLPT infants on the social interest areas associated with each eye tracking task. While a small sample of MLPT participants limits statistical exploration, descriptive data suggests MLPT participants looked at the social stimuli in the GeoPref tasks for less time when

compared to full term participants (MLPT; 54.9% dwell time, full term; 81.8% dwell time). This trend in differences continues when considering the biological and phase scrambled point light displays, with MLPT infants looking for less time at point light displays that represent biological motion (MLPT; 48.5% dwell time, full term; 55.8% dwell time). Yet, when considering the final eye-tracking task (biological point light displays presented next to a spinning point light display), this trend is no longer seen with MLPT infants looking for longer at the biological stimuli (MLPT; 63.3% dwell time, full term; 46.78% dwell time).

Looking patterns outlined in Table 5.5 are further depicted through static heat maps (Figure 5.5). These heat maps were generated by aggregating trial data for all full term and preterm infants in turn, with longer looking times represented by a darker red colour. As outlined in Table 5.5, Figure 5.6 shows that on the GeoPref task MLPT infants looked for *less* time at the social interest area when compared to their full-term peers, indeed looking for *longer* at the genomic interest area. However, when considering both point light display eye tracking tasks, the two MLPT infants showed a similar pattern to the term-born children.

Table 5.5: Mean dwell time and % across the three eye tracking tasks for full term and preterm participants

	Full Term (N = 9)		**Preterm (N = 2)**	
Eye Tracking Task	**Mean Dwell Time Social Stimuli (ms)**	**Mean Dwell Time Social Stimuli %**	**Mean Dwell Time Social Stimuli (ms)**	**Mean Dwell Time Social Stimuli %**
GroPref	38236.7	81.8	20827	54.9
Biological / Phase scrambled	1858.7	55.8	2189.3	48.5
Biological / Non Biological	1729.7	46.7	1346.6	63.3

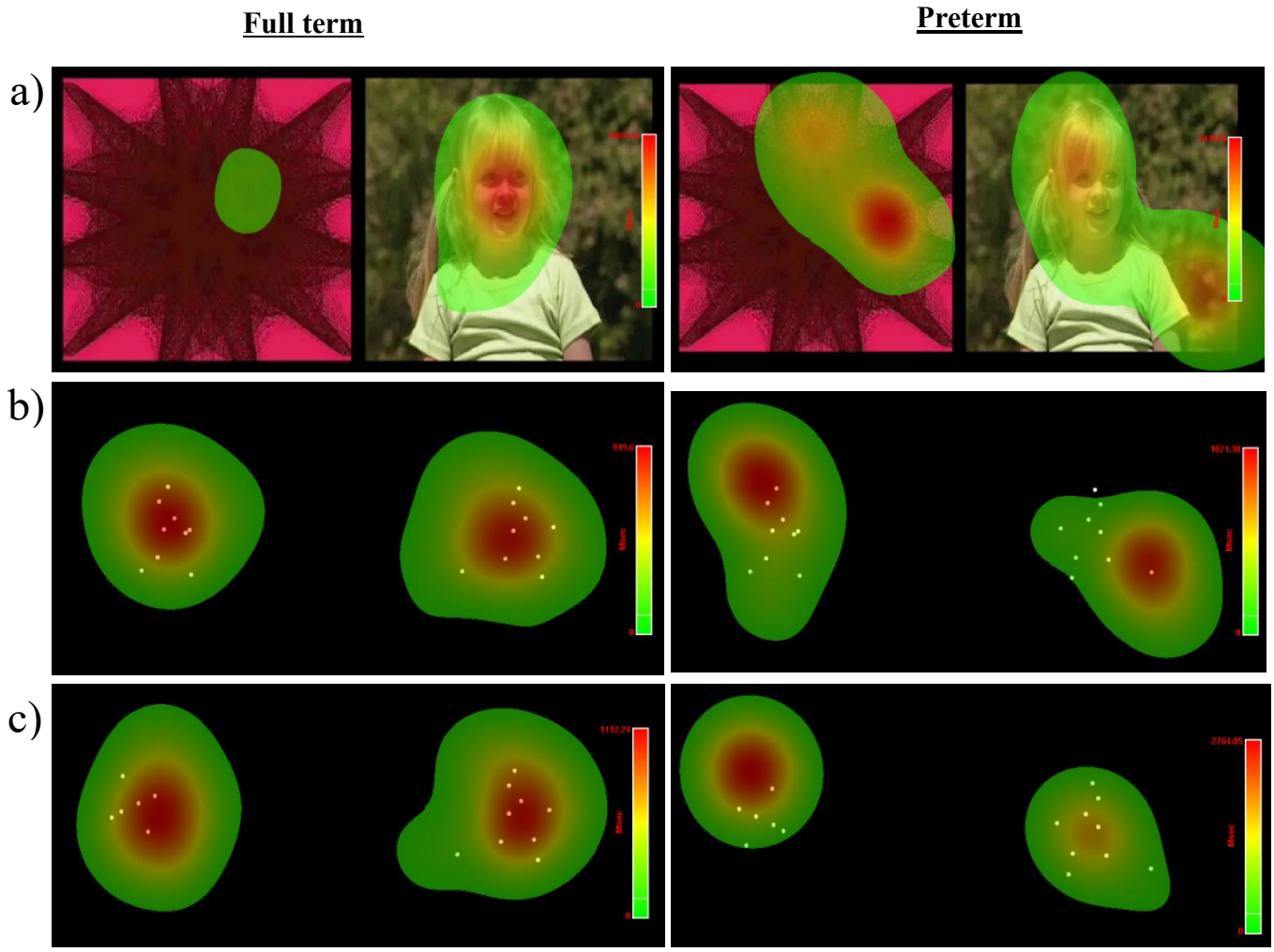


Figure 5.6: Static heat maps across the three eye tracking tasks presented to participants split by gestational age group. Images are presented in order of task presentation to infants; a) GeoPref, b) Biological and phase scrambled motion, c) Biological and non-biological point light displays

The relationship between social attention and social behaviours

To address aim iii), data from the GroPref eye tracking task was combined with behavioural assessments to explore any potential relationship between social attention and social behaviours.

Social Cognition Battery (SCB) scores were first calculated by scoring each individual task (in line with pass and fail criterion outlined in Table 3.1 above). Two tasks had control trials which were first considered to ascertain if infants were performing behaviours as a

result of understanding and interpreting examiners cues and not simply by chance. Number and percentage tasks passed for the full term and MLPT infants are presented in Table 5.6.

Table 5.6: The number and percentage of full term and preterm infants that passed each task on the SCB

	Full Term N (%)	Preterm N (%)
Helping Control	9 (75)	2 (100)
Gestures Point	4 (33)	0 (0)
Gestures Gaze	4 (33)	1 (50)
Cooperation Tubes	6 (50)	2 (100)
Cooperation Trampoline	4 (33)	0 (0)

During the helping control trials, five infants picked up the pen and handed it straight over to the examiner and one infant picked up the paper cone and handed it straight over to the examiner. These behaviours indicate that while we can be certain infants were not obtaining the items for themselves, behaviours may not be exclusively 'helping', and infants could have for example been trying to reinstate the prior situation.

To assess the gesture control trials, data from infants who passed the *experimental* trials were taken and compared to chance levels of performance. This allowed for exploration of whether infants responses (choosing 0, 1 or 2 correct boxes) was as a result of specific gaze or point cues or no greater than performing at chance. Pearson's chi square tests revealed performance did not differ significantly from chance for either task; Control Gaze - X^2 (2) =.33, $p>0.05$; Control Point - X^2 (2) = .33, $p>0.05$, suggesting infants were using gesture cues to pick the correct boxes during the experimental trials.

Taking information from the control trials into account, the number of overall task passes were then calculated to provide each participant with an overall score. Data were then grouped based on a mean split of dwell time % in the social interest area for the GeoPref eye tracking task. Five participants had a dwell times above the mean, and five below which were plotted against the number of tasks passed on the SCB (Figure 5.7).

Visual inspection of Figure 5.7 shows no distinctive pattern or grouping, with no apparent relationship between those that had longer dwell times on the social interest area of the GroPref task and SCB scores.

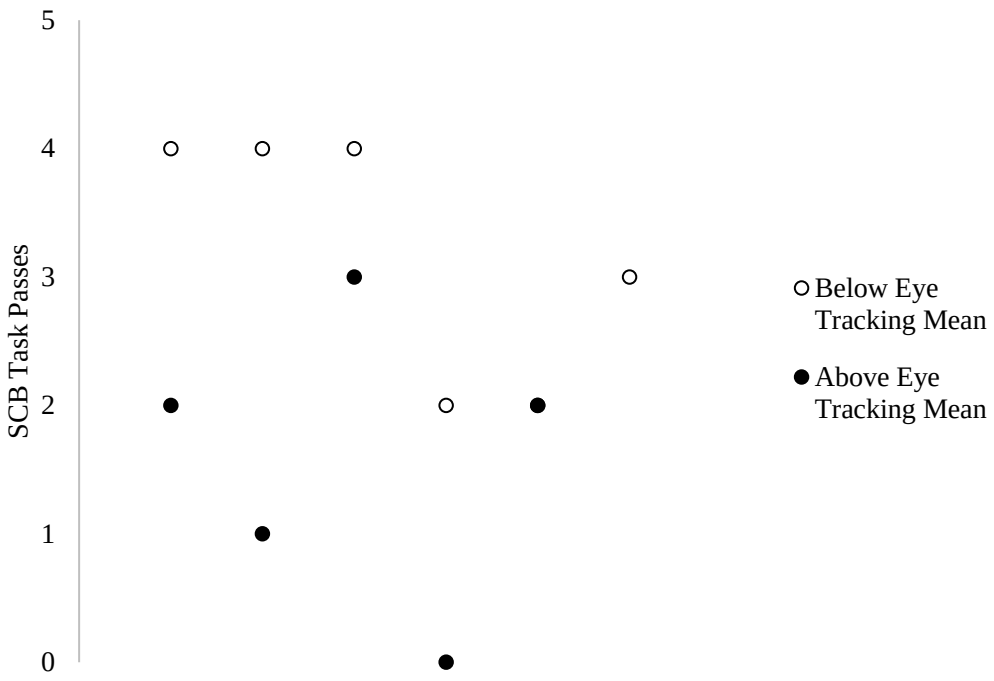


Figure 5.7: Number of tasks on the SCB passed by ten participants, split based upon dwell time % on the GeoPref task

Feasibility of testing protocol

The protocol described within the current study was designed and adapted to be age appropriate and feasible for participants. Practically, testing took place over two separate visits to the University of Birmingham that lasted between one and three hours. These visits were scheduled to take place within two weeks of each other given the varied and rapid development early skills. Many families found the most convenient way of taking part was to schedule in two sessions one week apart at the same date and time. Within the sessions, families were free to take comfort breaks whenever necessary. Older participants took fewer comfort breaks (on average children over two years took four comfort breaks) than younger participants, who took them regularly (on average children under two years took nine comfort breaks). The second testing session (comprising the early social cognition battery and the Mullen) took longer than the initial testing session (the ADOS and eye tracking tasks) on all occasions. In order to streamline data collection at the second session and reduce participant burden, researchers debriefed after the initial testing session and decided as a team where best to start the Mullen assessment, reflecting on the range of infant abilities that they had observed in session one. Questionnaire measures were given to families at the first visit, with the option of completing them within the first testing session or taking them home and bringing them back at the second session. Overall the current study presents a feasible testing protocol for collecting a range of behavioural measures from infants in a way that is accessible for families.

5.10 Discussion

The current Chapter presented a planned protocol for data collection alongside provisional data collected before the UK national lockdown during the Covid-19 pandemic. Given initial recruitment numbers and presented trajectories, the current research presents a feasible protocol that is tolerable for infants born MLPT and at term *and* clearly offers the ability to further enhance current knowledge surrounding MLPT social cognitive skills. Although planned pre-registered analysis could not be conducted due to a lack of power and limited recruitment of preterm participants, preliminary exploration of collected data. Firstly, MLPT participants obtained lower scores on the MSEL than full term infants, with early suggestions of a potential alternate profile of social communicative skills as measured on the ADOS-2. Detailed multi-modal exploration of the social cognitive profile of infants born MLPT remains necessary, with the current protocol offering a clear plan for future research.

Initial exploration of comparisons between MLPT and term born children on both the MSEL and ADOS-2 highlight potential important differences that future research should expand upon. The MSEL was included within the current research as a method of matching participants prior to analysis. While this could not be done with such a limited sample, visual inspection highlighted the necessity to perform such statistical controls across samples. The inclusion of lengthy measures, such as the MSEL or equivalent, across developmental research is not always standard practice (Miller, 2017). Matching strategies aim to control for confounding variables and noncentral constraints that may impact on dependant variables (Jarrold & Brock, 2004). This is particularly pertinent when considering topics such as social cognitive abilities, as literature highlights links between broader intellectual functioning and social cognition (Roberts et al., 2001). Children born preterm show higher levels of cognitive

difficulties (Yaari et al., 2018), an effect that has been evidenced also within those exclusively born late preterm (Setyorini et al., 2010). Research that does not control for such abilities may evidence poor internal validity of dependant measures, with differences confounded by general cognitive ability. Such studies may also overestimate differences that overshadow subtle but important differences only visible when participants are first matched. In line with studies of late preterm children *and* limited preliminary data collected within this study (that could in turn drive any social cognitive differences noted), matching for confounding variables is vital to ensure accurate and comprehensive conclusions can be drawn.

In addition to confirming the importance of controlling for cognitive abilities, preliminary profile analysis in this study indicated some interesting differences on ADOS-2 subdomain scores between term and MLPT groups. Visual inspection highlights the potential discrepancy across domains that may be missed in wider group level analysis. Such findings prompt interesting questions about the potential profile of social cognitive differences within those born MLPT and how these could map onto the current diagnostic algorithm. A recent large scale analysis of autistic participants that were born very preterm and autistic participant born at term highlighted that these two groups were distinguishable based on their behavioural profile (Chen et al., 2019). Those born very preterm displayed significantly more difficulties when compared to a matched term born group of children with autism in relation to their nonverbal social communicative behaviours as evidenced through parental report on the Autism Diagnostic Interview Revised. No such comparison data yet exists for those born MLPT, with the current research protocol providing a clear mandate to collect this evidence. The identification of an alternate profile of social cognitive difficulties when compared to

both those with idiopathic autism and those born at full term would provide a stable evidence base to consider appropriate service provision and support for those born MLPT.

Preliminary correlations between gestational age, chronological age, ADOS-2 and MSEL scores reveals some interesting associations. While sample size limited the ability to inferentially explore these associations, observations of the direction and apparent strength of some relationships highlight areas that would be of value to explore in a larger sample. Gestational age appears to be positively correlated with most areas within the matrix apart from the ADOS-2 social affect score. Given findings outlined this far in this thesis (such as those in Chapter 3), the exploration of the association between gestational age and a direct measure of social affect would be of particular interest. If corroborated within a larger sample, findings may point towards infants born at earlier gestations have greater difficulty with items contributing to the ADOS-2 social affect score. Similarly, ADOS-2 social affect scores appear to be negatively associated with all MSEL subdomains, with the MSEL receptive language domain of particular note due to its apparent strength. These associations potentially reflect the dynamic nature of early motor and language skills with infants' wider social development (Fogel & Thelen, 1987), and has been the focus of much research exploring these early skills in infants who later receive a diagnosis of autism (Bradshaw et al., 2018; Karmiloff-Smith, 1998; Neimy et al., 2017). The exploration of these associations through methods outlined in this chapter across a wider sample of participants would assist current understanding of the intricacies of early development and its putative links with gestational age.

