Measuring and assessing patient satisfaction with sexual health services

by

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ABSTRACT

There is a high prevalence of sexual transmitted infections (STIs) within Organisation for Economic Co-operation and Development (OECD) settings particularly among ethnic minorities and marginalized groups which contributes significantly to the overall burden of disease. STIs have direct cost implications and impact on the overall wellbeing of patients, in part due to the strong stigma associated with contracting a STI. The thesis aimed to highlight the various aspects of sexual health services considered most important by patients while accessing care to inform healthcare decision-making for evaluation and planning (designing or re-designing) of services to ensure they are patient centred.

A systematic review, qualitative synthesis and meta-ethnography, and primary research (qualitative) were conducted to establish themes pertaining to various aspects of services considered most important by patients and potential clients. This was further substantiated by generating an evidence-based discussion (based on existing theories in health economics and patient reported outcome measure (PROM) development processes) to justify the need for the development of a preference-based PROM specifically for sexual health services.

Analysis of existing theories in health economics suggested that an Extra-Welfarist approach (expanding the evaluative space within quality adjusted life year (QALY) measurement) as more appropriate for measuring and valuing outcomes in this area. The findings of the systematic review highlighted important structural and methodological limitations in the existing assessment tools whereas the qualitative synthesis and meta-ethnography reported that patients had expectations which were far more than being tested and treated for STIs and receiving advice on contraception. Nine main themes were identified in the primary qualitative research: involvement in decision-making; clear and comprehensive diagnosis and treatment; being seen and getting results quickly; having a choice of appointment type; feeling respected and put at ease; non-judgemental and friendly staff; feeling reassured about confidentiality; having support with partner notification & being able to find & get to services.

The findings of the thesis suggest that a standalone or de-novo sexual health services specific preference-based measure would better allow particular focus on the dimensions which are important to patients, with increased ability to detect meaningful changes in the status of patients

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I have learned over the years that our achievements are never our own. There are many factors which influence our growth as a professional and person. In my opinion, among these factors the most significant is the people we come across in our lives. I have been very fortunate in this regard particularly in the last three years of my life.

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"The worst form of inequality is to try to make unequal things equal."
Aristotle

LIST OF ABBREVIATIONS

Abbreviation	Explanation
CBA	Cost benefit Analysis
CEA	Cost-effectiveness analysis
CUA	Cost utility analysis
EC	Emergency contraception
FGD	Focus Group Discussion
HIC	High-income country
JR	Jonathan Ross
LIC	Low-income country
LGBT	Lesbian gay bisexual and transgender
LJ	Louise Jackson
LMIC	Low and middle-income country
MS	Muslim Syed
MSM	Men who have sex with men
NGO	Non-profit organisation
NICE	National Institute for Care and Excellence
NT	Nicola Thorley
OECD	Organisation for economic co-operation and development
PRO	Patient reported outcome
PROM	Patient reported outcome measure
PCA	Patient centred care

QALYs	Quality adjusted life years
SH	Sexual Health
SHC	Sexual health clinic
SHS	Sexual Health Services
SM	Self-management
STI	Sexually transmitted infection
SRHC	Sexual and reproductive health clinic
TR	Tracy Roberts
WHO	World Health Organisation
WTP	Willingness to pay
UK	United Kingdom

Table of Contents

ABSTRACT..... iii

ACKNOWLEDGEMENTS..... iv

68" LIST OF ABBREVIATIONS..... vi

CHAPTER 1: INTRODUCTION..... 16

1.1 Main motivation for thesis..... 16

1.2 Aim and objectives of thesis..... 18

1.3 Brief outline of thesis..... 18

CHAPTER 2: Background to sexual health services within OECD settings and the significance of capturing patient reported outcomes..... 21

2.1 Defining Sexual Health.....21

2.2 Prevalence and burden of disease of sexually transmitted infections & unplanned pregnancies..... 22

2.3 The different types and pathways of sexual health and contraceptive services..24

2.4 Issues associated with sexual health and contraceptive services..... 25

2.5 Economic burden associated with STIs and unplanned pregnancies, and the context of limited healthcare resources.....27

2.6 Economic evaluations in healthcare.....29

2.7 Introduction to the main techniques for economic evaluation in healthcare.....30

b) Cost-benefit analysis (CBA).....31

c) Cost-effectiveness analysis (CEA)..... 31

d) Cost-utility analysis (CUA).....32

2.8 Significance of patient satisfaction.....33

2.9 Patient-centred care.....34

2.10 Patient reported outcomes..... 35

2.11 Patient reported outcome measures (PROMs)..... 36

2.12 The role of PROMS.....37

2.13 Standard steps of PROM development process..... 38

2.14 Chapter summary..... 41

CHAPTER 3: Significance of patient-centred care and the need for a preference-based PROM for sexual health services..... 43

3.1 Significance of patient-centred care in modern healthcare system.....43

3.2 The importance of patient-centred care and capturing patient reported outcomes in the context to sexual health services..... 45

3.3 Logic model depicting the need of developing a preference-based PROM for sexual health services.....46

3.4 Conclusion..... 52

CHAPTER 4: Measurement and valuation of outcomes pertaining to sexual health services for use in economic evaluation..... 53

4.1 The theory of welfarism in a healthcare context.....54

4.1.1 Key theoretical foundations..... 54

4.1.2 Application of welfarism in healthcare.....56

4.1.3 The strengths and weaknesses of the Welfarist approach in relation to sexual health.....57

4.2 Extra-welfarism.....59

4.2.1 Methodological application of extra-welfarism.....60

4.2.2 The significance of the QALY as a 'common currency' for measuring health benefits.....61

4.2.3 The interpretation of 'Q' in QALY..... 62

4.2.4 Techniques for valuing Health-related Quality of life weights..... 63

4.3 The applicability of the extra-welfarist approach for measurement and valuation of benefits associated with sexual health services for use in economic evaluation.. 68

4.4 Approaches to expand the evaluative space within Extra-Welfarism..... 69

4.4. 1 Statistical mapping.....70

4.4.2 Valuing on a common scale using preferences.....72

4.4.3 Bolt-on dimensions.....73

4.5.4 Development of new condition specific preference-based measures..... 75

4.5 An assessment of the opportunities for applying these techniques to sexual health.....77

4.6 Conclusion..... 78

CHAPTER 5: Measuring and assessing patient experience and satisfaction with sexual health services: A systematic review of literature..... 80

5.1 Introduction.....80

5.2 Methodology..... 83

5.2.1 Initial Scoping Search.....83

5.2.2 Systematic research and screening..... 83

5.2.3 Search strategy..... 85

5.2.4 Selection of studies.....86

5.2.5 Data extraction and Analysis..... 86

5.2.6 Synthesis & analysis.....87

5.3 Results..... 89

5.3.1 Key study characteristics..... 89

5.3.2 Study aims..... 90

5.3.3 Study participants..... 91

5.3.4 Development of study tools..... 91

5.3.5 Types of study tool design utilized in studies included in the review..... 92

5.3.6 Attributes of the services assessed by study tools..... 92

5.3.7 Analysis of data..... 92

5.3.8 Main findings from studies..... 93

5.3.9 Quality of studies included in the review..... 94

5.4 Discussion..... 114

5.4.1 Principal Findings..... 114

5.4.2 Generalisability of the findings of the review..... 115

5.4.3 Strengths and limitations of the review process..... 117

5.4.4 Implications of the review & recommendations for future research..... 118

5.5 Conclusions..... 120

5.6 Chapter summary..... 120

CHAPTER 6: Patient experience dimensions pertaining to sexual health services: Qualitative synthesis and meta-ethnography..... 122

6.1 Introduction..... 122

6.2 Methodology..... 125

6.2.1 Systematic research and screening..... 125

6.2.2 Search strategy..... 127

6.2.3 Selection of studies.....128

6.2.4 Critical appraisal..... 128

6.2.5 Translating and synthesising studies using techniques of meta-ethnography 129

6.3 Results..... 132

6.3.1 Critical Appraisal.....132

6.3.2 Synthesis findings..... 132

6.4 Discussion..... 157

6.4.1 Principal findings.....157

6.4.2 Comparison with other literature.....158

6.4.3 Methodological considerations..... 159

6.4.4 Theoretical implications..... 160

6.4.5 Strengths and limitations.....160

6.4.6 Policy implications and recommendations for future research.....161

6.5 Conclusion..... 162

6.6 Chapter Summary.....163

CHAPTER 7: Capturing outcomes considered most important by current or potential users of sexual health services within UK settings: a qualitative study..... 164

7.1 Background..... 164

7.1. 2 Aim and objectives of research..... 165

7.2 Methodology..... 166

7.2.1 Study settings..... 166

7.2.2 Study participants..... 166

7.2.3 Eligibility criteria..... 167

7.2.4 Sample size and sampling technique..... 167

7.2.5 Participant recruitment strategy..... 168

7.2.6 Topic guide..... 169

7.2.7 Qualitative data collection..... 170

7.2.8 Analysis of qualitative data..... 170

7.2.9 Ethical considerations..... 172

7.3 Results..... 174

7.4 Discussion..... 189

7.4.1 Principal findings..... 189

7.4.2 Comparison of the study with previous published literature..... 191

7.4.3 Strengths and limitations of the study..... 194

7.4.4 Recommendations for future research and policy implications..... 196

7.5 Chapter summary..... 197

CHAPTER 8: Discussion..... 198

8.1 Summary of the thesis..... 198

8.2 Strengths and Limitations of the study..... 210

8.3 Meaning of the study..... 214

8.4 Policy considerations..... 218

8.5 Recommendations for future research..... 223

8.6 Conclusions..... 226

APPENDICES..... 228

Appendix 1 Example of Search strategy (Systematic review chapter 5)..... 228

Appendix 2: Example of search strategy (Qualitative synthesis & Meta-ethnography)..... 230

Appendix 3: Materials for ethics approval (that were submitted to receive central university ethics approval) (Chapter 7)..... 231

Study tool for Primary research: Topic guide for one-to-one interviews..... 247

APPENDIX 4: Initial analysis of qualitative data (Broader themes and direct quotations utilised to synthesize main themes and sub-themes for primary research, ref. Chapter 7)..... 251

Appendix 5: Qualitative research checklists (chapter 7)..... 292

Appendix 6: Proposed steps for future development of a preference-based PROM for measuring and valuation of outcome pertaining to sexual health services… 296

Appendix 7 Sample transcription of interviews……297

References……324

CHAPTER 1: INTRODUCTION

This PhD work aimed to highlight the various aspects of sexual health services that are considered most important by patients while accessing care, to inform healthcare decision-making for evaluation and planning (designing or re-designing) of services to ensure they are patient centred. In this chapter, an overview of the thesis is provided. The components include the motivation behind the thesis, the main objectives of the research and a brief overview of each chapter.