Exploration of gaze patterns across eye-tracking measures employed within the current study showed provisional evidence for those born MLPT looking less towards social stimuli. Within the GeoPref paradigm, the two children born MLPT had lower dwell time percentages towards the social stimuli than their full-term peers. This finding links with literature describing similar looking patterns within those born preterm (Imafuku et al., 2017). Evidence highlights those born preterm (mean GA 35wks) orient less towards faces within the first hours of life than term new-borns (Pereira et al., 2017) with this appearing to translate into a reduction in gaze following at nine months (mean GA 29.3wks) when compared to term born peers (De Schuymer, De Groote, Beyers, et al., 2011). Emerging research also highlights a potential visual field bias for preterm children (mean GA 29wks), with differential orienting preferences evidenced that may be indicative of later identified atypical lateralization (Davis et al., 2022). While sample size within the current study prohibited any inferential analysis of visual field bias for the two preterm participants, this would be of particular interest to explore across a larger sample. Importantly, eye-tracking methods have been noted as a useful tool for identifying meaningful differences within those born preterm that warrant further support (Telford et al., 2016). The current research plan shows such paradigms are both practical with infants born MLPT, and also yield meaningful data. Research further evidencing looking profiles seen in those born MLPT and their subsequent links with behaviour would greatly assist further service provision and support.

To conclude, though the present study was impacted by the Covid-19 pandemic, preliminary exploration of collected data yields important suggestions for future research. Visual inspection of the profile of social differences in MLPT infants alludes to a potentially unique pattern specifically of higher reciprocal social interaction difficulties. Further detailed

exploration of this is warranted to support adequate and timely service provision where necessary. Initial exploration of dwell time patterns corroborate findings across the wider prematurity literature and support the exploration of these patterns in relation to behavioural observations. The planned study is deemed both feasible within the population of MLPT children *and* necessary from initial exploration of preliminary data.

CHAPTER SIX

GENERAL DISCUSSION

6.1 Preface

The qualitative data in Chapter 4 provided insight into mothers' experiences of having a MLPT born child. The findings explored the 'relevance' of the MLPT label for families and highlighted areas where more information and support would be appreciated. Parental perspectives appeared to potentially contrast the quantitative data derived within this thesis (Chapters 2, 3 and 5), that highlighted specific areas of need for those born MLPT. In this chapter, findings across the thesis are synthesised and discussed in relation to existing literature and relevant clinical implications. The strengths and limitations of these findings are explored with directions for future research considered.

6.2 Introduction

Preterm birth accounts for 15 million births worldwide each year (World Health Organisation, 2018), with rates rising year by year (Vogel et al., 2016). Advances in neonatal clinical care have positively increased survival rates over the past decade (Stoll et al., 2015). Concomitant with this increase in survival rates is the exploration of longer-term neurodevelopmental outcomes following preterm birth. Much research has evidenced that those born at the earliest gestations (labelled extremely or very preterm) show difficulties in areas of cognition, language, social and emotional skills and eating behaviours (Johnson et al., 2015). Given the predominance of those born at the earliest gestations across the literature, a previously held prevailing view was that difficulties of those born nearer to term (labelled as MLPT) were less pronounced and similar to their term born peers (Raju, 2017). Yet, recent exploration of longer term neurodevelopmental outcomes of those born MLPT suggests a unique presentation of subtle differences (Gill & Boyle, 2017). Of note, heightened prevalence of autism and social differences have been documented (Agrawal et al., 2018), although poorly characterised for those born MLPT.

The broad aim of this thesis was to describe the neurodevelopmental and behavioural outcomes following MLPT birth, with a specific focus on social abilities. The results of studies conducted as part of this thesis contribute to clarification regarding the downstream consequences of preterm for both those born preterm *and* their families.

To achieve the aims described in section 1.7, a fine-grained systematic review of the literature was conducted detailing the prevalence of autism characteristics within preterm populations (Aim 1). This synthesis was the first analysis inclusive of both gold standard

diagnostic assessments of autism *and* screening measures (commonly used within MLPT populations). Three further empirical studies were conducted to address the remaining aims. Through a widescale cross sectional survey, the profile of social behaviours across childhood was described for a sample of MLPT born children (Aim 2), with a consideration of this social profile within the context of the wider observed profile of behaviour and executive functioning. A qualitative interview with mothers of those born MLPT was conducted to gather a crucial parental perspective (Aim 3). Finally, a study of MLPT born infants' early behavioural profile was planned that used gold standard autism assessments, a nuanced social cognition battery and eye-tracking methodologies (Aim 4). The main findings, strengths and limitations of this mixed-methods approach to MLPT children and their families is discussed below, alongside a consideration of how these findings fit with wider prematurity research.

6.3 Main findings

Given the broad aims of this thesis, key findings are synthesised within their application to three themes; the prevalence of autism characteristics, the profile of social differences and parental perspectives on having a MLPT born child.

6.3.1 Prevalence of autism characteristics (Aims 1 and 2)

The data in Chapter 2 extended current understanding of the prevalence of autism characteristics in individuals born preterm. The study meta-analysed data across both diagnostic and screening tools, providing novel estimates of prevalence across gestational age. Autism characteristics were present in 6-20% of preterm individuals, considerably higher than general population estimates (1.5%; Maenner et al. 2020). Findings were consistent with a recent meta-analysis of autism in preterm individuals that included only diagnostic tools (7%;

Agrawal et al., 2018), extending these results beyond those born very preterm. Alternate prevalence estimates for screening tools (20%) and diagnostic assessments (6%) were generated, which suggested those born preterm are more likely to have difficulties consistent with an autism diagnosis and show heightened rates of autism characteristics compared to the general population. It is acknowledged that, when comparing screening measures to diagnostic assessments, the differing tools are asking different questions; one surrounding the presence and levels of autism characteristics whilst the other only identifies those that reach diagnostic cut-off. High prevalence estimates obtained through a systematic gathering of evidence using screening tools alludes to an increase in clinically meaningful differences that do not meet the threshold for a formal diagnosis for some individuals born preterm. No association between gestational age and prevalence of autism characteristics was found, alluding to a *lack* of gradual decrease in prevalence as gestational age increases. This is an important consideration when later looking specifically at those born MLPT.

The data presented in Chapter 3 provided further evidence on the prevalence of autism characteristics, more specifically within those born MLPT across early childhood. The sample did not reach published cut-offs on age-appropriate validated autism screening tools (MCHAT – 'high risk' = 5.5%; SCQ - $\geq$15 = 2%). However, a slightly larger number of participants fell into the clinically meaningful categories (SRS – 'moderate or severe clinical differences' - 15.5%) on an alternate measure of social differences. In Chapter 3, the use of screening tools to identify those for whom further neurodevelopmental assessment may be warranted was discussed.

Taken together, findings from Chapter 2 present prevalence estimates of autism characteristics in those born preterm that are higher than those in the general population. No effect of gestational age was found, a surprising finding though perhaps in line with practical understanding of prematurity. This is partly contradicted by evidence collated in Chapter 3 suggesting equally low estimates of social differences for those born MLPT when using screening tools (MCHAT, SCQ and SRS). Yet, the precise picture of social abilities is unclear and not captured entirely through the use of questionnaire measures alone. High prevalence estimates evidenced through a systematic literature search and directly through the use of validated screening measures point towards a considerable area of need or wider neurodevelopmental follow up for those born MLPT. This directly contrasts current neonatal follow up recommendations as published in NICE guidelines, which reserves comprehensive additional developmental follow up to those born ≤30 weeks (McKinnon & Huertas-Ceballos, 2019).

The results of this thesis support a recommendation that, as a first step, the span of gestations eligible for comprehensive developmental follow up is widened to include those born at all preterm gestations (<37 weeks). Moving beyond the current clinical structure of service provision characterised as a reactive rather than proactive system (Root et al., 2022), evidence from this thesis would support the provision of screening tests to all children born MLPT and providing further neurodevelopmental assessment when indicated. A remaining question is the degree to which children born preterm are being diagnosed with autism in the absence of a more appropriate diagnostic label. This is an important consideration, with discrepant results within the current thesis (Chapter 2 and Chapter 3 providing alternate profiles of social cognitive differences). A wholistic approach to neurodevelopmental follow ups considering *all* aspects of social and cognitive development may be valuable for individuals born preterm. Tailored neurodevelopmental follow up can be costly, produce high numbers of 'false positive' cases and may not be in line with parental priories (such as those

documented in Chapter 4). Combining a formal neurodevelopmental follow up with research protocols such as those described in Chapter 5 may in fact provide a more comprehensive profile that is more useful to families and is a method of that future research and service provision should endeavour to adopt. Concomitant with this, the psychometric properties and appropriateness of screening tools commonly used across clinical services and in research should be explored.

6.3.2 Profile of social differences (Aims 1, 2 and 4)

A pre-registered planned analysis strategy for systematic data synthesis described in Chapter 2 was to explore the profile of autism characteristics *within* those born preterm. Due to insufficient data across the literature this was not possible, as subscale scores for social communication and restricted repetitive domains were consistently not reported. This highlights the lack of clarity within current reporting methods, limiting the progression in understanding the social profile of those born preterm. A shift within the research landscape highlights individual characteristics and traits are more valuable to consider than 'autism severity' scores as previously done (Robertson, 2009). As such, precise documentation of the profile of autism evidenced by individuals born preterm is vital to further understand the profile of need at an individual level.

In response to the limitations identified in Chapter 2, the data in Chapter 3 provided the first comprehensive documentation of the profile of social differences in those born MLPT. Appropriate comparisons were made within the sample of children born MLPT *and* to the general population allowing for a wider consideration of the profile of social differences for those born MLPT. Only a small proportion of participants scored above clinical threshold for autism on dichotomous screening tools preventing any analysis of group level profiles of

difficulties. Exploration of the social profile of MLPT children compared to the general population showed no apparent differences through visual inspection or inferential analysis on subscales of the SRS. This evidence provides important considerations for the use of support garnered from the wider autism intervention literature. Firstly, population level screening for those born preterm to identify individuals in greater need of support is both warranted and feasible. For MLPT children who do not meet diagnostic threshold but display clinically meaningful behaviours that impact daily life, a more useful approach would seek to support interactions as a whole between autistic and non-autistic individuals (rather than aimed solely at the autistic person), recognising the bidirectionality of social differences (Davis & Crompton, 2021). Wider research, such as the methodological approach outlined and preliminarily implemented in Chapter 5, would allow for the corroboration of these findings using behavioural measures such as ADOS-2 (Lord et al., 2012). Importantly, moving beyond evidence provided in Chapter 2, exploration of the association between skills such as theory of mind, executive functioning and social differences would build on Chapter 3's findings to explore whether, for example, the restricted and repetitive behaviour and social domains dissociate entirely for MLPT children. Such exploration would also allow for further understanding of the specific domains predicted by wider skills (such as theory of mind or executive functioning). These important questions derive from evidence provided in Chapter 3 and provide an exciting avenue for future exploratory research.

The study presented in Chapter 5 aimed to carefully describe the profile of autism characteristics using the MCHAT-R and ADOS-2, and early social cognitive behaviours through eye-tracking paradigms and ESCogS in a sample of MLPT children. Given evidence collated in Chapter 3, further exploration would have provided useful insight into questions

raised from the use of questionnaire measures that could only be answered confidently through direct behavioural and experimental observations. The Covid-19 pandemic had a significant detrimental impact on the completion of this research and as such planned data analysis was replaced with preliminary data exploration. Despite this, important considerations from this chapter have been raised. Continuation of this study would provide more precise evidence from a well-defined population of MLPT infants and should be considered as a priority for future research.

Preliminary data exploration within Chapter 5 also presented the method for identifying profile of autism characteristics within participants born MLPT. Within the 14 children tested, ADOS-2 subdomain scores highlighted considerably lower scores on the restricted and repetitive behaviour subscale when compared to social affect and overall scores. Though the Covid-19 pandemic meant that this chapter could not provide definitive clarification of the profile of social differences for MLPT infants, it highlights that such exploration is both feasible and necessary.

Combined, these findings provide useful insight into both the field of prematurity and the behavioural profile of those born MLPT. In line with a move towards more transparent reporting and open science, published research should provide sufficient detail towards the profile of scores across measures, rather than broader total score averages. Such clarity would immediately further our understanding of the profile of social differences across groups and greatly advance the capabilities of larger scale data collation methods. Evidence suggests that those born MLPT have specific difficulties in areas concerning reciprocal social interaction. Future research should consider the utility of providing a tailored package of support, rather

than broader early interventions that target all aspects of autism related differences. Importantly, any packages of support should be informed by and co-produced with parents of MLPT children to ensure what is created is aligned with their perspectives as well as with evidence (as discussed in consideration of Aim 3 below).

6.3.3 Parental perspective of moderate or late preterm birth (Aim 3)

In the first qualitative interview study of its kind, Chapter 4 of this thesis explored the experiences of six mothers of MLPT children. Contrastingly to earlier studies detailing the prevalence and profile of social differences, findings offered unique insights into the ways in which mothers of MLPT new-borns classify themselves as having a 'preterm' child and how this appeared to diminish with age. Mothers identified a need for more information about preterm birth to be provided throughout pregnancy and the early years, with many drawing comparisons to both those born at earlier and later gestations as a reference for their experiences. There appeared to be a disconnect between documented outcomes that in turn warrant further support and the support parents think is necessary. Arguments made around 'early intervention' by the research community should perhaps shift to be discussions around more timely support for those identified as being most vulnerable to the effects of MLPT birth. Further surveillance and interventions should take into account the fact that mothers of MLPT infants may not be aligned to the preterm identity and may, in fact, find the label and subsequent need for support stigmatising.

6.4 Strengths and limitations of the research

There are several key strengths that increase the validity of findings from this thesis. Firstly, empirical data was drawn from a range of methodologically appropriate techniques

across a sample of MLPT children. Methods throughout combined systematic searching, gold standard behavioural assessments, reliable eye-tracking paradigms, validated questionnaire measures and qualitative interviews to address the outlined aims. There is significant merit in addressing questions through mixed methods to collate a detailed and well-rounded perspective (Shneerson & Gale, 2015). For example, the qualitative interviews presented in Chapter 4 offered unique insight into an area of need for information that would not have been acknowledged in Chapters 2, 3 or 5. Conversely, the indicated need for further support and intervention in the domain of social cognitive differences that could be derived from the data in Chapters 2, 3 and 5 must be appropriately weighted against parental experiences and desires for such intervention, which were arguably not articulated in Chapter 4. Together, the generalizability and clinical utility of this research is broadened as a direct result of the range of methods employed in the thesis.

Alongside being methodologically valid, another key strength of the current research is its awareness and commitment towards more open developmental science. All research conducted within this thesis was pre-registered on appropriate open science platforms prior to data collection. Over the past decade, the discovery that many seminal scientific studies do not replicate, are not valid or now lack explanatory power is widespread (Yarkoni, 2020). This is a particularly pertinent issue, for example within the time frame of this PhD thesis, seminal papers used initially to contribute to power analysis calculations (Southgate et al., 2007; Section 3.4) have since been rebutted as non-replicable (Kampis, Kármán, Csibra, Southgate, & Hernik, 2021). This openness represents a shift towards rewarding open and transparent findings and not seeing non-replication as ‘failure’ (Hobson, 2016). This thesis made every attempt to progress with a movement to more open and available developmental

research. A mix of planned or preliminary analysis was presented, with *both* significant and non-significant results. This is in response to growing concern that current evidence bases are overly representative of significant findings only.

However, methodological limitations must be considered when interpreting the findings of this thesis. At the forefront of these is the considerably small sample across the three empirical studies. While data analysis in Chapter 3 did meet pre-planned thresholds for statistical power, further research with larger samples corroborating results would considerably strengthen their impact. Although studies presented in Chapters 3 and 4 were adapted to be completely remote in the context of the Covid-19 pandemic, recruitment was subsequently restricted to be entirely online which undoubtedly impacted the number of participants and introduced a level of bias in those that did respond. Planned recruitment strategies included visiting schools, nurseries and NHS sites (such as well baby clinics and health visitor appointments) and these were all incompatible with government restrictions. Specific recruitment plans outlined in Chapter 5 had to be stopped immediately, despite the knowledge that had the research continued on the early trajectory, sample size requirements would have likely been met in nine months. Despite this, the current thesis presents comprehensive evidence from a sample of MLPT children. In line with a movement towards a more replicable developmental research field, adopting methods presented with an alternate sample of MLPT born children would considerably enhance the reliability of conclusions drawn.

The generalizability of samples should also be considered when corroborating results. Chapter 3 presents a sample of parents and caregivers across nine different countries. Given

the small number of respondents from each of these countries, all of whom have different healthcare provisions and neonatal follow up recommendations, exploration of country specific factors could not be explored. Chapters 3 and 4 were also populated entirely by mothers of MLPT born children, with no paternal or wider caregiver' perspectives included. Larger samples that are inclusive of alternate geographical perspectives on a wider scale *and* paternal or other caregivers' perspectives would considerably benefit the generalisability of results.

A further limitation of the current research was the lack of consultation with parents and caregivers of MLPT born children within the design process of empirical studies. Patient and public involvement (PPI) is recognised as increasingly valuable at all stages within the research process (Department of Health, 2002; Jennings et al., 2018; Nilsen et al., 2006). Chapter 3 aimed to explore the prevalence of, and subsequent need to support social differences, yet findings in Chapter 4 suggest little concern specifically towards needing further neurodevelopmental assessment. Such discrepancies are evidence of the value in PPI inclusion to ensure; 1) our understanding of identifying areas of potential support needs are not based solely on questionnaire data, particularly when this is discrepant, and 2) future research priorities are in line with parental need. Wider exploration of research priorities for parents of preterm children corroborates themes developed in Chapter 4 such as the requirement for additional information throughout pregnancy (Franck et al., 2020) and regarding later cognitive and developmental outcomes (Ginnell et al., 2021). Future research should, where possible, be driven by the requirements and priorities of participants.

6.5 Clinical implications and considerations

There are several clinical implications that arise from the findings of this thesis. Firstly, the consideration that children born MLPT may present with an increased likelihood for autism characteristics compared to their term born peers (Chapter 2). Early identification of autism is closely linked to optimal development and timely access to appropriate support (Clark et al., 2018), with a diagnosis later in life associated with considerable emotional distress (Huang et al., 2020). In light of evidence presented showing that those born MLPT are more likely than their full-term peers to display social cognitive differences, additional neurodevelopmental follow up would be beneficial for this group.

Concomitant with this are parents' requests for further information surrounding preterm birth and its potential neurodevelopmental outcomes both throughout pregnancy and in the early years. NICE guidelines detail the extent to which parents of children born preterm receive information and support *after* the birth of their child; surrounding immediate postnatal care, at discharge and across the early years (McKinnon & Huertas-Ceballos, 2019). Yet, there are currently no guidelines surrounding information provided throughout pregnancy prior to birth. Evidence presented in this thesis would support the roll out of an easily accessible programme of information to be distributed at regular antenatal appointments or after a preterm birth. This should be co-created with parents, driven by their priorities for information needs. Such education strategies would complement additional neonatal follow ups suggested.

A more nuanced clinical consideration to take into account following both evidence provided within this thesis and the context in which it was collected is the impact findings

may have on an entire cohort of infants born since 2020. The Covid-19 pandemic had a significant detrimental impact on numerous areas of this thesis, yet it should be considered that this thesis yields the potential to have a significant positive impact on *all* infants for whom their earliest years have been affected. The past two years have seen numerous national lockdowns as well as the cancelation and disruption of routine health visitor checks (Conti & Dow, 2020). This will have been at a critical developmental period for an entire generation of children (Pelekasis, 2021), with initial discussion describing the potential impact mask wearing may have on early facial processing and later social cognitive developmental skills (Carnevali et al., 2021). Moreover, given the context of the Covid-19 pandemic, intervention efforts such as those mentioned targeting reciprocal social interaction may be beneficial for an entire cohort of children. The conclusion that population wide screening may be beneficial and support should be tailored at an individual profile level is not reserved primarily to those born MLPT and may be particularly pertinent for those whose early years have been impacted by the pandemic.

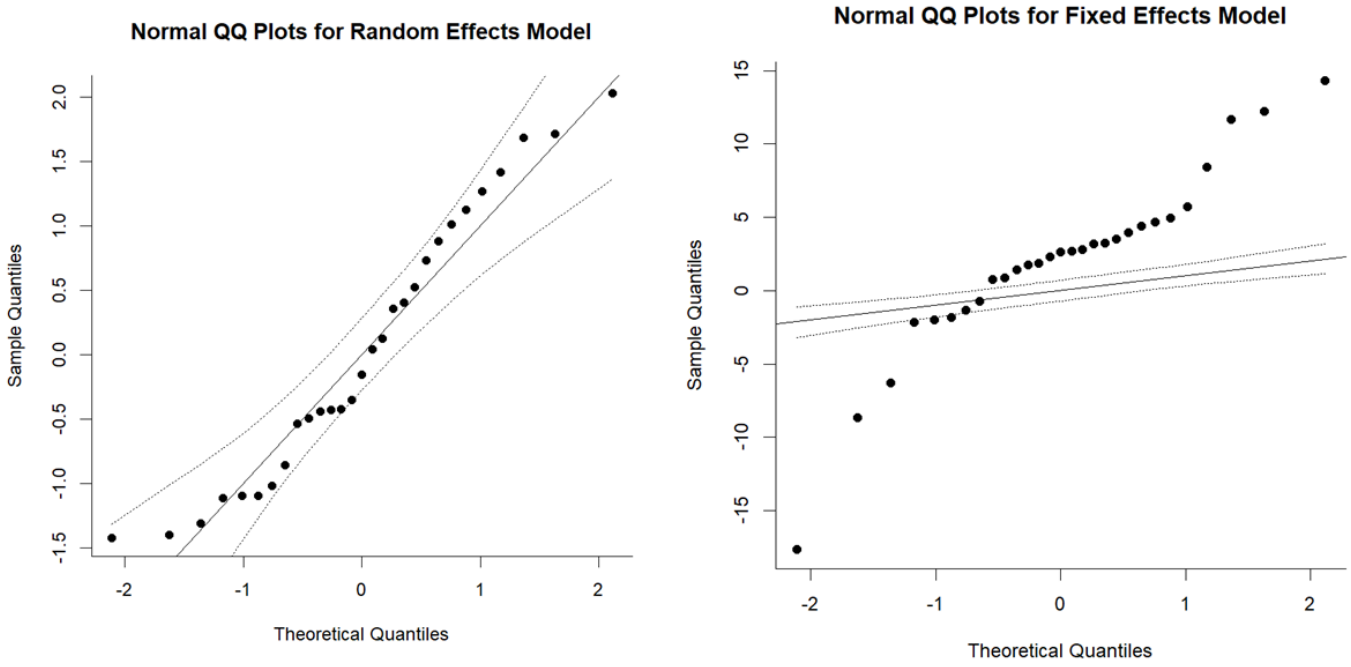
6.6 Overall conclusions

This thesis contributes to an exciting field of growing literature broadening our understanding of MLPT birth and its downstream impact. Research presented details the prevalence of autism characteristics, the profile of social differences and most of all the importance of considering differences specifically for those born $32^{+0/7}$ - $36^{+6/7}$ weeks gestation. For many years, a narrative prevailed that exclusively described a range of outcomes for those born at the earliest gestations only. Though a previous predominant narrative was that those born MLPT were considered 'similar' to their term born peers, this thesis contributes to a shift in thinking (Raju, 2006). The value of research is in its ability to answer questions in a robust way that is meaningful to those for whom it is about. Ultimately

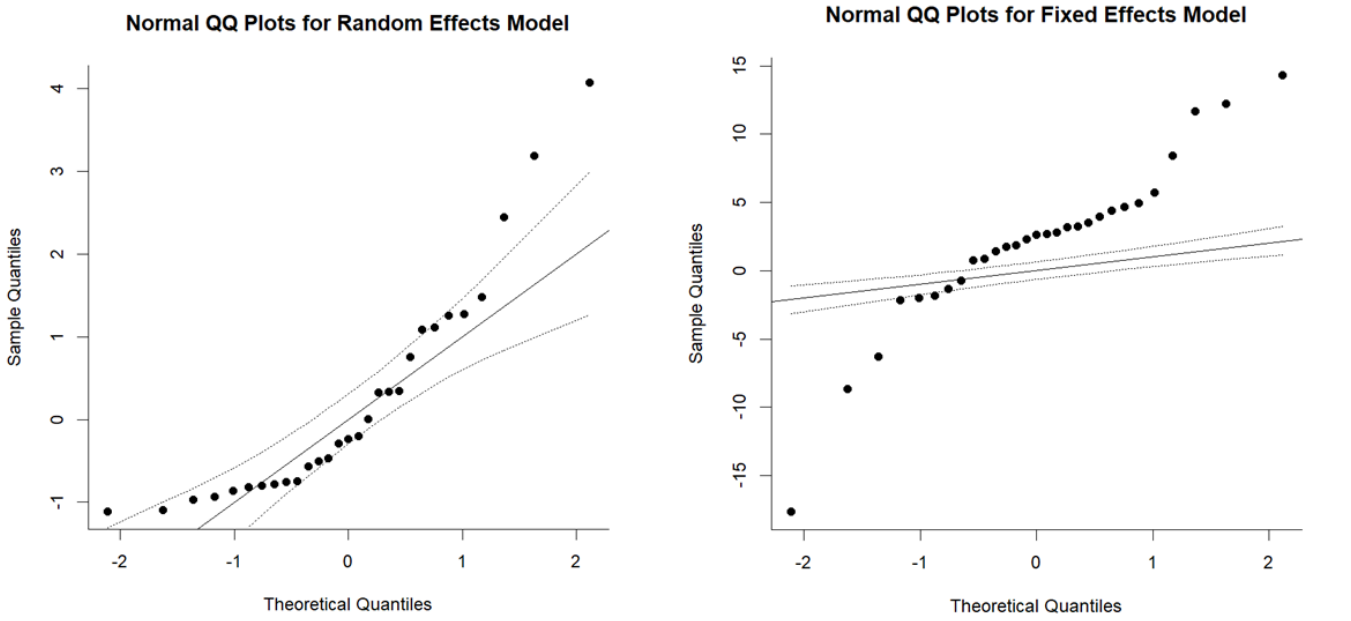
researchers, clinicians and the community must work together to provide each child with the support they need in a timely manner. Every individual start in life is important, the goal of adequate research and service provision must be one in which each child has the means to flourish.