1.1 Main motivation for thesis

The dynamics for sexually transmitted infections (STIs), their prevalence and patient engagement with the services related to STIs are dependent on various factors which are quite different from other illnesses and their associated care pathways. These include a high prevalence of disease among marginalized and minority groups (sexual and ethnic) ADDIN EN.CITE (1-3), a high proportion of asymptomatic patients (high infectivity rates) ADDIN

EN.CITE (2, 4), complications (health and cost implications) of untreated disease(5, 6) and unwanted pregnancies(7), strong stigma and embarrassment associated with accessing the services ADDIN EN.CITE (3, 8-10) and issues relating to different routes of delivery of care. (11) Additionally there have been major changes in the service delivery mechanisms in recent times (particularly in the UK), with little or no patient involvement. (11) Moreover, the World Health Organization (WHO) has increasingly recognized over the last few years the profound global impact of STIs on sexual and reproductive health.(12) Consequently, WHO updated its global strategy for STIs emphasizing the need to strengthen the existing evidence base for new and improved interventions and promoting patient-centred services.(13)

Furthermore, there has been a rise in the prevalence of sexually transmitted diseases across Organisation for Economic Co-operation and Development (OECD) countries. For example in 2018, there were 67.6 million prevalent and 26.2 million incident cases of STIs estimated in the United States.(14) There is also high cost associated with sexually transmitted infections globally which is often met with limited healthcare resources.(15) In the US alone, in 2018, STIs annually cost 16 billion dollars to the healthcare system.(16) Similarly in the UK, a recent estimate reports approximately, £572 million spent on sexual health services across the UK in 2017-18. (11) In addition to that the high rate of unplanned pregnancies in England have significant cost implications on NHS as direct medical costs.(7)

Hence, it is important to consider and explore the concept of patient satisfaction & patient-centred care as a way forward to address the key challenges mentioned above and to engage the patients with sexual health services. This may lead to desirable outcomes such as timely testing of STIs, compliance to treatment and increased engagement (high

attendance rates and recommendations to friends and family) with services.

To achieve these objectives, it is important to incorporate patient feedback for evaluating the existing service or it's planning (design or re-design). Therefore, the motivation behind this PhD is to establish all the key aspects of sexual health services in clinical settings considered most important by patient or potential clients accessing the services.

1.2 Aim and objectives of thesis

The primary aim of the PhD is to systematically highlight the various components and aspects of sexual health services which are considered most important by patients or potential clients while accessing services within OECD settings. Additionally, the research also aims to identify important themes by gathering information (literature reviews and primary research) and analysing existing theories and methodologies (pertaining to health economics) to inform the future development of a sexual health services specific preference -based patient-reported outcome measure (for measuring and valuation of outcomes). The objectives are as follows:

- Generating an evidence-based argument (in the context of health economics) around the need for the development of a preference-based patient-reported outcome measure for sexual health services
- Assessment of the existing tools utilized to capture patient perceptions pertaining to sexual health services and identification of existing gaps in services
- Exploration of patient experience dimensions relating to sexual health services

- Establishing important themes that can utilized to develop outcomes that can be utilized for the future development of a preference-based PROM (for the measurement and valuation of outcomes pertaining to sexual health services)

1.3 Brief outline of thesis

A brief overview of each chapter of the thesis is as follows:

Chapter 2 includes a presentation of the definition of sexual health, the prevalence and burden of disease associated with common sexually transmitted infections mainly within OECD countries, an overview of the different routes of delivery of care and the economic burden associated with complications of untreated STIs and unwanted pregnancies. Additionally, important concepts pertaining to patient satisfaction, patient-centred care, patient reported outcome measures and the existing theories in health economics and their applied methodologies are also introduced in the chapter.

In Chapter 3 and Chapter 4, the aim is to provide an evidence-based argument for the need of development of a preference-based PROM for sexual health services. ***Chapter 3*** builds on the concepts and significance of patient-centred care and patient satisfaction (in the context of sexual health services) and presents a logic model based on findings of published literature and other scientific evidence justifying the need for the development of a preference-based PROM for sexual health services. ***Chapter 4*** further analyses the existing theories in health economics (Welfarism and Extra-Welfarism) and its applied methodologies, to evaluate which is more suited for measurement and valuation of

outcomes pertaining to sexual health services.

Chapter 5 presents the systematic review which was conducted to assess the existing tools utilized to capture patient perceptions while accessing sexual health services and the identification of existing gaps in services. This chapter discusses the methodological limitations of the existing tools and highlights key quality indicators and gaps in services from a patient's perspective.

In Chapter 6 a qualitative synthesis and meta-ethnography are reported to further explore patient experience dimensions while engaging with sexual health services. Important themes (1st, 2nd and 3rd order constructs) were identified in the context of patient experiences relating to various aspects of the service considered most important by them. The chapter concludes by suggesting further exploration of patient and potential clients' experiences pertaining to individual components of services by conducting primary research (qualitative study).

Chapter 7 presents the findings of the primary research which was conducted among patients and potential clients to establish important themes pertaining to the various aspects of the service.

Chapter 8 documents the summarized findings of each chapter comparing and discussing in the context of the overall aims and objectives of the thesis. The strengths and limitations of the thesis are also presented. This is followed by meaning of the study (including potential policy implications and recommendations for future research) and overall conclusions.

CHAPTER 2: Background to sexual health services within OECD settings and the significance of capturing patient reported outcomes

Introduction:

This chapter aims to provide an overall background to the thesis. The key elements relate to the definition of sexual health, before considering the importance of patient satisfaction, patient-centred care and capturing patient reported outcomes, and then finally outlining the methods associated with economic evaluation. The high prevalence of STIs in the UK and OECD countries and their associated adverse health outcomes makes this an important health, economic and social issue.

2.1 Defining Sexual Health

The definition of sexual health has evolved over the decades and has been influenced by historical, political and social events.(17, 18) Most recently the World Health Organisation (WHO) defines sexual health as ′a state of physical, emotional, mental and social well-being

in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.′(19)

However, the literature suggests that the definition of sexual health is a dynamic concept and may evolve further due to events like it did in the past. (17) The main contributing factors over the years which have influenced the understanding of what should be included in sexual health have been the constant struggle over reproductive rights and abortion, the progression of gay rights movements, exponential increase in population rate and the detrimental impact of HIV/AIDS globally.(18)

It is important to acknowledge the need to develop a clear and comprehensive understanding of sexual health which resonates with patients, policy makers and health professionals.(20)

2.2 Prevalence and burden of disease of sexually transmitted infections & unplanned pregnancies

Sexually transmitted infections are a major public health concern and are categorized as one of the most common acute disease conditions globally.(21) STIs are clinically, epidemiologically and etiologically diverse and there are more than 30 parasitic, viral and bacterial pathogens associated with their transmission.(6) According to an estimate by the World Health Organisation (WHO), every day 1 million people get infected with one of the

four common curable STIs, namely, chlamydia, gonorrhoea, syphilis & trichomoniasis.(5) Similarly, in 2020 it was estimated that there were 374 million new cases of these four STIs worldwide.(22) Presently, there is also a global recognition of increased antimicrobial resistance in *Neisseria gonorrhoeae* and *Mycoplasma genitalium*.(23)

Additionally, there is also a high prevalence of unplanned pregnancies globally with 40% of these resulting in 76 million unintended births. (7) In developed countries half of all pregnancies are unplanned.(24) This has cost implications on the healthcare systems and adversely affects the overall wellbeing and mental health of pregnant women. (25, 26) Moreover, there can also be negative impacts for the wellbeing and mental health of a child born as a result of unplanned pregnancy.

In recent times, there has been a rise in the prevalence of sexually transmitted infections across OECD countries. For instance in 2018, there were 67.6 million prevalent and 26.2 million incident cases of STIs estimated in the United States.(14) Similarly, a few years back there was also a dramatic increase in STIs reported by the Centre for Disease Control (CDC) namely; 5.9% for chlamydia and 12.9% for gonorrhoea (in 2015 in comparison to 2014).(27) Moreover, STIs continue to be the most frequent health condition reported to Australian National Notifiable Diseases Surveillance System with a rise in the number of cases.(2) Furthermore, due to the infectious nature of STIs, their rates are expected to rise exponentially over time.