APPENDICES

Screening Tools

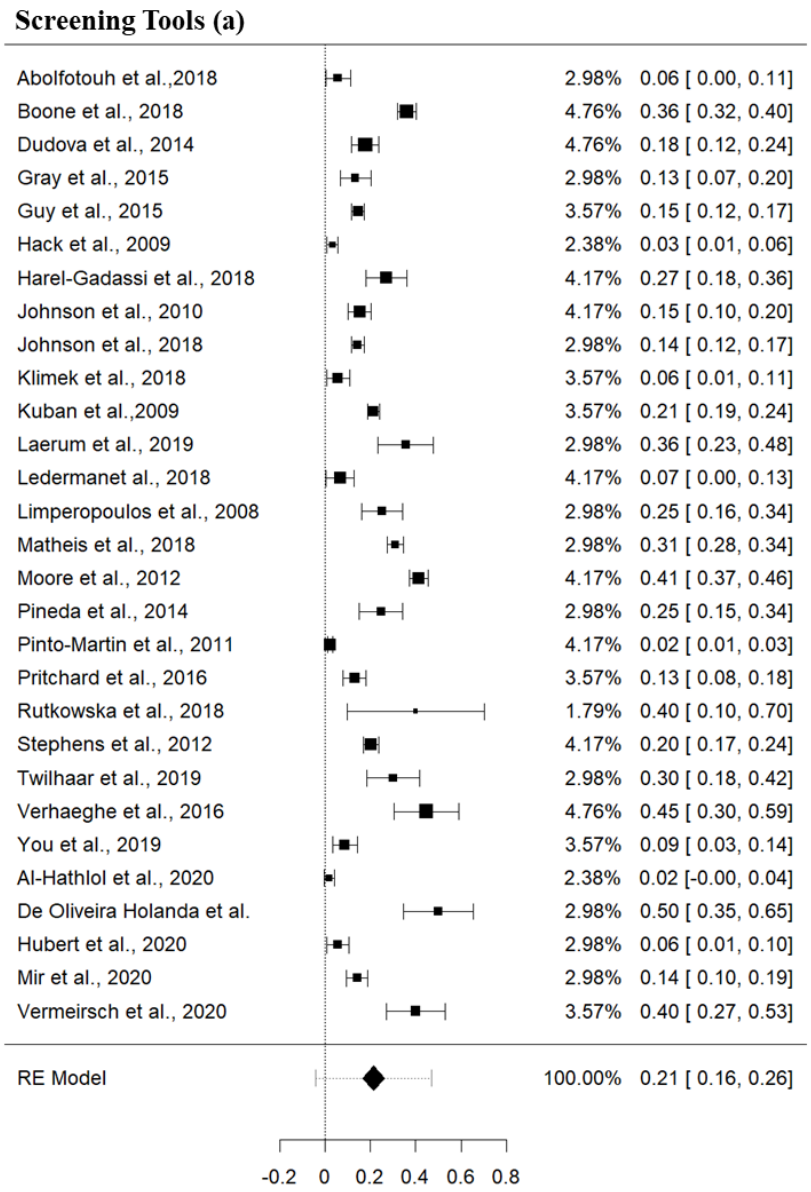


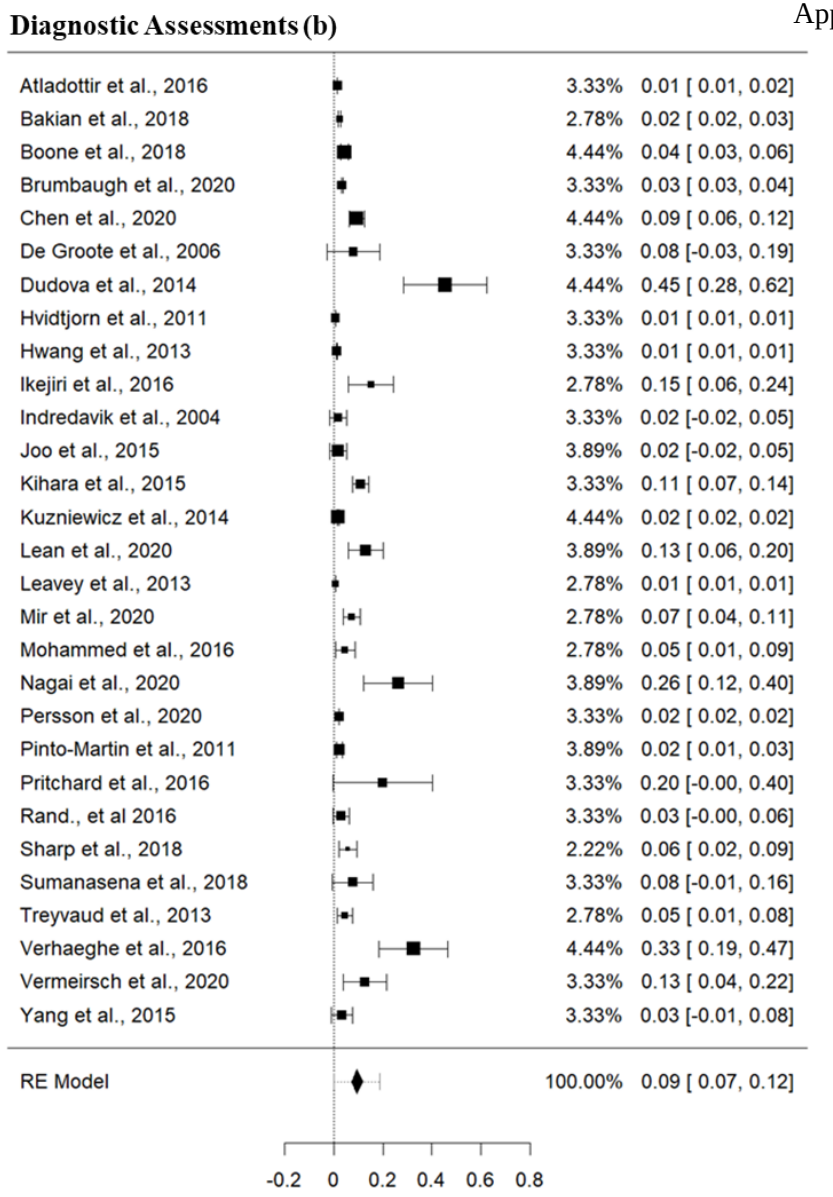
Diagnostic Assessments



Appendix 1: Quantile-Quantile Plots

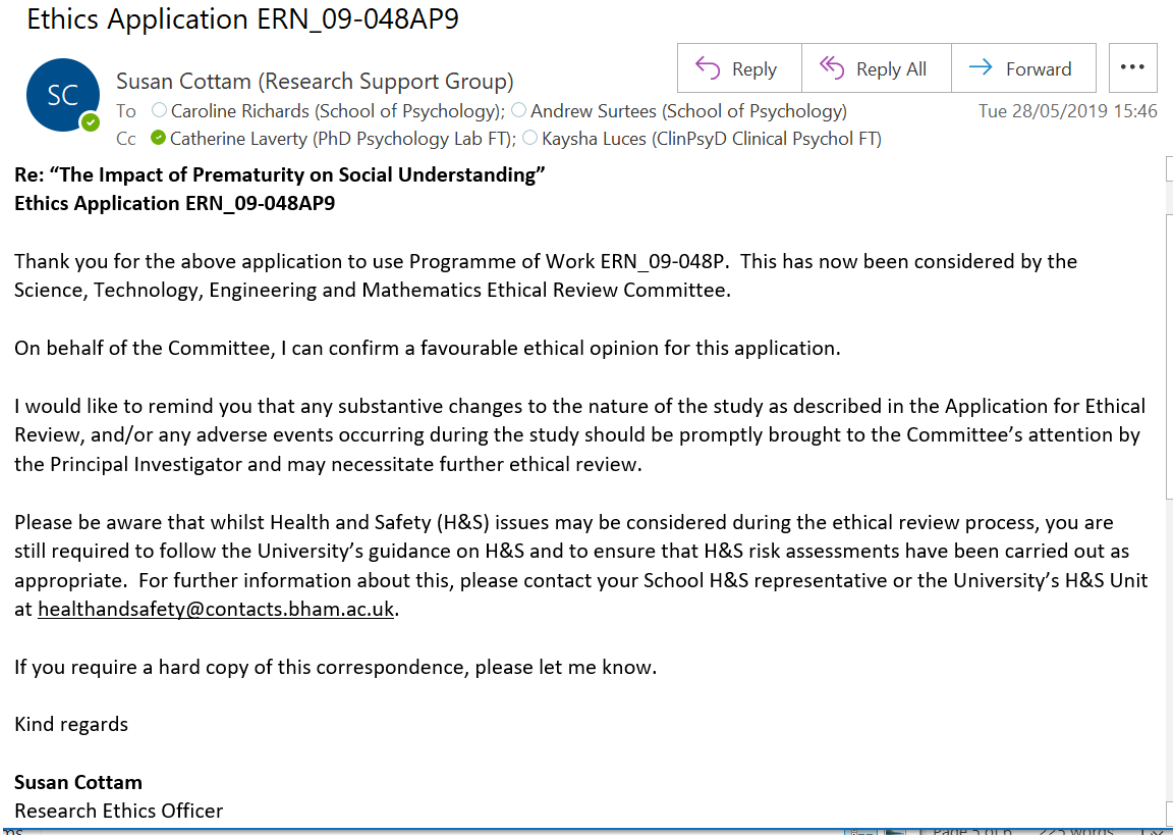
The Quantile-Quantile plots show that the observed distribution for the fixed effects model does not conform to the expected distribution prompting the decision to adopt the use of the restricted maximum likelihood estimator.





Appendix 2: The random effects model weighted by the quality effects matrix for pooled prevalence estimates for autism characteristics in individuals born preterm using screening (a) and diagnostic (b) tools.

Appendix 3: Ethical approval confirmation from the Science, Technology, Engineering and Mathematics Ethical Review Committee at The University of Birmingham



Ethics Application ERN_09-048AP9

SC

Susan Cottam (Research Support Group)

Reply | Reply All | Forward | ...

To Caroline Richards (School of Psychology); Andrew Surtees (School of Psychology)

Tue 28/05/2019 15:46

Cc Catherine Laverty (PhD Psychology Lab FT); Kaysha Luces (ClinPsyD Clinical Psychol FT)

Re: "The Impact of Prematurity on Social Understanding"
Ethics Application ERN_09-048AP9

Thank you for the above application to use Programme of Work ERN_09-048P. This has now been considered by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I can confirm a favourable ethical opinion for this application.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly brought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

If you require a hard copy of this correspondence, please let me know.

Kind regards

Susan Cottam
Research Ethics Officer

Appendix 4: Questionnaire pack distributed to families of MLPT children (as described in Chapter 3)

Background Information

Are you male or female? Male ☐ Female ☐ Prefer not to say ☐

Postcode: _____

Country of current residence: _____

What was your age in years on your last birthday? _____ Years

What is your relationship to your child participating (e.g. mother, father, stepmother, grandmother, adoptive parent)? _____

In total how many people currently live in your home? _____ Adults **_____** Children

How many older siblings does the infant /child you are completing this survey about have? _____

How many younger siblings does the infant /child you are completing this survey about have? ___

Does your infant or child have a sibling that has received a formal diagnosis of autism? YES / NO

(Some examples are included below)

Autism

Autism Spectrum Disorder

Asperger Syndrome

High Functioning Autism

Autistic Features

Autistic Continuum

Pervasive Developmental Disorder

Atypical Autism

Autistic Spectrum

Has your infant / child been given a formal physical diagnosis? YES / NO

For example, a physical diagnosis such as diabetes

What age was your infant / child given this diagnosis? _____

Who diagnosed your infant / child?

Paediatrician

Clinical Psychologist

GP

Other_____

Has your infant / child been given a formal mental health diagnosis? YES / NO

For example, a mental health diagnosis such as depression

What age was your infant / child given this diagnosis? _____

Who diagnosed your infant / child?

Paediatrician

Clinical Psychologist

GP

Other_____

Has your infant / child been given a formal developmental diagnosis? YES / NO

For example, a developmental diagnosis such as developmental delay

What age was your infant / child given this diagnosis? _____

Who diagnosed your infant / child?

Paediatrician

Clinical Psychologist

GP

Other_____

Has your infant / child had any medical/health difficulties in the last six months? YES / NO

If yes, please give details:

_____

Have you ever had any concerns about your infant / child's development? YES / NO

If yes, please give details:

_____

Please tick the highest level of your educational qualifications.

No formal educational qualifications..... ☐

Fewer than 5 GCSE's or O Level's (grades A-C), NVQ 1, or BTEC First Diploma..... ☐

5 or more GCSE's or O Level's (grades A-C), NVQ 2, or equivalent..... ☐

3 or more 'A' Levels, NVQ 3, BTEC National, or equivalent..... ☐

Polytechnic/University degree, NVQ 4, or equivalent..... ☐

Masters/Doctoral degree, NVQ 5, or equivalent..... ☐

What is your current marital status?

Married, and living with spouse..... ☐

Living with partner.....☐

Divorced/Separated/Widowed/Single and NOT living with a partner.....☐

Prefer Not To Say..... ☐

If living with partner/spouse, please answer the following questions, if not, please skip to the next question.

Is your partner male or female? Male ☐ Female ☐ Prefer not to say ☐

What was their age in years on their last birthday? _____ Years

Please tick the highest level of your partner/spouse's educational qualifications.

No formal educational qualifications..... ☐

Fewer than 5 GCSE's or O Level's (grades A-C), NVQ 1, or BTEC First Diploma..... ☐

5 or more GCSE's or O Level's (grades A-C), NVQ 2, or equivalent..... ☐

3 or more 'A' Levels, NVQ 3, BTEC National, or equivalent..... ☐

Polytechnic/University degree, NVQ 4, or equivalent..... ☐

Masters/Doctoral degree, NVQ 5, or equivalent..... ☐

What is your partner/spouse's relationship to your child participating (e.g. mother, father, stepmother, adoptive parent)?_____

What is your current total annual family income? Please include a rough estimate of total salaries and other income (including benefits) before tax and national insurance/pensions.

Please tick one box only:

Less than £15,000…… ☐

£15,001 to £25,000…… ☐

£25,001 to £35,000……..…...☐

£35,001 to £45,000…….....☐

£45,001 to £55,000……..……....☐

£55,001 to £65,000…….…….☐

£65,001 or more…….…….…….....☐

Please answer the following questions about the infant or child you are completing this survey about:

Maternal History

Did the mother smoke during pregnancy?	**Yes**	**No**
Did the mother drink during pregnancy?	Yes	No
Did the mother exercise during pregnancy?	Yes	No

What was the mother's age at birth? _____

Did the mother take antenatal steroids during pregnancy? Yes No

Was this child part of a multiple pregnancy? Yes No

If yes how many babies? _____ babies

Were any of the multiples identical? Yes No

Birth

When was your child born? ___/___/___

What was your child's due date? ___/___/___

Place of birth (please circle) Hospital / Birthing Centre / Home

Please detail any known birth complications:

_____

_____

_____

_____

Was a NICU stay required? Yes No

If yes, for how long? Weeks_____ Days_____ Hours_____

Did your child require the use of a ventilator? Yes No

Were neonatal Surfactants Used? Yes No

Did your child experience any Intracranial haemorrhages (also known as brain bleeds)? Yes No