In the UK, STIs are also an important public health issue. The screening for sexually transmitted infections (STIs), chlamydia, gonorrhoea, syphilis and HIV, has also risen by 18% (‘1,513,288 in 2013 to 1,778,306 in 2017’)(28). The prevalence of Chlamydia trachomatis

infections is approximately 4% in females aged 18-24 in England, Scotland and Wales according to evidence from national probability surveys(29). Furthermore, England has the second highest rate of unplanned pregnancies among developed countries despite free provision of contraception by the National Health Service (NHS).(7)

STI's are associated with a range of adverse health outcomes, which may occur many years after infection. These include pelvic inflammatory disease, infertility, ectopic pregnancy, cervical cancer, cardiovascular and neurologic damage, epididymitis, foetal and neonatal morbidities and mortality.(5, 6) Furthermore, there is a strong stigma associated with STIs particularly among vulnerable and sexual minority groups which has negative implications on their engagement with the services and adversely affects their mental health & overall wellbeing. ADDIN EN.CITE (3, 8, 9) Hence, although most STIs are usually not fatal, they constitute a substantial burden of disease.(21)

2.3 The different types and pathways of sexual health services

There are a range of services that are included within the overarching term of sexual health services. There are many different models of service provision but generally most services include general advice on STIs and preventive measures, testing for STIs, information on different options for contraception, and the provision of contraception including emergency contraception. ADDIN EN.CITE (30-32) Some services may also include additional amenities such as; providing specialised support and referral to victims of sexual assault, Hepatitis A and B vaccination, cervical screening and post-exposure prophylaxis for HIV patients, advice on planning a pregnancy, abortion services and the management of sexual problems

including psychological and health related. ADDIN EN.CITE (30-32)

Sexual health and contraceptive services are provided through different routes in OECD countries. Some of the main pathways include STI clinics specifically designed to provide service ADDIN EN.CITE (33-35), genitourinary medicine departments in hospitals ADDIN EN.CITE (36, 37), pharmacy- based contraceptive and STI testing services ADDIN EN.CITE (38, 39), sexual health clinics integrated with rural outreach clinics(40), online services ADDIN EN.CITE (41, 42), public health clinics and services within non-profit organisations.(43)

In the UK, the commissioning of sexual health services moved to local authorities in 2013 and there have been major changes in service delivery processes.(11) Examples of changes in mechanisms of service delivery include; increased use of postal based testing using self-taken samples, delivery of services via pharmacies and third sector providers. (11) There has also been shift in clinic staff roles with increased utilization of health care assistants and nursing staff to deliver care. (11) Additionally, there has been increased integration of services (i.e. contraception services with infection testing services) and a significant reduction in funding over the last few years. (11)

Furthermore, the literature suggests that the Covid-19 pandemic has significantly impacted the accessibility to sexual health and contraceptive services, particularly in terms of a reduction in face to face consultations with the patients in clinical settings.(44) For instance at the start of the pandemic accessibility to services was dramatically reduced or completely cut in the United States.(45) It is now increasingly recognized that sexual health services should be a component of future pandemic and emergency preparedness planning.(45) There has been more emphasis on online services (Telemedicine) which has gained

recognition as an important route of delivering sexual health and contraceptive services.(44)

Having discussed the service delivery pathways, the next section will highlight the main issues associated with the accessibility of sexual health and contraceptive services in relation to patient characteristics, and the stigma associated with STIs.

2.4 Issues associated with sexual health services

There are certain challenges which are unique to sexual health which relate to the specific patient characteristics and the strong stigma associated with sexually transmitted infections

a) Specific characteristics associated with accessing sexual health services

Patients attending a sexually transmitted infection (STI) clinic can be differentiated from general outpatient attendees based on a range of characteristics. These specific patient characteristics include:

- Age – the highest incidence of acquiring STIs is among young individuals (between 16 and 25 years of age) (46)
- Ethnicity – there is a high prevalence among ethnic minorities. For example, 26% of all diagnosed cases of gonorrhoea in STI clinics are black Caribbean men who represent less than 1% of the general population(47)
- Socioeconomic deprivation – marginalised and underprivileged segments of population are at significantly higher risk of STIs (48)

- Sexual orientation – Literature suggests that sexual orientation of individuals is also associated with the prevalence of STIs. For instance, men who have sex with men have a higher rate of STIs (1, 2)
- Concerns about confidentiality – one of the key priorities for patients attending STI clinic services is confidentiality due to the stigma associated with STIs(3, 49)
- Source of referral – the patients who visit STI clinics are mostly self-refer with only a quarter initially seeing their general practitioner prior to accessing services (50)
- Absence of symptoms – patients presenting at STI clinics are often asymptomatic and request screening rather than seeking treatment ADDIN EN.CITE (2, 4)

The above-mentioned patients' attributes make it challenging to increase the accessibility of services and improve screening rates.

b) Stigma and embarrassment associated with STIs and contraception

There is a strong stigma associated with sexually transmitted infections and accessing sexual health services.(51) This has negative implications for the mental health and overall wellbeing of the patients as previously mentioned.(52) Literature suggest that the stigma is experienced more among men who have sex with men and ethnic minorities.(53) Studies(51, 54) report patients feel embarrassed to attend the service and feel a strong stigma associated with being diagnosed with a sexually transmitted infection. This often prevents them from accessing services or attending routine visits. (51, 54) This can lead to the negative health implications of untreated disease, unplanned pregnancies, undiagnosed

cases which may lead to spread of infection and affect the mental health of patients.

Having outlined the challenges associated with delivery of sexual health services the next section will highlight the economic burden associated with STIs and unplanned pregnancy STIs.

2.5 Economic burden associated with STIs and unplanned pregnancies, and the context of limited healthcare resources

There is high cost associated with sexually transmitted infections globally which is often met with limited healthcare resources.(15) According to a latest estimate, in 2018, the costs associated with STIs to the healthcare system in US alone were approximately 16 billion dollars.(16) Similarly approximately, £572 million was spent on sexual health services across the UK (2017/18) (11) and there were 3.3 million visits to sexual health clinics in England, an increase of 13% from 2013. Moreover, the high rate of unplanned pregnancies in England have significant cost implications on NHS as direct medical costs.(7)

Moreover, there are cost implications in terms of different types of contraceptive services and its uptake. According to an estimate by National Institute for Health and Care Excellence (NICE) if women convert from contraceptive pill to long acting reversible contraceptive methods NHS can save £100 million.(25)

In the UK there have been considerable cuts in the funds provided to sexual health services since commissioning was transferred to local authorities in 2013.(15) Since 2015 public health budgets have been 'ring fenced' and the within the 'ring fence' the proportion spent on sexual health services has been substantially reduced.(15) A unscheduled 6% (£200

million) cut was reported in 2015-2016 and a scheduled cut of 9.6% in 2020-21.(15) With the financial constraints and increased demand for the services (with some local authorities reporting 6% increase in visits per year) there is ongoing pressure to ensure that services are designed efficiently.(15) The NHS currently already faces the challenge of shortage of medical doctors(55) specially genitourinary medicine where there is scarcity of specialists.(56) Alarmingly, it is reported that one third of sexual and reproductive health consultants are due for retirement in next 5 years.(56) However, different programmes are being introduced to engage healthcare professionals other than medical doctors within services to compensate for the shortage of healthcare staff. An example of this is the advanced clinical practitioner (ACP) program.(56, 57)

Having highlighted the economic burden associated with STIs and poor reproductive health it becomes relevant to consider economic evaluation in healthcare and its basic principles, so this is introduced in the next section. The topic of economic evaluation in healthcare, main theoretical underpinnings and methodological techniques will be covered in depth in chapter 3 of the thesis. Section 2.6 will briefly introduce economic evaluation in health, main theoretical foundations and examples of the mostly applied methods in healthcare.

2.6 Economic evaluations in healthcare

It has been long established that the resources available to spend in health care are inadequate to meet all demands, with limits existing around staffing, equipment, facilities and knowledge.(58) There are resource implications associated with important decisions about what services to provide, to whom, when and where.(58) The main aim of economic evaluation in healthcare is to support decision makers to make the best use of scarce

resources by comparing the costs and benefits of interventions.(59)

Economic evaluations in healthcare provide information to inform optimal decision making. Economic evaluations have been increasingly utilized in recent decades in the policy making process due to the establishment of organisations in the UK such as National Institute for Health and Care Excellence (NICE)(60), the Scottish Medicines Consortium(61) and similar organisation in other OECD settings such as Commonwealth Department of Health in Australia(62), the Canadian Agency for Drugs and Technologies in Health.(63) Moreover in the USA there has also been an increased emphasis on the role of cost-effectiveness analysis in the evaluation of healthcare and non-healthcare interventions (in association with their impact on health).(64, 65)

Presently two main approaches exist which are commonly discussed in the literature and can be utilized for normative analysis (making value judgements) in relation to health and healthcare.(66) These approaches are Welfarsim and Extra Welfarism.(67) Each approach has its own theoretical and methodological basis to underpin economic evaluations.(68) Both the frameworks and their methodological applications will be further analysed in chapter 4. Briefly, the Welfarist framework assumes that the outcomes associated with healthcare should be judged in terms of their contribution towards the overall welfare of individuals with the aim to maximise social welfare (wellbeing).(69) Whilst the Extra-Welfarist approach focuses on maximising health and the outcomes associated with healthcare are judged according to their contribution to health itself rather than preference for health in comparison with other goods.(66) Therefore, the types of economic evaluation conducted within these approaches differ markedly in terms of the measures of costs and benefits utilized.

There is an exploration and debate among health economists and the scientific community regarding the limitations of these paradigms and which approach is best suited for guiding decision making process in the healthcare sector.(68, 70) Decision makers such as NICE are more inclined towards the Extra-Welfarist approach to economic evaluation, particularly cost-utility analysis, due to the ability to allow comparison across interventions and programmes and different diseases/ conditions.(69)

2.7 Introduction to the main techniques for economic evaluation in healthcare

The main methods for economic evaluation in health care are namely cost-consequence analysis, cost-benefit analysis, cost-effectiveness analysis & cost-utility analysis. The different approaches differ in terms of the costs and benefits utilized in the economic evaluation.

a) Cost-consequence analysis (CCA)

The technique involves listing of all the direct and indirect costs and all possible consequences (outcomes) of the alternative interventions or programmes without any attempt to aggregate these results. (58) The results of CCA are presented in a tabular form with all the relevant factors clearly shown. It is then left to the decision makers to make normative judgements based on the information presented. (58) The main disadvantage of CCA that it forms a weak basis for decision making process as the decisions based on this type of economic evaluation are often unclear and not based on explicit values.(58)

b) Cost-benefit analysis (CBA)

The main characteristic of cost-benefit analysis (CBA) is that the costs and benefits of an intervention are valued in monetary terms.(71) In this analysis an intervention is considered worthwhile if the benefits of the intervention exceed the cost of the intervention in monetary terms.(71) This technique can be utilized to address the question of whether an intervention or programme is beneficial to society overall, rather than just being restricted to the health sector or one objective. (71) Moreover, CBA can include a wide range of outcomes including non-health benefits. (71) There are various techniques for obtaining the monetary valuation of benefits and there are limitations of application of CBA in healthcare, which will be discussed in detail in Chapter 4.

c) Cost-effectiveness analysis (CEA)

Cost-effectiveness analysis is a type of economic evaluation in which the costs of interventions are measured in monetary terms and the outcomes are presented as 'natural units' which are directly related to the condition of interest (i.e. death averted).(72) The analysis compares the interventions to estimate the costs to gain a unit of a health outcome and presented in a ratio of incremental cost to incremental outcome. (72) The health outcomes may include: the number of cases of disease prevented, quality-adjusted life years, life years saved etc. (72) A wide range of endpoints can be considered in a cost-effectiveness analysis such as detecting STIs, reduction in blood pressure and improvement in mineral bone density. (72) However, there are certain limitations associated with this technique.(58) CEA cannot be used to compare interventions affecting two or more outcomes. Moreover, it cannot inform policy decisions on the efficient allocation of resources across different healthcare programmes or disease states with health outcomes

across different dimensions.(58)

d) Cost-utility analysis (CUA)

This technique of economic evaluation also compares interventions in terms of cost per unit of effect like CEA where the unit of effect is a 'year in full health'.(58, 73) The measure of year in full health used extensively in CUA is quality-adjusted life year (QALY). (58) The QALY is the product of the multiplication of a person's life expectancy with the value of the health -related quality of life spent in each period.(58) The procedure to estimate the quality adjustment values of QALYs are based on two components: description of the state of a person's health and the valuation of these descriptions. (58) QALYs are measured on a scale of 0 (dead) to 1 (full health).(58, 74) The valuation techniques of the description of health states in estimating a QALY and issues around their practical application in economic evaluation in healthcare are discussed in detail in chapter 4. A CUA allows comparison across programmes, as the QALY is a common metric which can be used to estimate benefit across different interventions and different disease conditions.(75)

The next section will introduce the concept of patient satisfaction, patient-centred care, patient reported outcomes and the role of preference-based patient reported outcome measures in economic evaluations.

2.8 Significance of patient satisfaction

Patient satisfaction is a complex and dynamic concept. ADDIN EN.CITE (76-80) Patients are increasingly recognized as important stakeholders and contributors in quality assurance.(81) Patient satisfaction has been increasingly recognized as an important indicator of healthcare quality also encompassing the clinical results, economic measures and health related quality of life. ADDIN EN.CITE (76, 82-86) The concept has been the focus of many scientific studies conducted worldwide and patient satisfaction surveys have been utilized globally in healthcare organisations. ADDIN EN.CITE (87-93) Results of such surveys help identify service factors which need improvement and provide important information for policy makers to acknowledge patient needs. This information can be utilized to devise strategic plans for effective and improved quality services. ADDIN EN.CITE (87-93) Literature suggests that patient satisfaction influences their engagement with service and behaviours such as compliance to healthcare provider advice pertaining to treatment and appointments to follow ups with positive effect on health outcomes(94, 95) and recommendation of service to friends and family members.(96)

A latest concept analysis using Rodgers' method (an inductive method of concept analysis) highlighted attributes of patient satisfaction in healthcare context. ADDIN EN.CITE (97) The attributes identified were; 'provider attitude, technical competence, accessibility and efficacy'. ADDIN EN.CITE (97) The demographics of patients and personality and expectation in relation to perception were described as prerequisites to patient satisfaction. ADDIN EN.CITE (97) Similar to findings of previous research ADDIN EN.CITE (76, 82-85, 94, 95) the outcomes of patient satisfaction identified in the analysis were; patient compliance clinical outcomes, loyalty and referrals. ADDIN EN.CITE (97)

The next section will introduce the concept of patient-centred care which is closely linked with patient satisfaction and has been increasingly recognized as an integral component to improve the quality of healthcare services.

2.9 Patient-centred care

Patient centred care (PCC) is a widely used model in healthcare systems in recent times(98) and is considered as 'elemental to the definition of quality of care'.(99) PCC is championed by the World Health Organisation and supported by UK and USA health policy.(100-102) The concept of patient centred care is based on the principle of 'treating the patient as a unique individual' (103) and places patients at the centre of the healthcare system, recognizing them as a whole person with physical, psychological and social needs.(104) There are major advantages associated with implementing PCC models in healthcare systems. PCC enhances continuity of care, reduces the costs of care, promotes active collaboration of healthcare providers and patients in making decisions regarding treatment and improves efficiency and service quality. (104)

Despite the salient features of the PCC model, in reality it is often not fully implemented and patients frequently have limited input and opportunities to define key elements in the design and redesign of healthcare services.(102) This leads to patients finding services difficult to navigate, disempowering, burdensome and having lower satisfaction levels. ADDIN EN.CITE (102, 105-107) The aim of PCC is to improve care and increase patient satisfaction.(108) Patients feedback or report of their health condition, patient satisfaction (all the attributes associated with as mentioned in section 2.8), experiences of treatment etc

are included in patient reported outcomes.

Therefore, it is important to highlight and understand what patient reported outcomes are and the various measurement tools utilized to capture them.

2.10 Patient reported outcomes

Patient reported outcomes (PROs) is an umbrella term which refers to 'any report of a patient's health condition that comes directly from the patient, without interpretation of the patients response by a clinician or anyone else'.(109) The PROs can provide important information pertaining to the wellbeing, functioning, symptoms, and experiences of treatment from a patient's perspective.(109)

The next section will briefly discuss patient reported outcome measures and the different types utilised.

2.11 Patient reported outcome measures (PROMs)

A Patient Reported Outcome Measure (PROM) is a tool or questionnaire which is utilized to capture PRO information directly from patients. (109, 110) It has been increasingly emphasized in the recent literature that 'measuring what matters to patients is central to improving patient care and service delivery'. ADDIN EN.CITE (110-113) PROM assessment within healthcare can generate evidence which can facilitate doctor-patient communication, substantiate patients input to their care and can help inform commissioners how the service can be designed or redesigned.(110, 114)

PROMs can be either classified as preference based or non-preference based.

a) Preference-based PROMs

Preference based measures usually entail a number of domains (or descriptive sets) that patients can utilize to describe various aspects of their health such as limitations in daily activities and mobility, pain etc. (115) These patient-reported values, referred to as 'profile scores' are then converted to an index score using a selected algorithm.(115) This will be discussed further in detail in chapter 3 & 4.

Preference-based PROMs can be either generic or condition specific. Examples of generic PROMs include the EuroQol five-dimensional questionnaire (EQ-5D)(116), the six-dimensional health-state short form (SF-6D) (117) and the Health Utilities index (HUI).(118)

There are national guidelines in many OECD countries that suggest or require the use of these generic measures for economic evaluation. ADDIN EN.CITE (119-121) However, there are certain conditions where generic measures like EQ-5D are inadequate to capture values which are truly reflective of patient preferences because of their generic nature. There is suggestion that the domains may not be sensitive enough to pick meaningful changes pertaining to the consequences of the condition suffered by the patient.(75) In such cases a condition specific preference-based measure can be constructed either from an existing condition specific measure or developed de novo. Examples of condition specific preference based measure include dementia-specific DEMQoL-U (122) and the cancer-specific EORTC-8D (123).

b) Non-preference-based PROMs

Non-preference-based measures are often utilized in clinical studies but lack an associated preference-based scoring system and therefore cannot be utilized in a economic evaluation (i.e. cannot be utilized to calculate a quality adjusted life year).(115)

The concept of QALY and its calculation methods in context to preference-based PROMs will be discussed in detail in Chapter 4.