Did your child require any surgeries during their first year of life? Yes No

If yes, please detail

_____

_____

_____

_____

Baby

Birth weight _____

Birth height _____

Head circumference _____

APGAR score (at 1 minute)_____ (at 5 minutes)_____ (at 10 minutes)_____

Was your baby breastfed? Yes No Prefer Not To Say

If no, please circle the formula details Milk / Soy / Organic / Homemade

Does your baby take any supplements directly? Yes No Prefer Not To Say

If yes, please detail

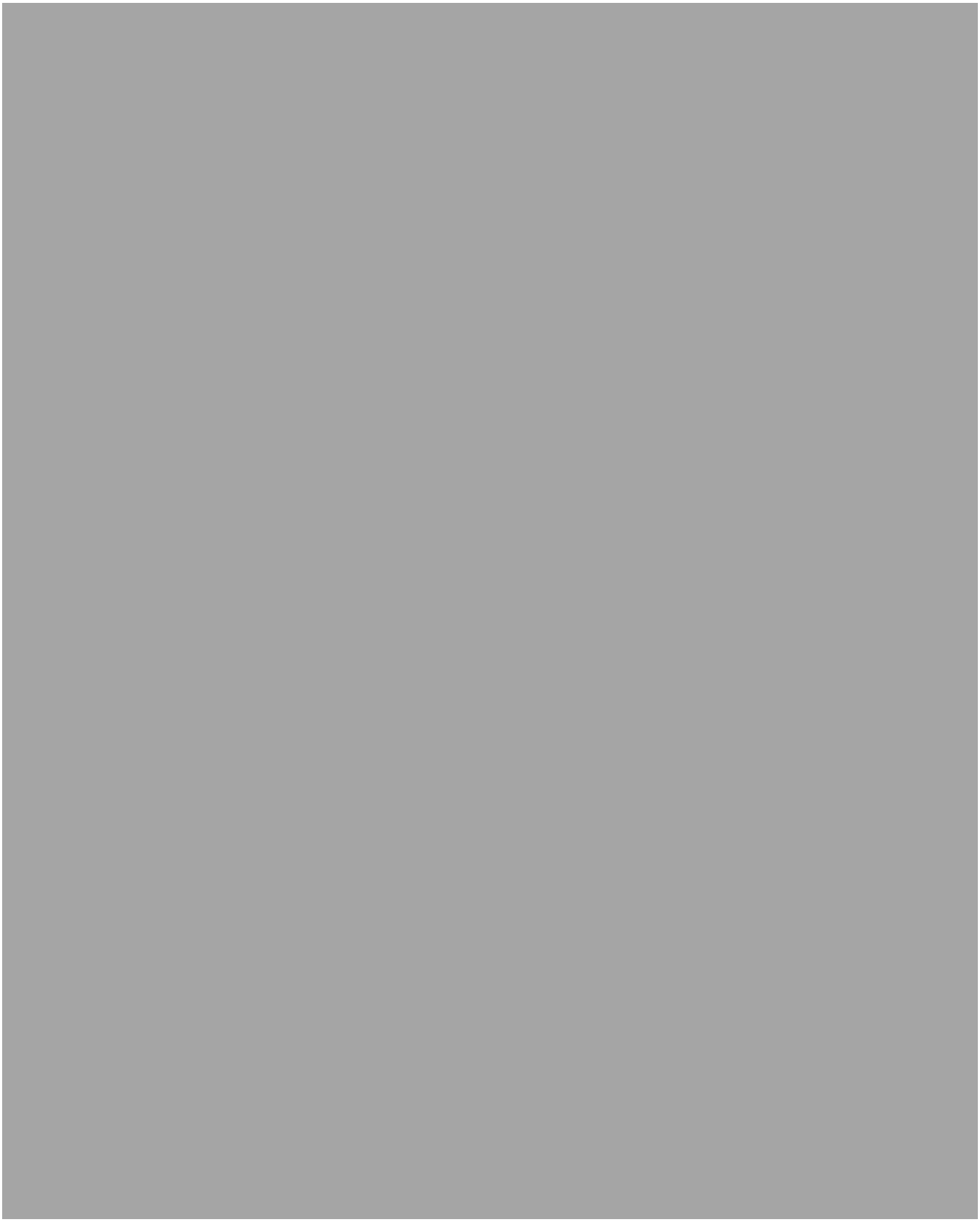
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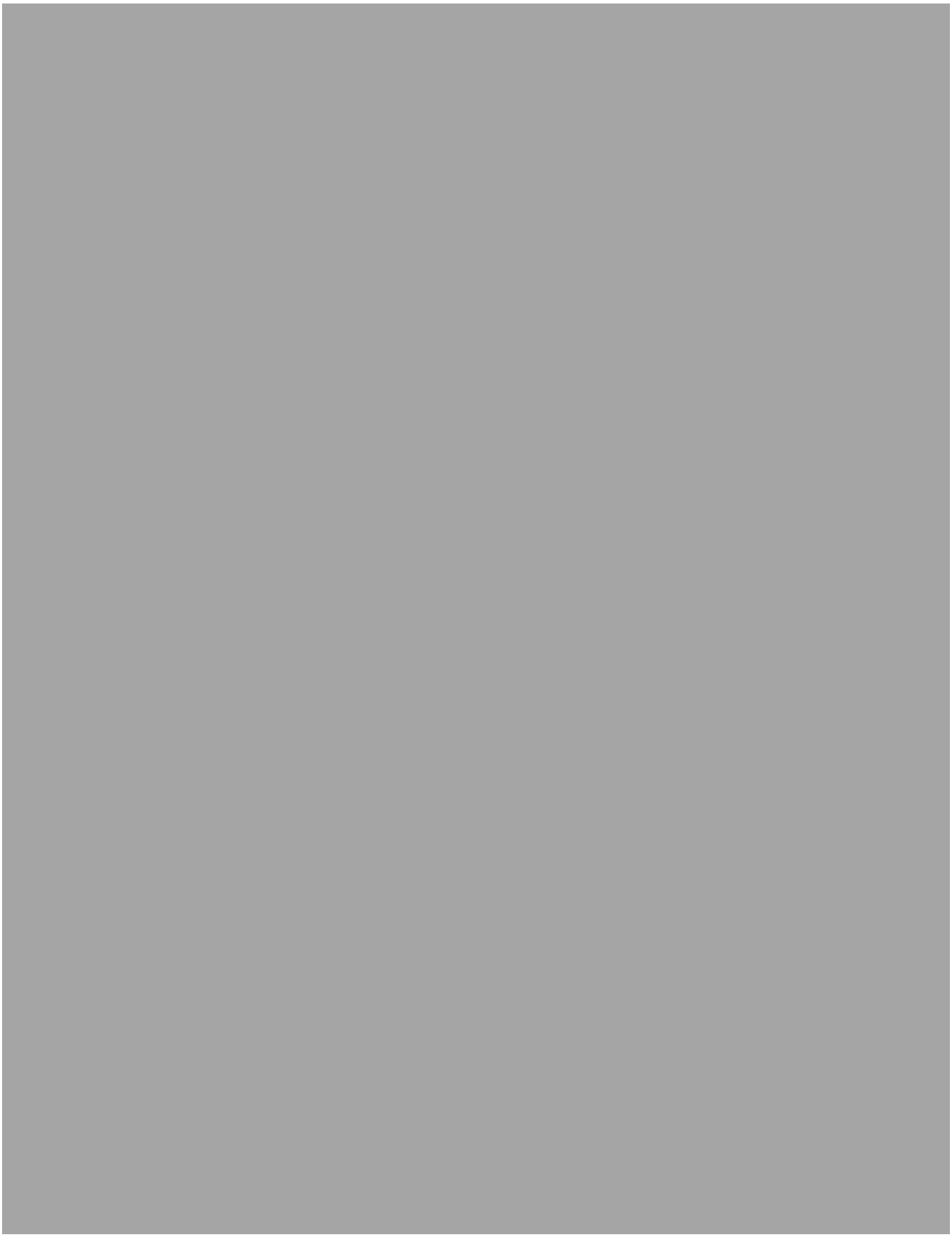
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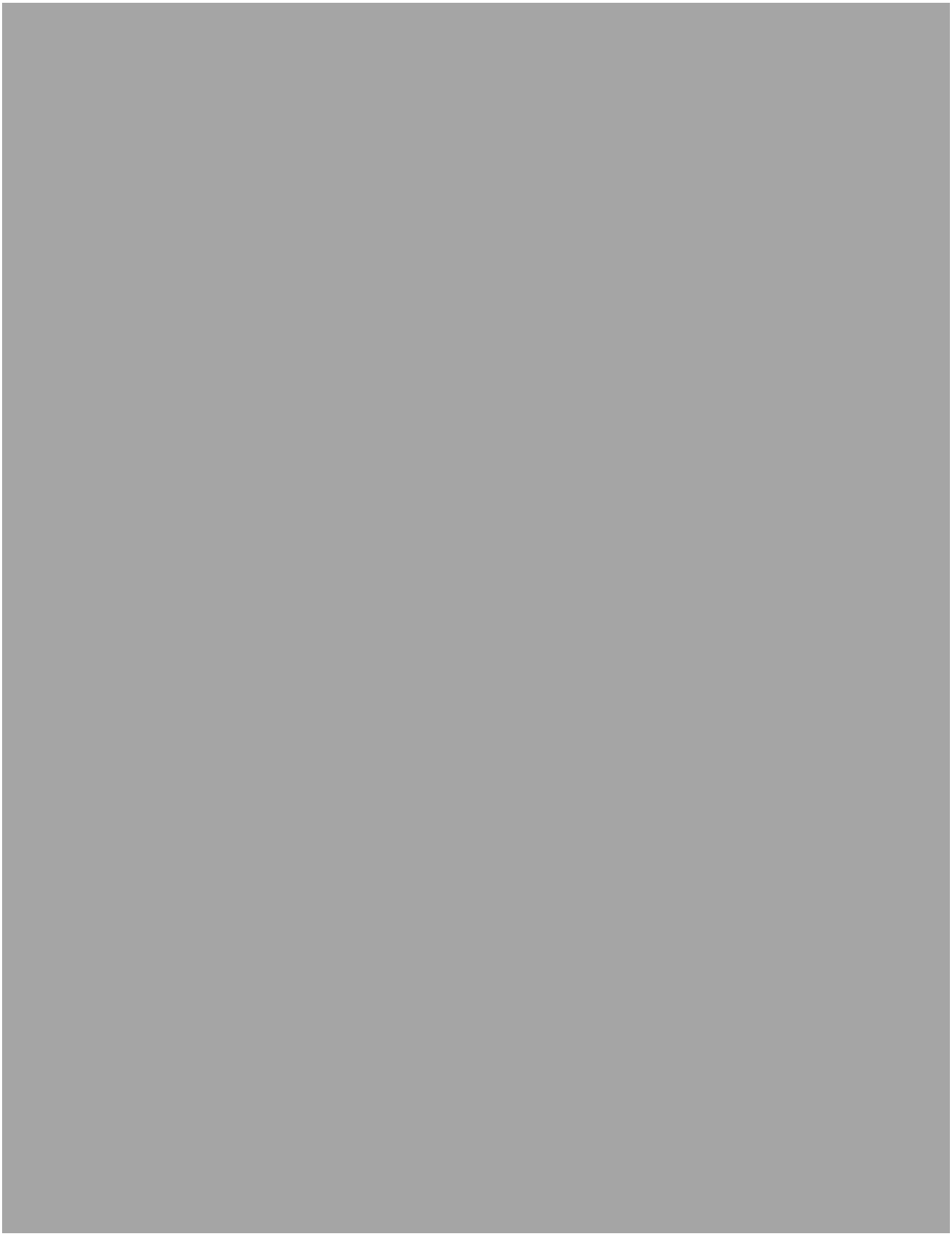
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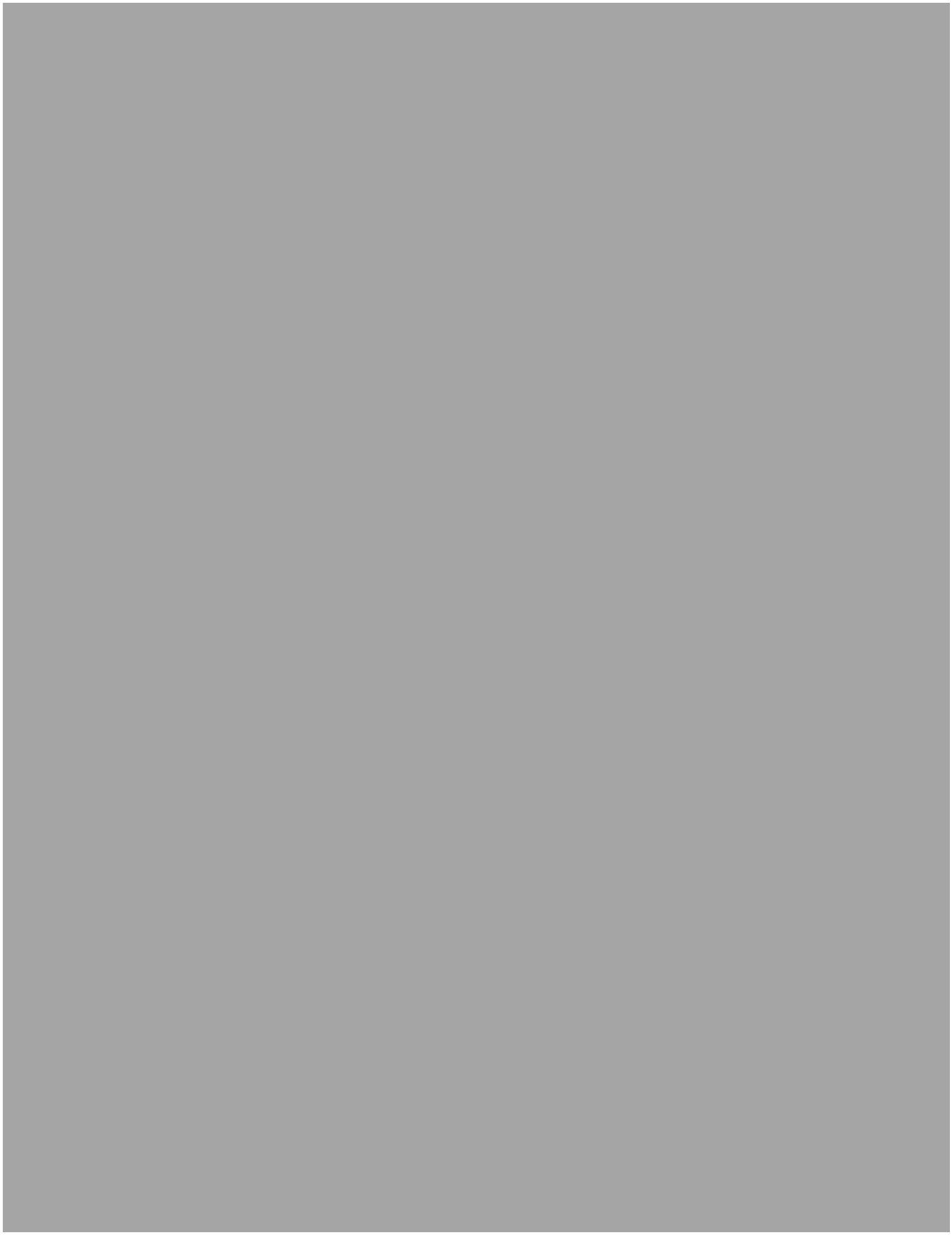
Social Responsiveness Scale (SRS) – PreSchool