2.12 The role of PROMS

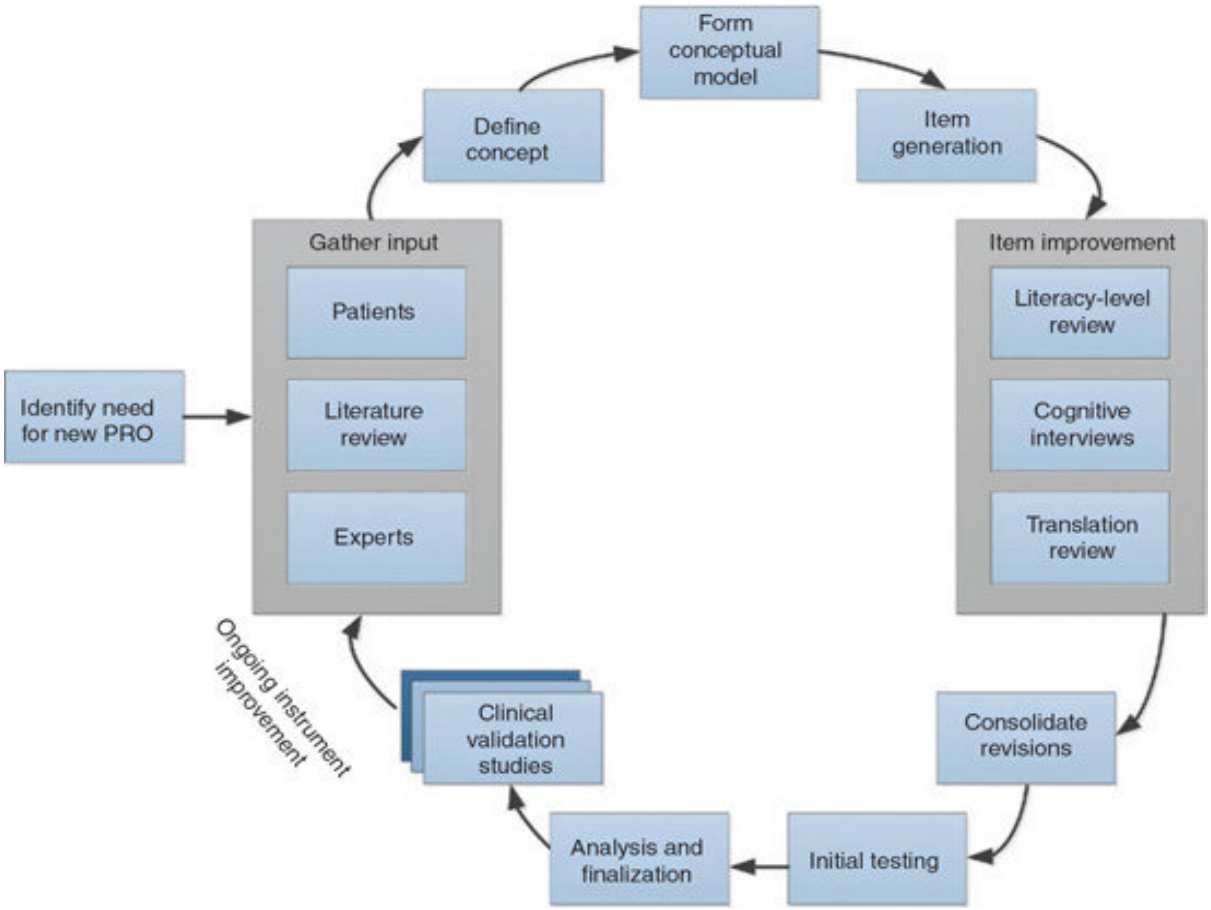
The role of PROMs has evolved from being utilized primarily for assessment of disease activity parameters to being applied for diagnosis, assessment of disease activity, monitoring of co-morbidities, adherence to therapy and patient self-management.(113) There are various potential benefits of PROM assessment in research and clinical practice with regard to 'clinicians and individual patient care, healthcare management teams, regulators and commissioners and policy makers'.(111) The utilization of PROMs in observational studies and clinical trials is well established.(111) PROMs can be used to capture and measure valuable evidence on the burden of disease, and the efficacy, effectiveness and the otherwise intangible costs of interventions solely from a patients' perspective. ADDIN EN.CITE (111, 124, 125) There has been a growing recognition within healthcare of the importance of PROMs.(126) Moreover, preference-based PROMS have been widely used to inform economic evaluations. For example, EQ5D-3L/5L and SF12/36 are well-known generic PROMs and have been widely used as part of economic evaluations in healthcare.(127, 128)

Having discussed the different types of PROMs and their utilization in healthcare and economic evaluation the next section will present a brief overview of the standard steps of PROM development process.

2.13 Standard steps of PROM development process

The general standard steps for PROM development process are depicted in figure 2.1 and are briefly outlined below.

Figure 2.1 Standard steps for PROM development process(109)



i) Identification for the need of a new patient reported outcome and gathering input

The initial step of the development of a patient reported outcome measure is to identify its need that why a new measure is needed.(109) This is determined by comprehensively reviewing the existing literature, conducting interviews with patients and receiving expert feedback from the experts in the relevant disease area (Figure 2.1). This information is important to define the concept pertaining to the condition of interest which can be utilized to construct a conceptual model (Logic or End-point model) signifying the justification of development of a new PROM in the area of interest. (109)

This is followed by developing themes (items and domains) of the measurement tool.

ii) Item improvement

The following steps are carried out once items and domains of the instrument are established

1) Validation of outcomes (items and domains)

The items that will be included in the PROM need to be improved and validated through standardized techniques namely, a) literacy level review, b) cognitive interviews and c) translation review.

a) Literacy review

The literacy review step will ensure that the items included in the PROM are presented in simple easy to read format.(109) This is an important consideration as the tool should be applicable to participants with different literacy levels.

b) Cognitive interviews:

The cognitive interviews will help to determine the clarity and importance of each item for patients. This step will involve a patient answering the items included in the PROM and then interviewed pertaining to the interpretation and thought processes involved in selecting a response.(109) This will be an important assessment process which will allow the researchers (developers) to determine whether the understanding of an item included in PROM is same as themselves and patients. (109) This step would allow fixing any issues of jargon, culture specific constructs technical language etc.

c) Translation review

This step will allow the developers to assess whether it is possible to translate the PROM in other languages and any issues relating to verb tenses, units of measure etc can be corrected as depicted in figure 2.1.

These steps should be followed by consolidation revisions and initial testing of the tool. Once the steps outlined above are followed analysis and finalization of the outcomes included in the PROM can be determined and tested in clinical validation studies.(109)

As depicted in figure 2.1, PROM development is ideally an iterative process, and the tool undergoes continues revisions for it to be validated and report reliable findings.

2.14 Chapter summary

This chapter has presented an overview of sexual health, sexually transmitted diseases their prevalence and burden of disease, and the important issues associated with sexual health and contraceptive services particularly in the UK. There are significant pressures associated with delivering the services due to the rise of prevalence of STIs, their associated adverse outcomes and reductions in funding over the years. Moreover, services have gone through considerable changes and new models of service delivery have been introduced. Overall, there has been limited patient involvement in the redesign of services. In addition, services tend to use clinical outcomes to measure success, rather than exploring with patients which outcomes are important for them.

The next chapter will expand on the concepts and significance of patient-centred care in context of sexual health services and present a logic model as a component of the evidence-

based argument (covered in chapters 3 & 4) for the need for the development of a preference-based PROM for sexual health services.

CHAPTER 3: Significance of patient-centred care and the need for a preference-based PROM for sexual health services

Introduction

This chapter aims to outline the significance of patient-centred care in modern healthcare systems in context to sexual health services. This chapter (alongside chapter 4) provide an evidence-based argument for the need of a preference-based PROM specifically for sexual health services.

3.1 Significance of patient-centred care in modern healthcare system

As mentioned in chapter 2, the concept of patient-centred care (PCC) is based on the principle of 'treating the patient as a unique individual' (103) and the concept advocates patients as integral components of the healthcare system recognizing them as a whole person with physical, psychological and social needs.(104) It can be described as a standard of practice that fully acknowledges and takes into consideration the patients point of view and circumstances in the decision making process and not merely limited to setting goals with patients.(104, 129) PCC is commonly considered by two approaches; (i) a systems model and (ii) a process model.(104)

The system model is based on the principal of establishing a patient centred environment. (3 -7) this is primarily implemented by focusing on meeting individualized patient care needs by streamlining the staff and services in accordance with their needs. ADDIN EN.CITE (129-133)

Whereas, the process model encompasses patients perspectives consisting of seven dimensions(134) which describe a range of activities essential for PCC which mainly include; 'consideration of the patient's beliefs, values and expressed needs; coordinating and integrating the care; informing, communicating and educating the patient on treatment and

care; providing physical comfort and emotional support; involving patients and families in decision-making; and ensuring transition and continuity of patient care′.(104, 135)

There are major advantages associated with implementing PCC models in healthcare systems. Literature ADDIN EN.CITE (130, 136-138) indicates that there are certain advantages associated with PCC which mainly include enhancing the continuity of care, reducing costs of care, promoting integration with healthcare providers and patients & improving efficiency and service quality according to patients′ needs, wants and preferences. It also provides autonomy to patients and provides them with abundant opportunities to be informed and involved in decision making process. ADDIN EN.CITE (130, 136-138) Moreover, PCC emphasizes the principals of holistic care, improving communication skills between healthcare providers, patients, and their relatives. (13-16) It also focuses on total care rather than just body care; it advocates a collaborative approach, reduces stress, increases empowerment in patients and stimulates meta-cognition processes among healthcare professionals(so they can reflect on their skills and abilities strengthening the learning process of healthcare management of patients). ADDIN EN.CITE (104, 139-142) Furthermore, evidence suggests that patient centred care interventions improve clinical outcomes, adherence to treatment and patient satisfaction with healthcare services. ADDIN EN.CITE (143-145)

Despite the salient features of the PCC model, in reality patients have limited input and opportunities to define their values (perceptions and expectations) in the design and redesign of healthcare services.(102) This leads to patients finding services difficult to navigate, disempowering & burdensome which may lead to lower satisfaction levels among them. ADDIN EN.CITE (102, 105-107) The next section will highlight the significance of PCC in

context to sexual health services.

3.2 The importance of patient-centred care and capturing patient reported outcomes in the context to sexual health services

Patient centred care in sexual health services is strongly advocated by the World Health Organisation(146, 147) and supported in UK and USA health policy. ADDIN EN.CITE (148-150) The needs and expectations of patients accessing sexual health services have been found to be different to those of patients accessing other health services, partly due to the strong stigma and embarrassment attached with sexual health. ADDIN EN.CITE (43, 146, 151, 152) As set out in chapter 2, 'sexual health' is a complex concept and is more than the absence of disease and dysfunction. The World Health Organisation recommends that sexual health services should be patient-centred and designed around what matters to patients so they are empowered to access services and take responsibility of their sexual health.(146, 147) Similarly, Public Health England's suggested national service specification for integrated sexual health services emphasises the need for non-judgemental and confidential services, informed by patient engagement and measurement of patient reported outcomes.(150)

Moreover, a latest published systematic review(153) (focusing on young individuals) highlighted that patients have expectations which were far more than being tested and treated for STIs and the provision of advice on contraception. The findings of the review indicated that patients had serious concerns around confidentiality, were affected by staff attitudes and behaviours, and had important preferences about the process of care. (153) In addition, the review suggested that there were unmet needs for marginalized and

vulnerable patients, that there were accessibility issues and that patient had important suggestions to improve the service and overall quality of care. (153)

Furthermore, as previously mentioned in chapter 2, in the UK, the commissioning of sexual health services moved to local authorities in 2013 and there have been major changes in models of service delivery.(11) These models have included the increased use of postal based testing using self-taken samples, self- management, delivery of services via pharmacies and third sector providers, changes in clinic staff profiles with increased use of health care assistants and nursing staff to deliver care, and integration of contraception services with infection testing services. ADDIN EN.CITE (11, 154, 155) In addition as mentioned in chapter 2, funding for sexual health services has reduced significantly over the last few years (11, 15). The speed of change has been rapid and there has often been little patient input into the redesign of services.(154) Therefore, it is important to explore, highlight and incorporate outcomes considered most important by potential clients and patients in evaluating the service and planning its design or re-design.

3.3 Logic model depicting the need of developing a preference-based PROM for sexual health services

As mentioned in chapter 2, non-preference-based measures are often utilized in clinical studies but lack an associated preference-based scoring system, therefore cannot be utilized for economic evaluation of healthcare interventions.(115) On the contrary, as previously highlighted preference-based measures entail a number of domains (or descriptive sets) that patients can utilize to describe various aspects of their health such as limitations in daily activities and mobility, pain etc. These patient-reported values, referred to as 'profile scores'

are then converted to an index score using a selected algorithm.(115) The methods of valuation of outcomes using a preference-based PROM will be discussed further in chapter 4.

A logic model (Figure 3.1) is presented below illustrating how a preference-based PROM can be used to capture how well sexual health services are patient-centred, delivering outcomes that are important to patients and can be utilized in an economic evaluation. The model shows patient-centred sexual health services are linked with better engagement with services (leading to increased screening uptake, diagnosis, compliance to treatment etc.) which leads to desirable outcomes of reduced transmission of STIs and complications of untreated disease and unplanned pregnancies (Figure 3.1). The evidence for the associations depicted in the logic model are based on scientific studies and summarized in Table 3.1. Due to the limitations of cross-sectional study designs it is difficult to establish a direct cause-effect relationship.(156) However, the associations (links in the logic model) are based on the established theories of patient-centred care, concept analysis of patient satisfaction and findings of published literature (table 3.1).

Additionally, it is important to mention that various modelling studies ADDIN EN.CITE (157-161) have also demonstrated that increased uptake of screening, timely treatment of infection and partner notification leads to a reduction in infections at the population level. Furthermore, the recently published national service specification(150) requires services to provide evidence on the effectiveness of care from the patients' perspective and the patient experience of the humanity of their care.

Figure 3.1: Logic model(162) illustrating the need to develop a preference-based PROM for sexual health services

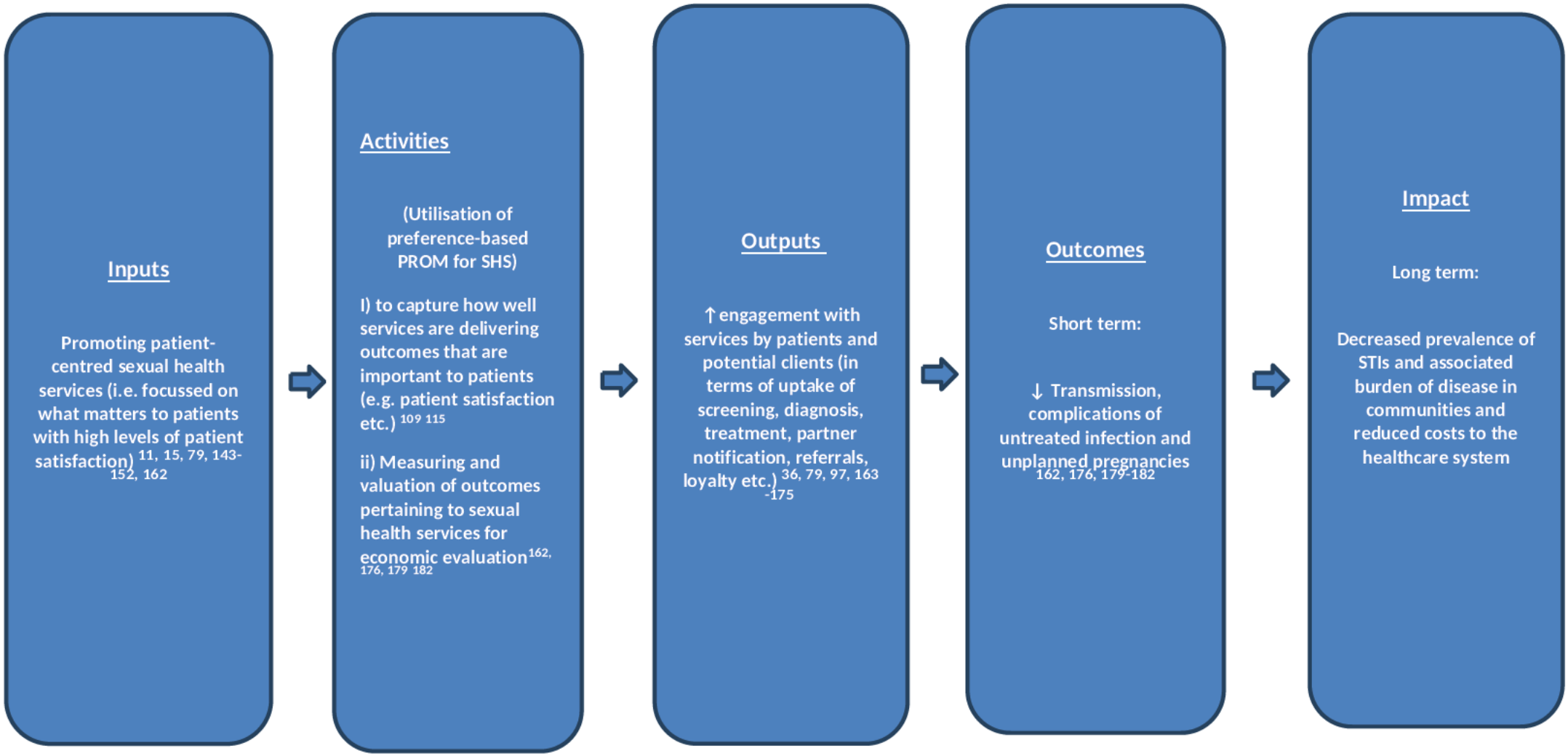


Table 3.1: Summary description of the logic model (building blocks) illustrating the need to develop a preference-based PROM for sexual health services