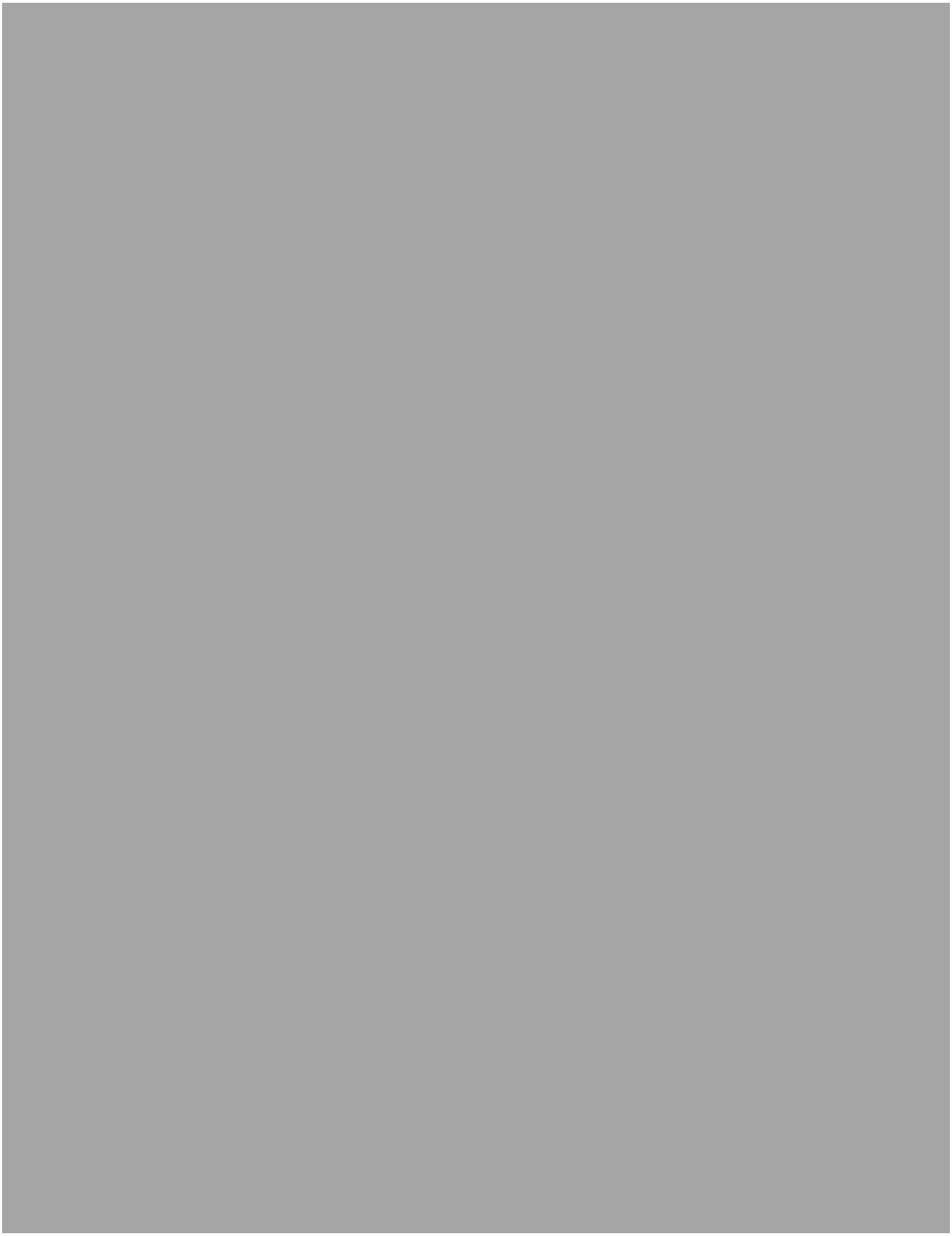


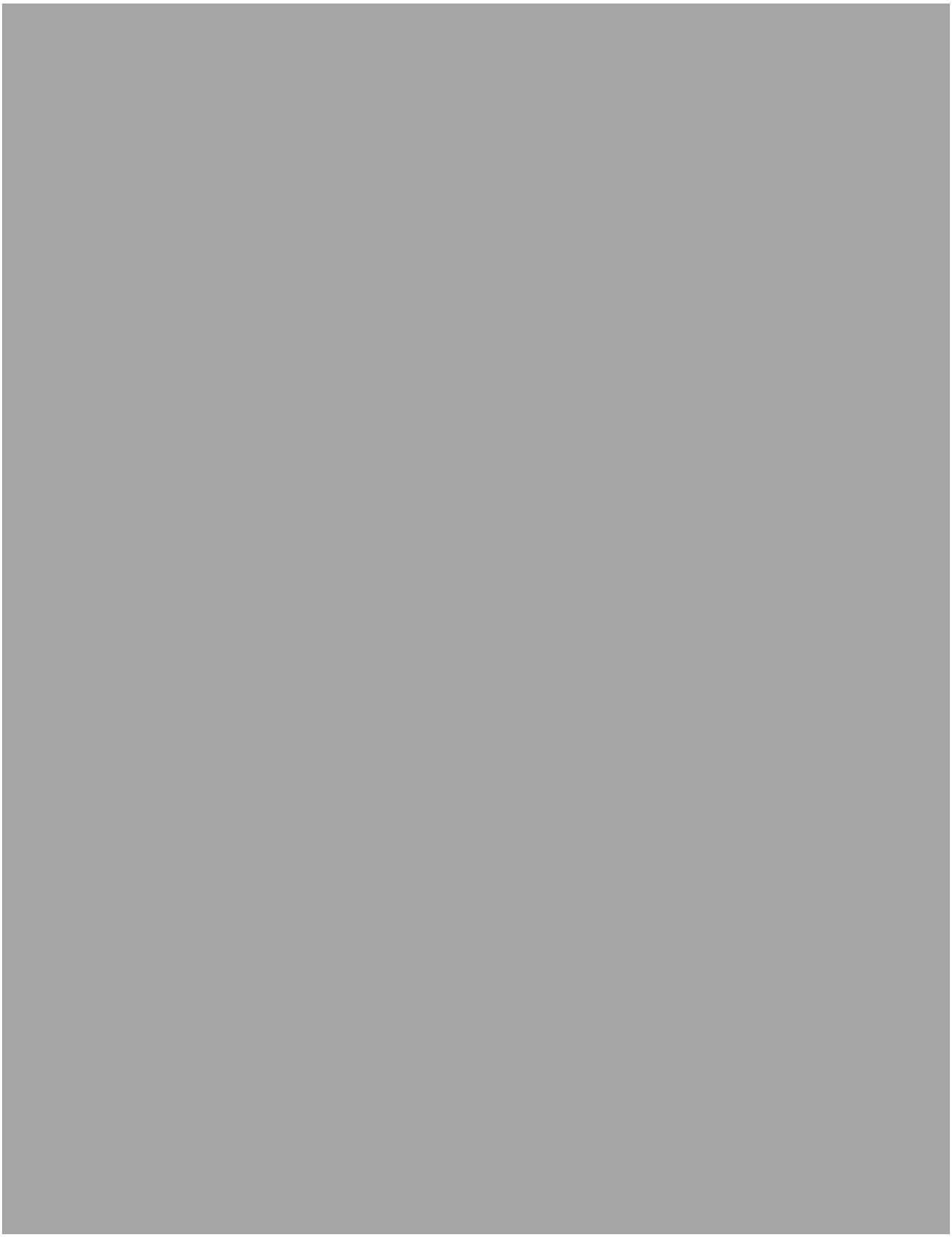




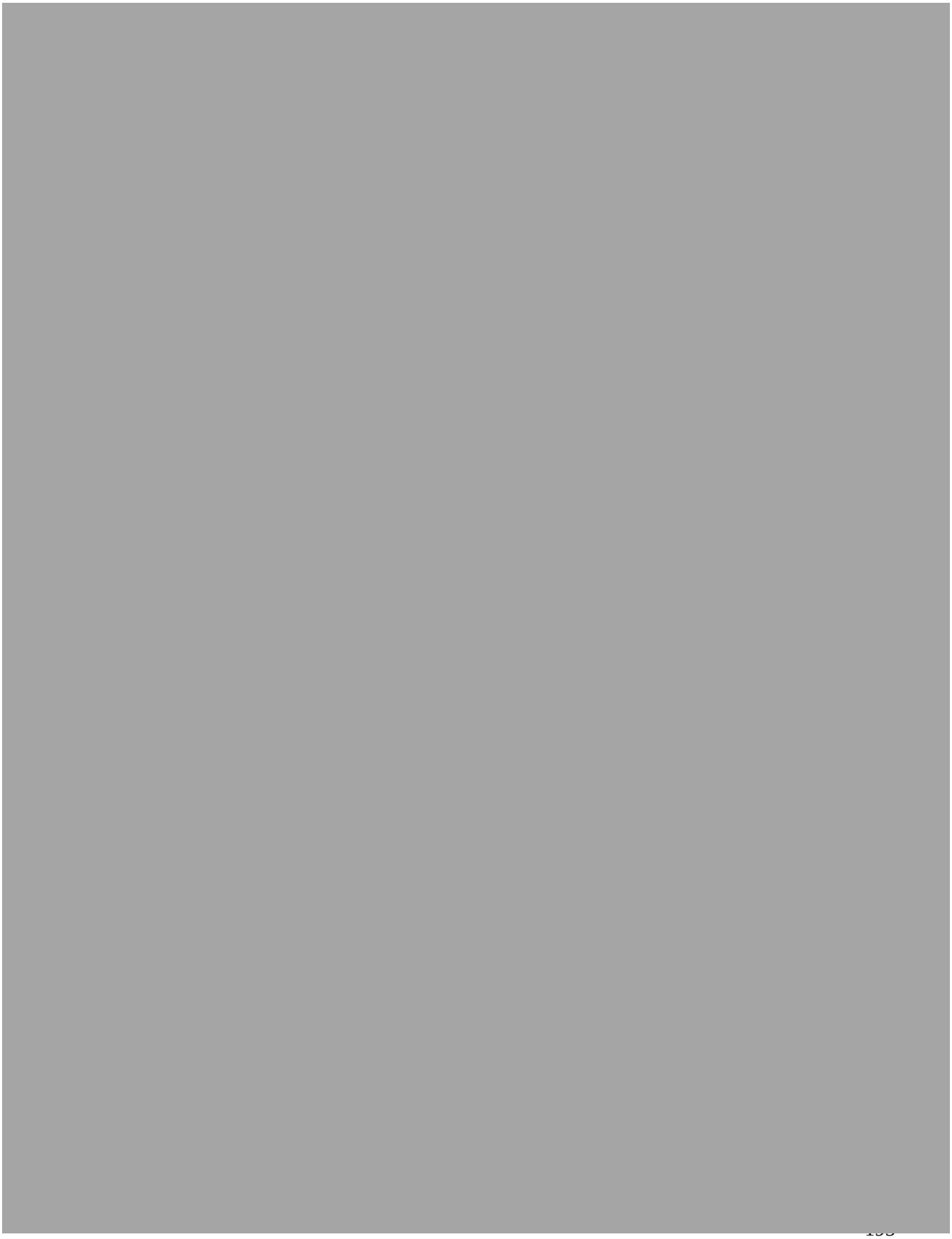
Social Responsiveness Scale (SRS-2)

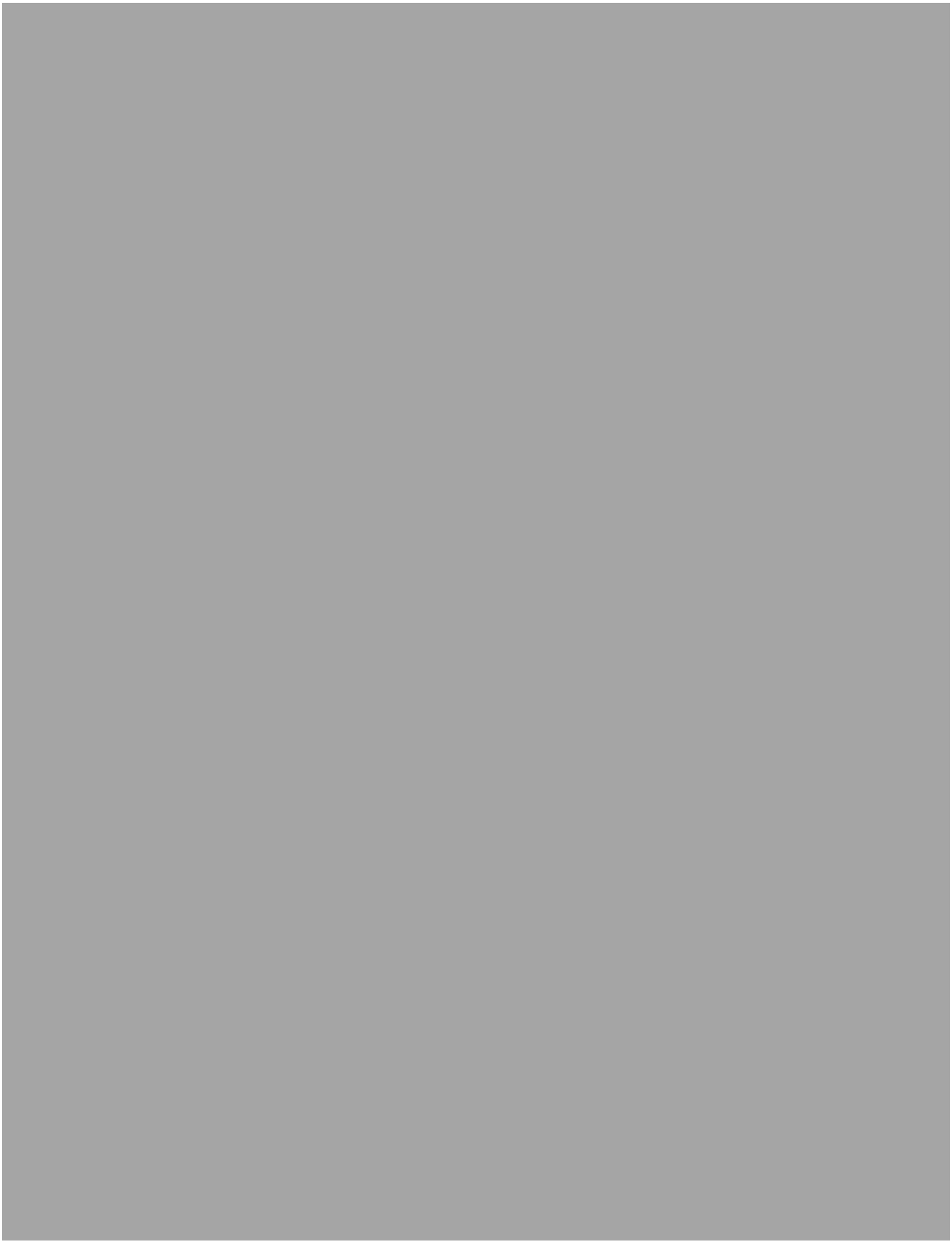




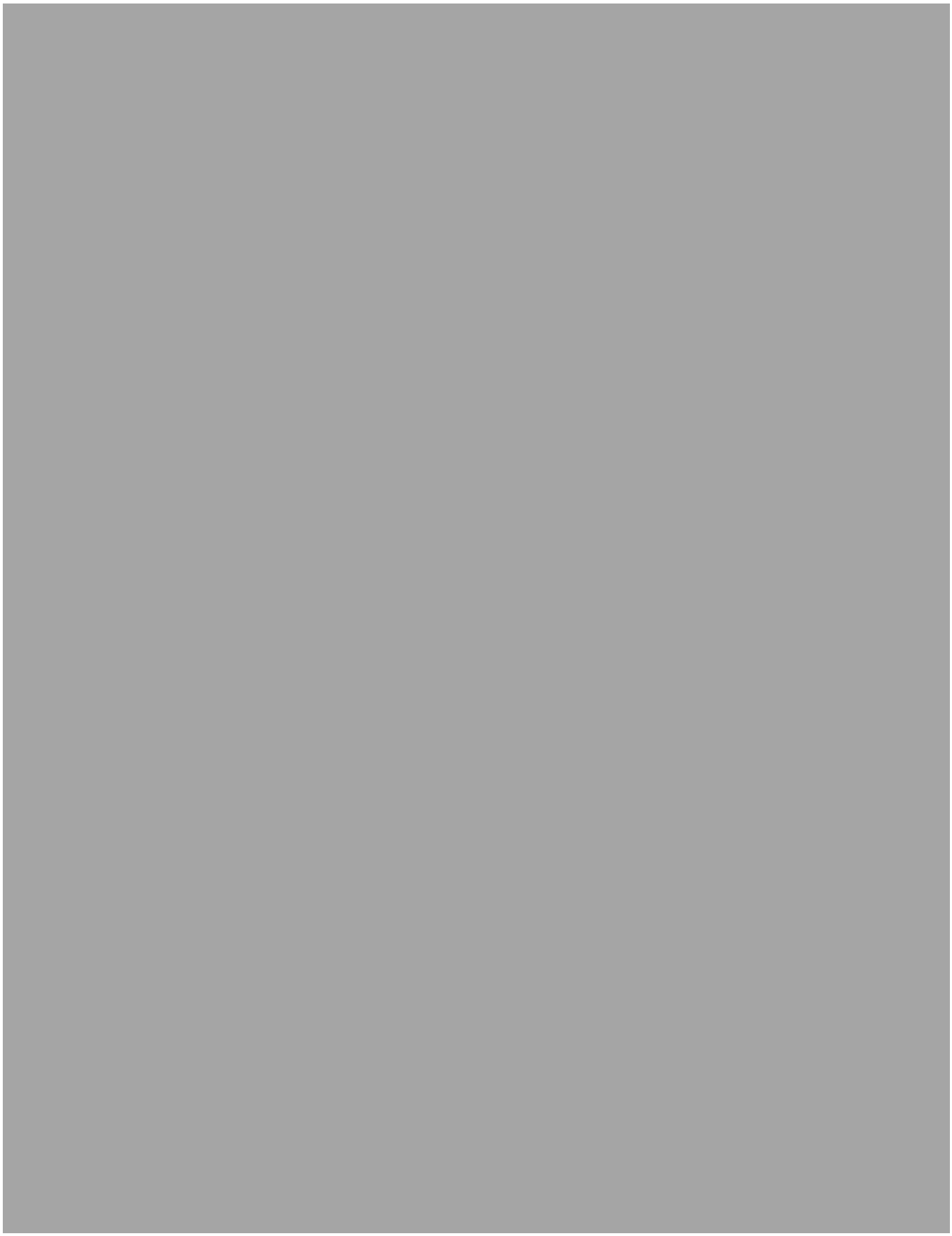


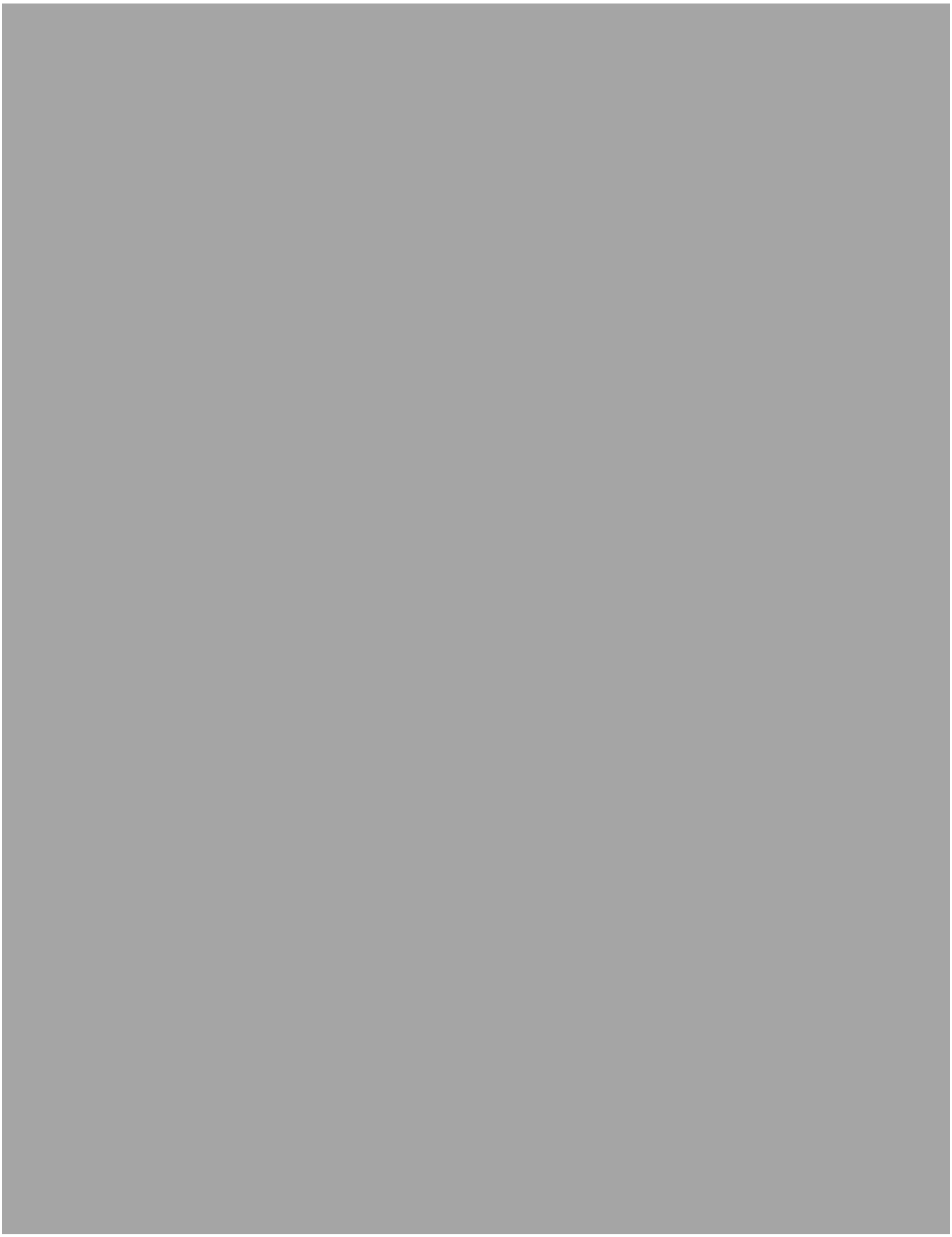
The Strengths and Difficulties Questionnaire