Indicators	Brief background of indicators (building blocks)	Relevance to patients accessing, utilisation and uptake of sexual health services
Patient-centred sexual health services (i.e., focussed on what matters to patients which aims for high levels of patient satisfaction)	• WHO recommends that sexual health services are patient-centred and designed around what is important to patients. (146, 147) • It is important to acknowledge that patients can play important roles as a contributor, reformer and as a stakeholder in quality assurance. (79)	• The needs and expectations of patients accessing sexual health services are different within patient groups and from other disease conditions partly due to the strong stigma and embarrassment attached with sexual health. ADDIN EN.CITE (43, 146, 151, 152) • In a developed country like the United States sexual health is being increasingly recognized as a national health priority with more than 20 million STIs and 3 million unintended pregnancies reported annually.(148, 149) • In recent times there is emergence of resistant strains of gonorrhoea which are labelled as 'superbug'.(163) There are highest rates of syphilis reported in the UK since 1949. These are some of the examples of the increasing relevance of engaging patients with sexual health services.(163) • As mentioned in chapter 2, in the UK, the commissioning of sexual health services moved to local authorities in 2013 which resulted in major changes in models of service delivery.(11) • In addition, funding for sexual health services has reduced significantly over the last few years (11, 15). The speed of change has been rapid and there has been little patient input into the redesign of services.(154)
↑engagement with services by patients and potential clients (in terms of uptake of	• Literature suggests that when services are designed around what matters to patients, it leads to greater engagement with services, in	Studies conducted to assess various aspects of sexual health services from a patients' perspectives mainly report:

screening, diagnosis, treatment, partner notification, referrals, loyalty etc	terms of increased screening uptake, faster diagnosis and treatment, more effective partner notification etc. ADDIN EN.CITE (97) • Patient satisfaction with healthcare services can lead to more confidence in service and its increased utilisation which can result in timely diagnosis and testing of disease and compliance to treatment and healthcare advice.(164) • Evidence suggests that clinical outcomes and care are strongly associated with patient satisfaction. ADDIN EN.CITE (164-166) • The consequences of patient satisfaction identified by concept analysis in recent literature mainly include; patient compliance, clinical outcomes, referral and loyalty. (79)	i) There are serious concerns of confidentiality, fear and stigma among patients accessing sexual health services. If these concerns are not met this adversely affects their utilization of care including STI testing and compliance to treatment. ADDIN EN.CITE (42, 43, 167-171) ii) Higher patient satisfaction levels are positively associated with contraception use and prevention of unplanned pregnancies and STI rates ADDIN EN.CITE (172-175) iii) Patients who are satisfied with service have more willing for referrals ADDIN EN.CITE (36, 168, 176) iv) Patients who are satisfied with a clinician or a particular service report to be more willing to avail the same service on a continuous basis and refer friends demonstrating loyalty ADDIN EN.CITE (43, 152, 171)
Decreased Transmission, complications of untreated infection and unplanned pregnancies	• Recent modelling studies conclude that timely screening and diagnosis and adherence to treatment lead to lower STI rates at population level. ADDIN EN.CITE (157-161) • Evidence suggests that increased patient compliance, utilization of services and adherence to treatment leads to improved clinical outcomes and an overall improved quality of care. ADDIN EN.CITE (94-96) • The positive health outcomes are interlinked with higher patient satisfaction with healthcare services.(84)	• Evidence suggests that provision to sexual health and contraception are highly cost effective. ADDIN EN.CITE (163, 178, 179) • There is a higher prevalence of STIs among vulnerable and marginalized groups of patients with significant barriers associated with accessing care as previously highlighted in chapter 2. Early diagnosis, testing and treatment can prevent the transmission, complications and unplanned pregnancies which can have health and economic implications for them, their families, and the health service if unaddressed.

	• Better clinical outcomes and improved quality of care are associated with reduction in costs of untreated disease and its associated chronic complications.(177)	
Why is a preference-based PROM needed	As mentioned in chapter 2, patient reported outcomes (PROs) is an umbrella term which refers to 'any report of a patient's health condition that comes directly from the patient, without interpretation of the patients response by a clinician or anyone else'.(109) The PROs can provide important information pertaining to the well-being, functioning, symptoms, and experiences with treatment from a patient's perspective.(109) A Patient Reported Outcome Measure (PROM) is a tool or questionnaire which is utilized to capture PRO information directly from patients. (109, 110) It has been increasingly emphasized in recent literature that 'measuring what matters to patients is central to improving patient care and service delivery'. ADDIN EN.CITE (110-113)	PROMs can be either classified as preference based or non-preference based. Preference based measures usually entail a few domains (or descriptive set) that patients can utilize to describe various aspects of their health such as limitations in daily activities and mobility, pain etc. These patient-reported values referred as 'profile scores' are then converted to an index score using a selected algorithm.(115) Non-preference-based measures are often utilized in clinical studies but lack associated preference-based scoring system therefore cannot be utilized in economic evaluations.(115) Therefore, a preference-based PROM specifically for sexual health services can be utilized for measuring and valuation of outcomes in this area.
Preference-based PROM and its important health economics implications.	Low levels of patient satisfaction may lead to decreased utilization sexual health services resulting in high prevalence of disease and other health related complications which can have wide reaching and long lasting impact with far reaching economic implications.(163)	Unfortunately, significant stigma still surrounds sex and STIs, which disproportionately affect the vulnerable and marginalised.(163) Untreated disease and lack of utilisation of services has health complications and additional costs directly affecting the patients, their families and health services. ADDIN EN.CITE (180-183) Therefore it is important for measurement and valuation of outcomes pertaining to sexual health services. A preference-based PROM designed to capture outcomes (measuring and valuation) considered most important for patients and can be utilized in an economic evaluation. (177)

3.4 Conclusion

The chapter initiates the evidence-based argument pertaining to the significance of patient-centred care and capturing patient reported outcomes in context to sexual health services. It was suggested that this practice may lead to desirable health outcomes, increased overall efficiency, and improve the quality of care. The importance of a preference-based PROM for measuring and valuation of outcomes pertaining to sexual health services was also discussed. It was depicted through the logic model that development of such a measure can be utilized in economic evaluation of the service as well as promoting patient-centred care. It is important to highlight that only preference-based PROMs are utilized in economic evaluations to capture outcomes (benefits) associated with interventions alongside costs to assess efficiency. It was discussed that preference-based measures usually entail several domains (or descriptive set) that patients can utilize to describe various aspects of their health such as limitations in daily activities and mobility, pain etc. These patient-reported values referred as 'profile scores' are then converted to an index score using a selected algorithm.(115)

Having discussed the significance of patient-centred care and the need for preference-based PROM in context to sexual health services the next chapter will cover in depth the theoretical foundations underpinning economic evaluations in healthcare and its applied techniques. The analysis will help develop a better understanding and determine the most appropriate theory (and its applied methodology) in health economics for measuring and valuation of outcomes pertaining to sexual health services.

CHAPTER 4: Measurement and valuation of outcomes pertaining to sexual health services for use in economic evaluation

Introduction:

The aim of this chapter is to explore the most appropriate approaches to use in the economic evaluation of services in sexual health. This assessment is necessary because there are several aspects of sexual health and their services which are arguably different to many other clinical areas as discussed in previous chapters. For a significant number of patients, STIs are asymptomatic, which means that the recommended measures for use in economic evaluations, such as EQ5D which focuses on pain, mobility, self-care etc. are less useful in a sexual health context. The long-term complications, referred to as the sequelae of the disease, can have important impacts on physical and reproductive health, e.g., infertility, pelvic inflammatory disease etc, and these cannot be properly captured at the time point of diagnosis but are mostly likely to be apparent a few years later. Moreover, the findings of a latest systematic review(153) as previously mentioned in chapter 3, report that there are other outcomes that are important to patients at the point at which they access services, which are broader than health. For example, patients often have concerns about confidentiality, how they are treated, and they want to be supported with feelings related to stigma, shame, embarrassment and fear. (153) This links to a wider debate in the health economics literature about the need for consideration of outcomes beyond health in economic evaluation, particularly in relation to social care and public health.(58, 75)

This chapter seeks to identify optimal approaches for the measurement and valuation of outcomes pertaining to sexual health services:

Thus, the key aims are:

1. Examine the main theoretical frameworks which underpin economic evaluation (Welfarism and Extra-Welfarism).
2. Assess the applied methods associated with each framework.
3. Examine the most appropriate approach for the evaluation of sexual health services.
4. Explore attempts to expand the evaluative space within Extra-Welfarism in the context of sexual health services.
5. Assess the most appropriate approach to expand the evaluative space within Extra-Welfarist framework for the evaluation of sexual health services.

As introduced in chapter 2, there are different approaches to economic evaluation which are underpinned by two main theoretical frameworks, Welfarism and Extra-Welfarism.

To determine which economic evaluation methods are best suited to assessing the cost effectiveness of interventions in a sexual health services context, it is important to discuss these two main frameworks in detail. The next sections will describe the two main paradigms, their methodological applications, and limitations in a sexual health context.

4.1 The theory of Welfarism in a healthcare context

4.1.1 Key theoretical foundations

The main objective of the Welfarist approach is to maximise social welfare or wellbeing by maximising individual utility.(184) The concept of utility has historically been considered as

synonymous with satisfaction, wellbeing, happiness or preference.(66) Welfarism stems from one of the four main key tenets of the neo-classical framework of welfare economics.(185) The main four key tenets of welfare economics include(185):

i) **Individual sovereignty**

This tenet entails that individuals are exclusively the best judge to decide what contributes to their utility and to what extent that contribution is made. (185)

ii) **The utility principle**

Welfare is maximized by individuals by rationally ordering options and selecting the preferred option. (185)

iii) **Consequentialism**

The estimation of utility is solely based on the outcomes of behaviours and processes rather than the output of processes or intentions leading to outcomes. (185)

iv) **Welfarism**

The concept of Welfarism restricts the goodness of any situation or state of affairs based on the prime judgment of utility levels attained by individuals (utility information) in that given situation.(66, 186)

Hence, Welfarism is one the four main tenets of welfare economics in which the evaluative space is focussed on individual utility only, and individual utilities are the function of commodities consumed by individuals such as good or services.(66, 69)

The Welfarist approach underpinning resource allocation in healthcare is based on some key assumptions: (i) 'social welfare is the function of individual utilities and (ii) individual utilities are a product of the goods and services consumed by these individuals'.(70) Another important assumption is that individuals are the best judge of their of their wellbeing.(59) In Welfarism, the desirability of different options for resource allocation are assessed in relation to effect on individual utility.(66)

As mentioned previously, the welfarist approach 'restricts' the evaluative space to individual utilities. (66) The individual utilities are summated to assess whether a resource allocation decision results in an improvement in social welfare. Since utility cannot be measured directly, the change in utility is presented by a proxy, which is money. (66, 69)

According to the Pareto principle, a Pareto improvement is achieved when a reallocation leads to at least one person better off (increase in social welfare or utility) and no one worse off.(67) A state of Pareto optimality which is a state of efficiency is achieved, when it is no longer possible to increase individual utility without making someone else worse off .(67, 69) In real life settings, particularly in health care, it is difficult to devise policies and interventions which would only create benefits without depriving others. Therefore, Kaldor-Hicks compensation principle is applied to address this issue. (69) According to this principle, a program can be considered to contributing towards social welfare if those who gain from it would be able to pay enough for their gains to compensate the losers.(58, 187) The next section will consider how Welfarism is applied in practice in relation to healthcare.