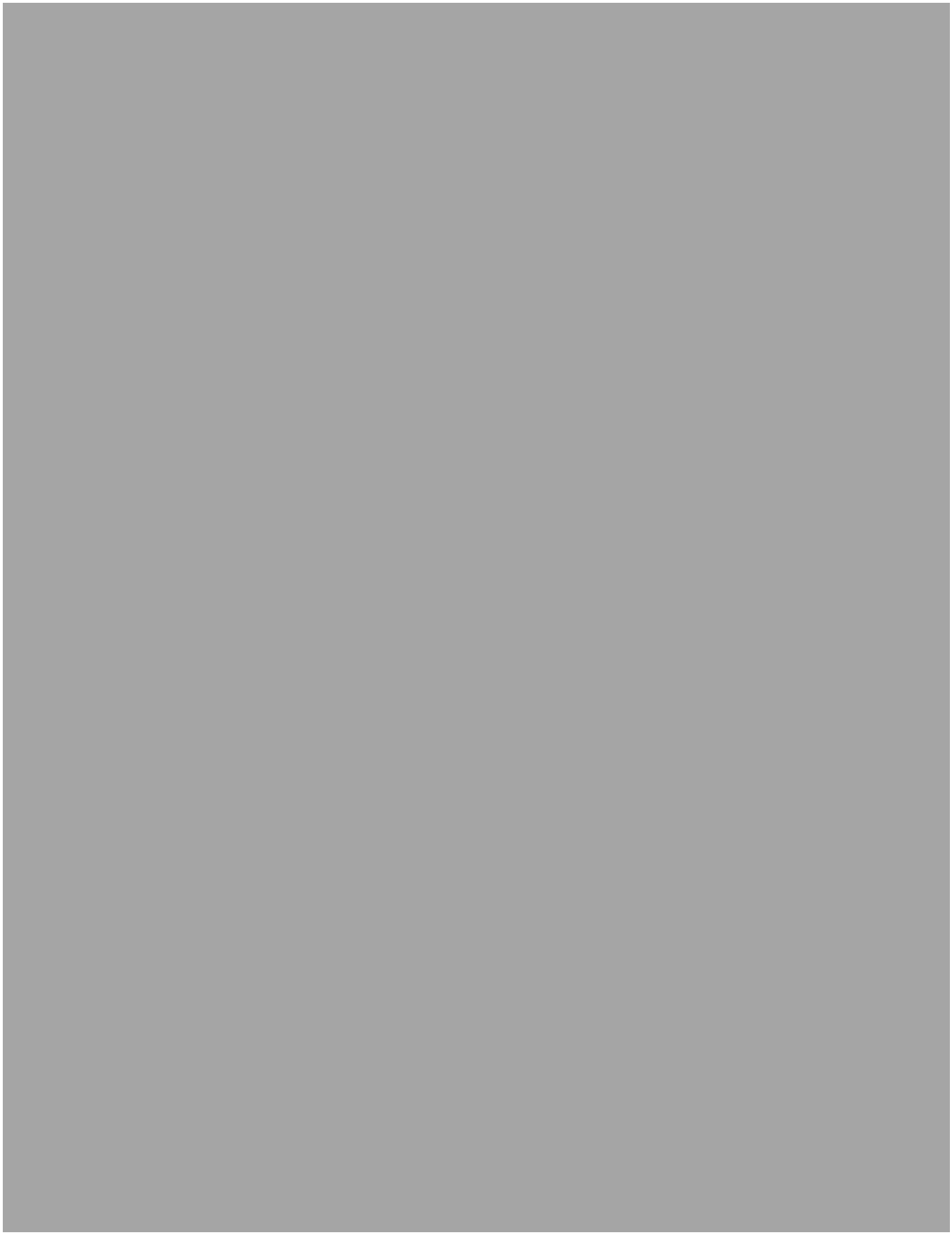


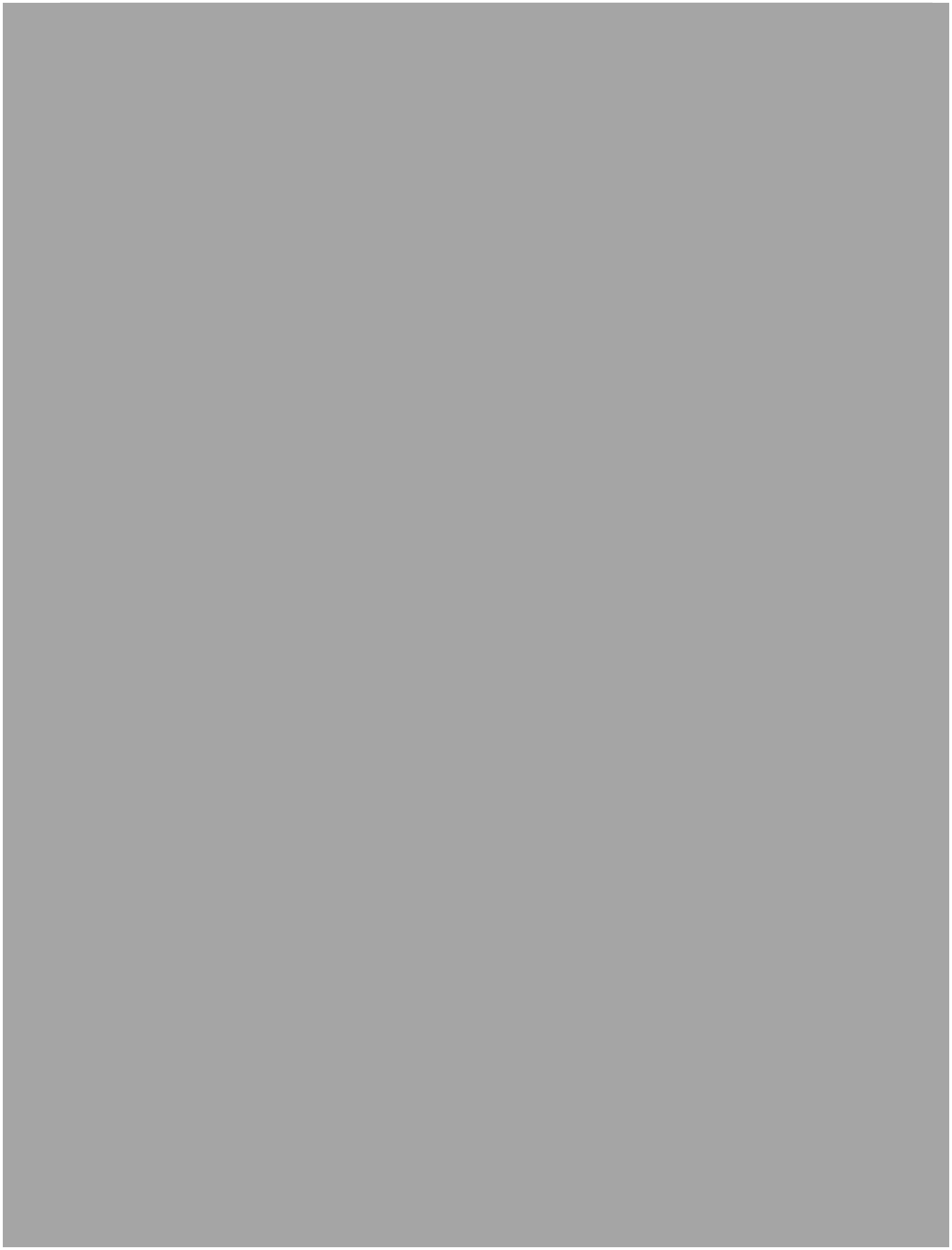
The Modified Checklist or Autism in Toddlers (M-CHAT)

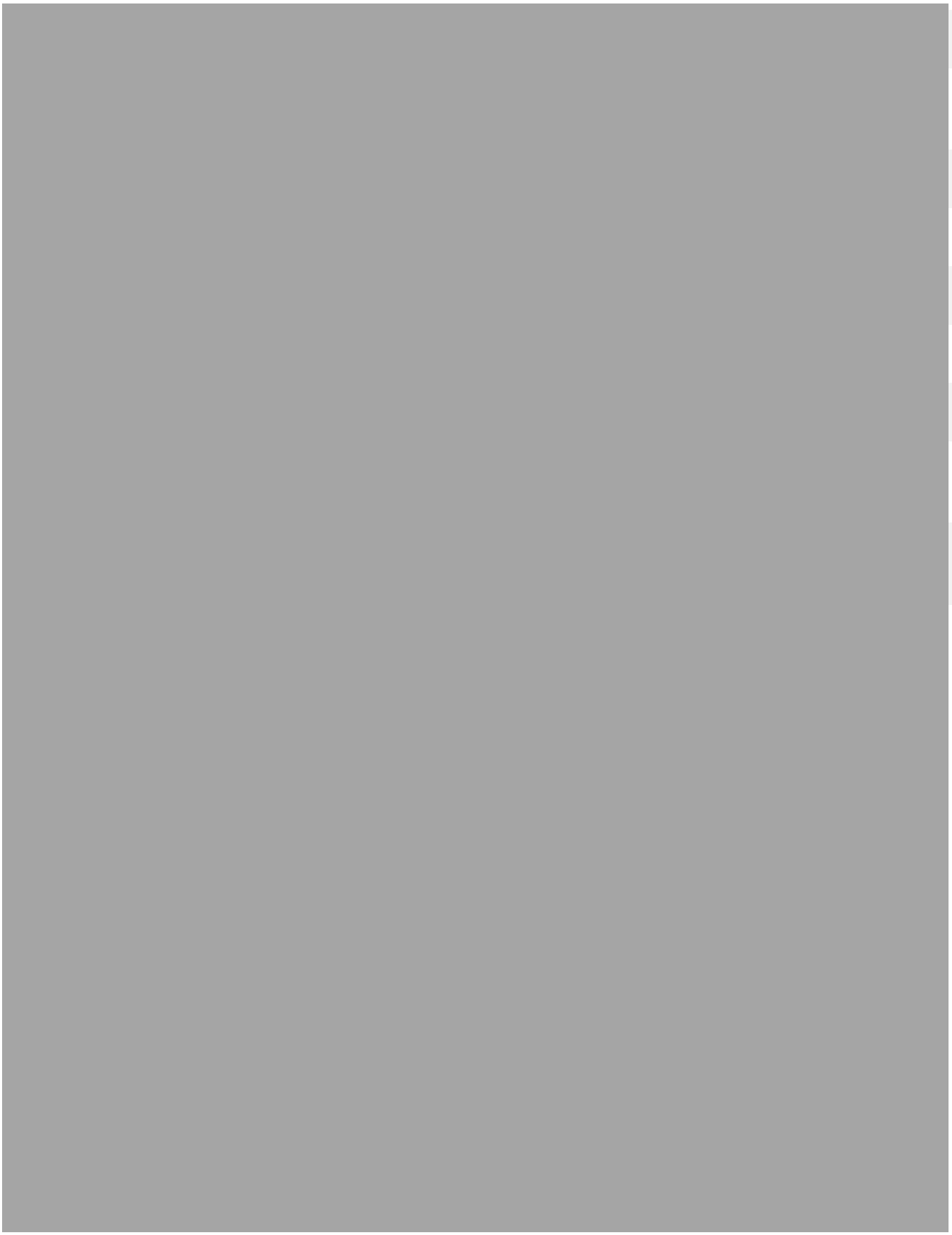




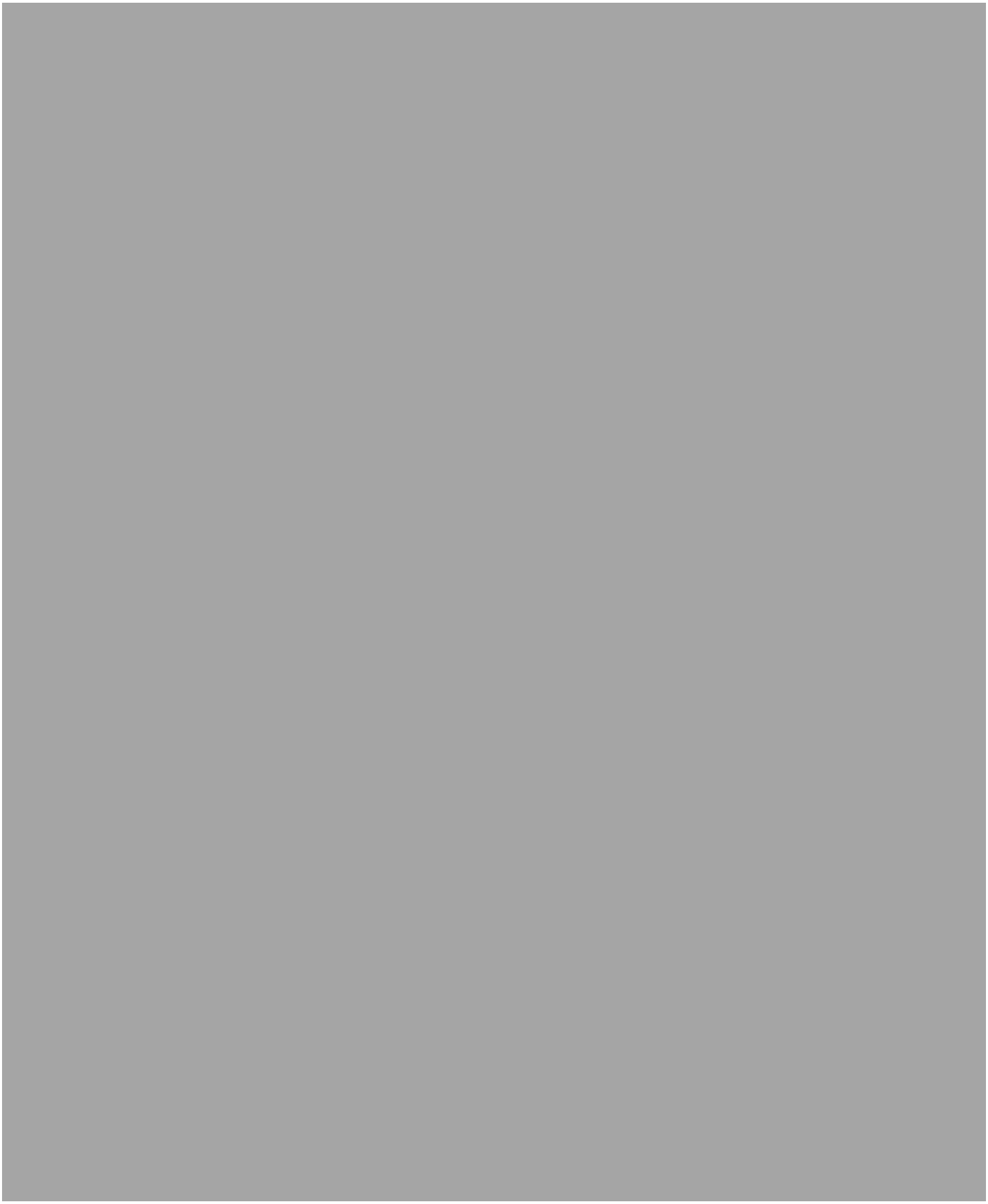
The Social Communication Questionnaire (SCQ)

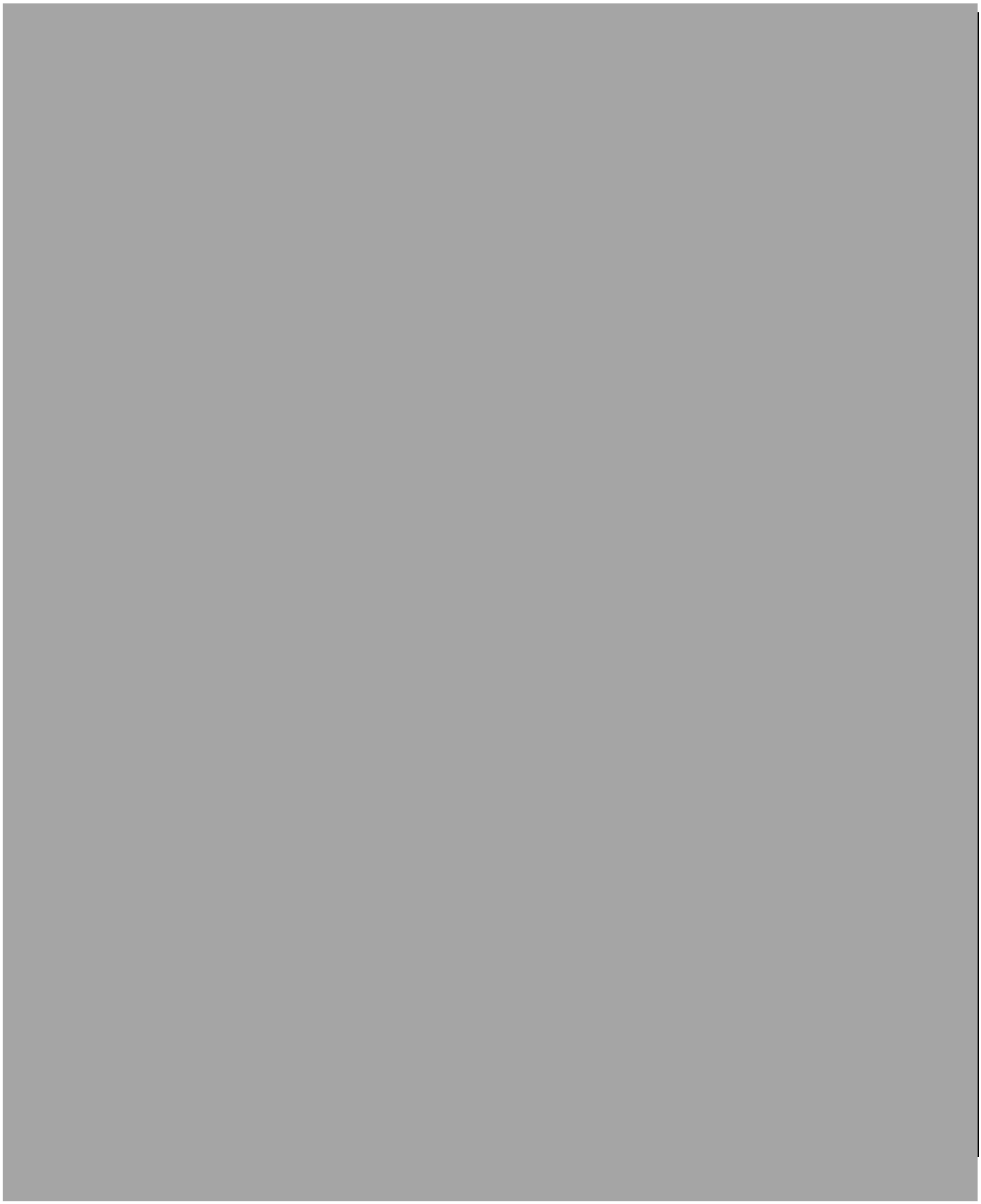




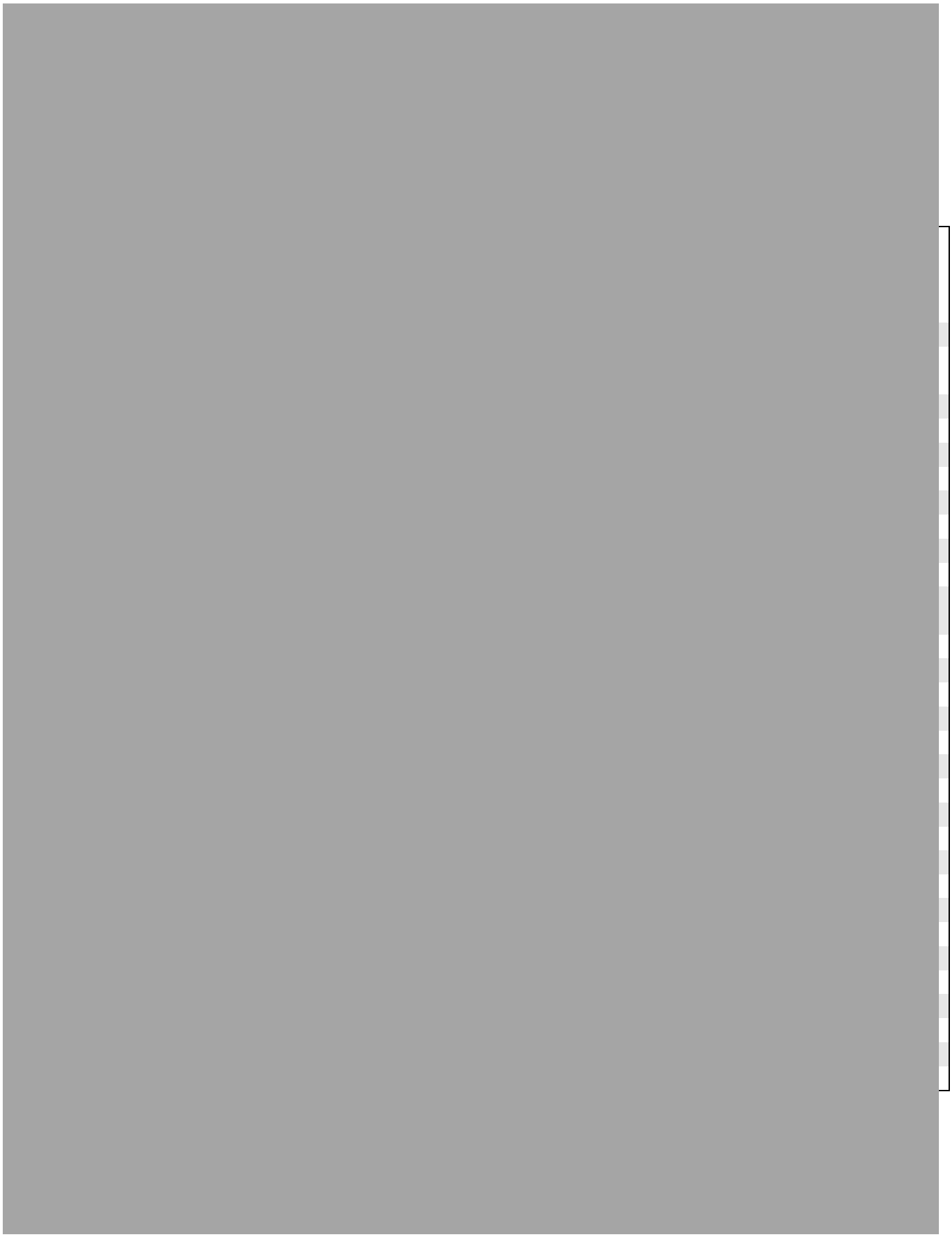


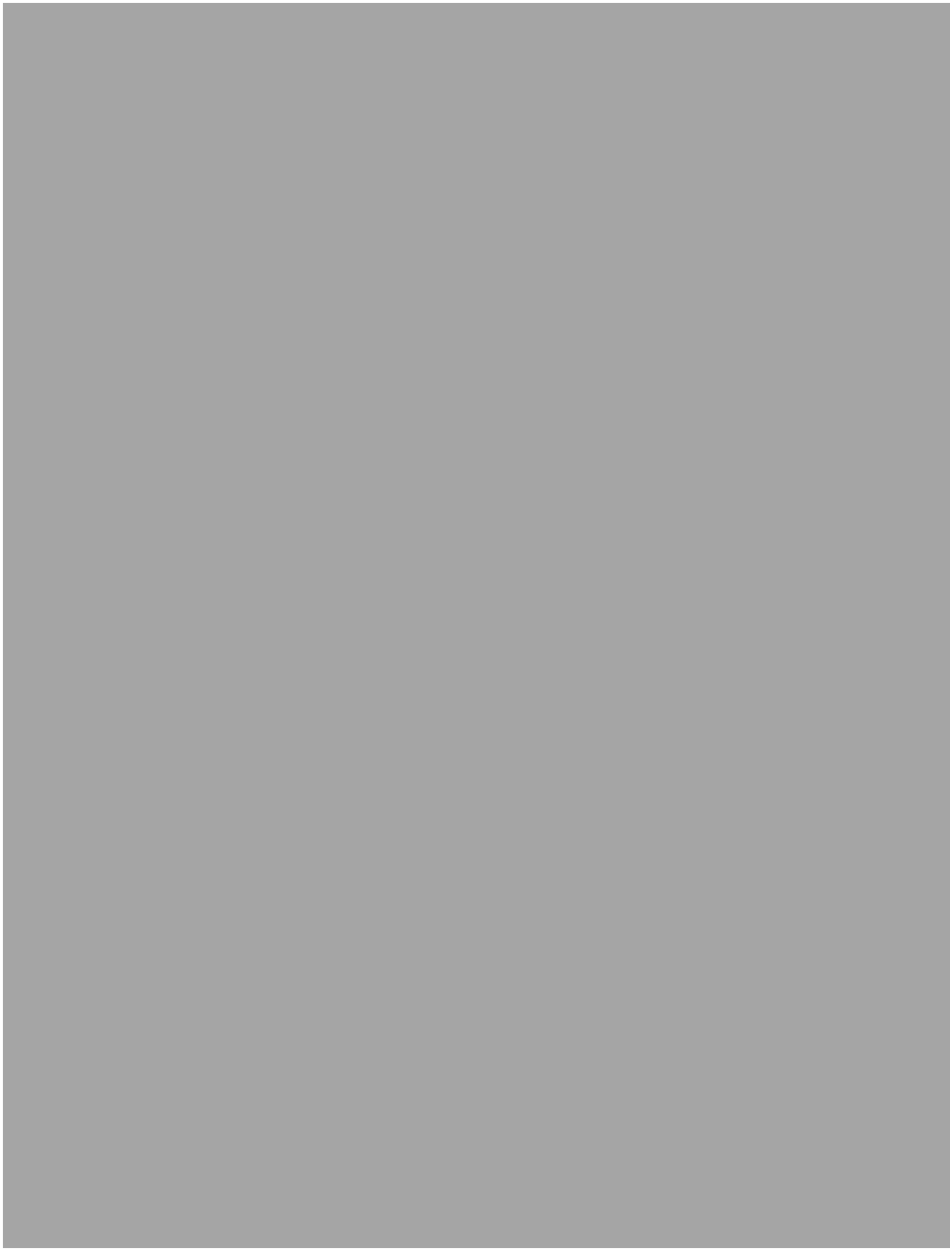
BRIEF-P





BRIEF-2





Appendix 5: NHS Ethical approval letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Caroline Richards
Psychology
University of Birmingham
B15 2TT

Email: hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

18 November 2019

Dear Dr Richards

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The Impact of Prematurity on Social Understanding (IPSU)**
IRAS project ID:	**265040**
Protocol number:	**RG_19-146**
REC reference:	**19/WM/0282**
Sponsor	**Research Support Group**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern

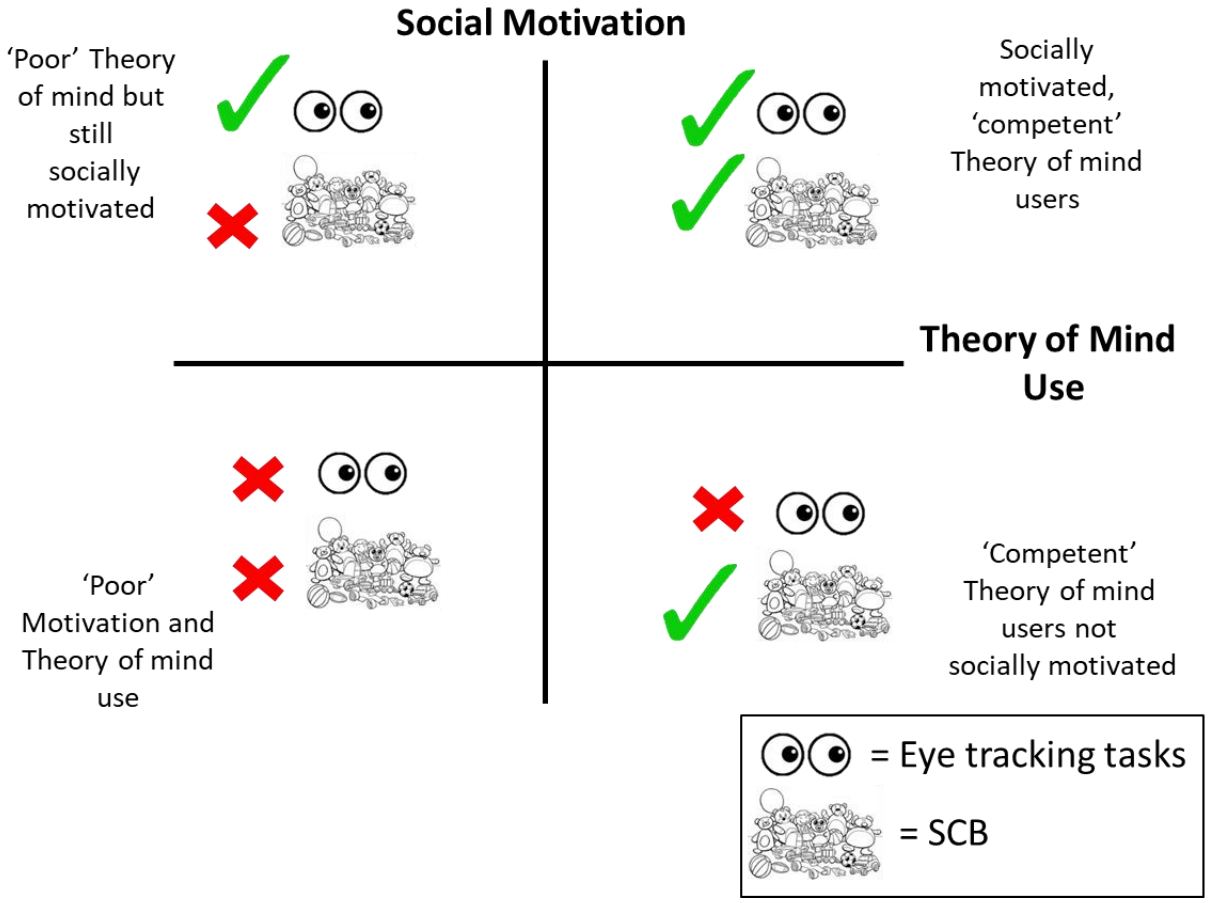
Appendix 6: Semi structured interview



- Can you tell me a little bit about _____?
- If you feel comfortable, can you tell me a little bit about the birth?
- Can you tell me about your experience of the care you received at birth and immediately after your baby was born?
- What sort of information about preterm birth was given to you by professionals or clinical staff?
- Do you feel you had enough help and support after _____ was born?
- Can you tell me about taking _____ home for the first time?
- Do you feel your experience is different to other parents you might know?
- How did you feel at their two-year development check?
- Can you think of any support networks around this time that particularly helped (perhaps friends / family / groups?).

- Does _____ attend nursery?
- Do you have any worries about your child's development?
- How do you feel about _____ starting school?
- What are some of the strengths of _____?
- Can you sum up your experiences of having a prematurely born infant
- Do you think there is anything important you would like to say and I have not asked you about?

Appendix 7: Proposed associations between eye-tracking and behavioural observations of helping behaviour and what these outcomes might mean



Appendix 8: ADOS-2 assessment certificate with both administrative and researcher reliability.



Certificate of Training

Awarded to

Catherine Laverty

for successfully completing a course in administration and coding of the Autism Diagnostic Observation Schedule (ADOS-2) to the level of

Research Reliability

This is to certify that the above named has demonstrated research reliability in use of the ADOS-2 having attended a course of study from

18th March to 21st March 2019

and having completed post-course assignments to the required standard.

Course Leader

beginningwithA
Autism Consultancy and Training

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