4.1.2 Application of welfarism in healthcare

Cost-benefit analysis (CBA) represents the application of Welfarist principles to inform resource allocation decisions. CBA assesses the costs and effects (outcomes) associated with a resource allocation decision such as the provision of a new healthcare intervention. (188) As discussed previously in section 4.1.1, money is used as a proxy within the Welfarist framework to capture the associated change in utility. An intervention is judged to be worth implementing if the overall benefits outweigh the costs; leading to a net positive social benefit (i.e. the sum of the benefits is greater than the sum of the costs).(188)

Contingent valuation techniques are used to measure individual utility. (58) Contingent valuation is a technique of placing a monetary value on good or service which is not available in the market place.(58) Willingness to pay (WTP) methods involve asking individuals to state the amount they would be willing to pay to receive a commodity (good or service).(189) An alternative approach involves asking people how much they are willing to accept (WTA) to forgo the intervention and be compensated for their welfare loss.(190) In practice WTP is used more than WTA because the welfare gains from an intervention are an important indicator in economic evaluations.(189, 190)

4.1.3 The strengths and weaknesses of the Welfarist approach in relation to sexual health

The Welfarist approach might be seen to have some potential strength in relation to economic evaluation in sexual health. The approach allows individuals to consider a range of factors when they consider the value of an intervention or service to them. This has been found to be useful in relation to disease areas such as menorrhagia where benefits beyond health are important to patients such as impacts on family life and work.(191)

However, there are several limitations associated with the Welfarist approach which limit its usefulness in a sexual health context. Firstly, although the Welfarist approach focuses on individual utilities which allow a wide range of factors to be captured, there are potential drawbacks associated with focusing primarily on individual utilities. The individual level valuation of benefits and the costs required in Cost Benefit analysis means that the value of a unit of health benefit may vary among different individuals depending on their socio-economic status.(58, 69) So individuals who are having a higher socio-economic status may be willing and can afford to pay more for a health benefit in comparison with those who have a lower status. Secondly, the objective of the PhD is to explore techniques within health economics which can measure outcomes that are representative of patients' perceptions and holistically capture the various components of the sexual health services. This may be difficult to achieve by focusing on individual utilities as the different aspects of the service will not be teased out while measuring outcomes. Thirdly, the Welfarist approach is mainly concerned with allocative efficiency(68, 69) (which relates to the distribution of outcomes) which can be difficult to operationalise. But in a sexual health context the specific concern is mainly around technical efficiency which focuses the best way of achieving a given health objective - e.g. what is the best way of delivering sexual health services. Technical efficiency can be described as the physical association of resources with health outcome.(192) A technical efficient state is obtained when maximum level of improvement is achieved from a set of resource inputs.(192).

Notwithstanding the concern that the Welfarist approach might be too broad given its focus on overall utility that it may miss the items that are the objective of this thesis. In addition of the three issues highlighted above, there are also other generalised limitations associated

with the CBA approach and the measurement of utility in this context through the use of contingent valuation. Thus it has been widely recognised that 'willingness to pay' is closely related to ability to pay as mentioned earlier.(69) Given the highest rates of sexually transmitted infections are found amongst the most socially marginalised groups, it is likely that concerns about equity would prevent the WTP approach being the most appropriate tool in this setting.

There are also the typical concerns about CBA being used in a publicly funded healthcare resource allocation in the context of sexual health services.(58) Attaching monetary value to the health (life) of a person is not generally well met by the medical community and general public.(59) Consequently key guidance bodies such as NICE (in the UK) recommend the Extra -Welfarist approach in evaluation of health interventions.(67)

In summary, the Welfarist approach 'restricts' the evaluative space to individual utilities ADDIN EN.CITE (66, 68, 69) which is a likely to be a limitation for the evaluation of sexual health services (and other health services) since it will mask the elements that impact on health and other components of the service. Extra-welfarism was developed to address some of these issues which will be described in detail in the next section.

4.2 Extra-welfarism

If the Welfarist approach is not obviously appropriate in a sexual health context the alternative approach of Extra-Welfarism needs to be considered. Extra-Welfarism incorporates non-utility information about individuals into the process of comparing states and considers individual utilities as an inadequate as a basis for assessing social welfare. (70) Extra-Welfarism encompasses 'extra' measures and indicators of wellbeing such as health or

health gain, distribution of health or health gain, patient satisfaction, caregiver burden etc.(69) There is an argument in literature about the 'extra' that Extra-Welfarism offer.(69) Although in theory Extra-Welfarism can be broad in terms of the evaluative space, in practice Extra-Welfarsim has been primarily based on a restricted focus of the maximisation of overall health .(68) The approach has been criticized for being too narrowly focusing on health, but the framework allows the flexibility of specifically focusing on health outcomes as well as incorporating wide range of non-utility indicators contributing towards overall wellbeing.(69) This is supported by the recent development of techniques and emphasis on empirical research to broaden the evaluative space within this approach.(75)

In contrast to Welfarism, the Extra-Welfarist approach for resource allocation is potentially more practical for decision makers as it allows flexibility in the weighting of relevant outcomes, and this can, in theory, facilitate the inclusion of equity considerations.(68) Extra-Welfarism is widely implemented in health economics with the aim to maximise health based on assessment of the impact of alternate resource allocations on health status. The approach also allows comparability of relevant outcomes, enabling explicit comparisons pertaining to characteristics such as health.(67)

4.2.1 Methodological application of extra-welfarism

Cost-effectiveness analysis (CEA) and cost-utility analysis (CUA) are examples of the methods adopted within the Extra-Welfarist approach to economic evaluation. As mentioned in chapter 2, this method is used to measure differences in costs and health outcomes between different interventions or of a new intervention in comparison with standard care. The difference in health outcomes can be captured in natural units (cost

effective analysis) or quality adjusted life years (QALYs) (cost utility analysis).(193) Both types of analysis aim to calculate the relative efficiency of treatments so that the healthcare budget is allocated in the most prudent way possible.(193) The terms CUA and CEA are interchangeably used internationally but in the UK, CUA specifically assess outcome in QALYS.

4.2.2 The significance of the QALY as a 'common currency' for measuring health benefits

The QALY is a widely utilized measure of health improvement that provides a generic measure of health outcome.(74, 194) QALYS were introduced to measure health outcomes by including both the length and quality of life into the common numeraire of a year in full health.(195) The main concept of the conventional QALY is based on decision science and expected utility theory.(74) The main construct of QALY is based on the notion that individuals pass through different health states over time with each health state having a value associated with it. (74) The benefits of health interventions are represented by QALYS by assigning each period of time a weight, ranging from 0 to 1, pertaining to the health-related quality of life during that duration.(195) These quality weights reflect the desirability of living in that health state, where perfect or full health is weighed 1 and the weight of 0 corresponds to the health status equivalent to being dead.(195) The basic concept embedded in QALYS is that for an individual the likelihood of living in state 'A' which can be considered less than full health is equated to a state 'B' which is the prospect of living in full health where B < A. (58) QALYS can be utilized to inform economic evaluations if different 'A's can be converted into equivalent 'B's (i.e. QALYS) and more QALYS are preferred. (58)

Hence, the value given to a particular health state multiplied by the time spent in that health state is expressed as the number of QALYS pertaining to a health outcome. (58)

However, there are uncertainties associated with outcomes of interventions and the benefit of the intervention is not the same as the outcome of the treatment as patients may recover even without undergoing the intervention. (196) The net benefit of treatment can therefore be interpreted as the difference between expected outcome with and without the treatment. (3) The benefit at population level of an intervention is the sum of the net benefits to individual patients. The aggregate benefit of a healthcare service or programme can be calculated by individual benefit with the number of patients expected. The QALY algorithm is a summation of probabilities (P), duration (D), value of health states (Q) and the number of patients. (58, 196)

The main assumptions supporting the adoption of the QALY are that the decision maker's main objective is usually to maximize health or improved health related outcomes across the population with scarce resources and that health or health improvement can be measured or valued in context to the time duration spent in those health states.(74) The QALY measure is used extensively in economic evaluation to evaluate the cost effectiveness of interventions and can also be utilized at individual level to inform decision making in clinical settings between medical interventions for the same condition. (74) The QALY provides a 'common currency' to enable comparison across different diseases or conditions due to its ability to summate the effects on health interventions pertaining to morbidity and mortality into a single index.(58)

4.2.3 The interpretation of 'Q' in QALY

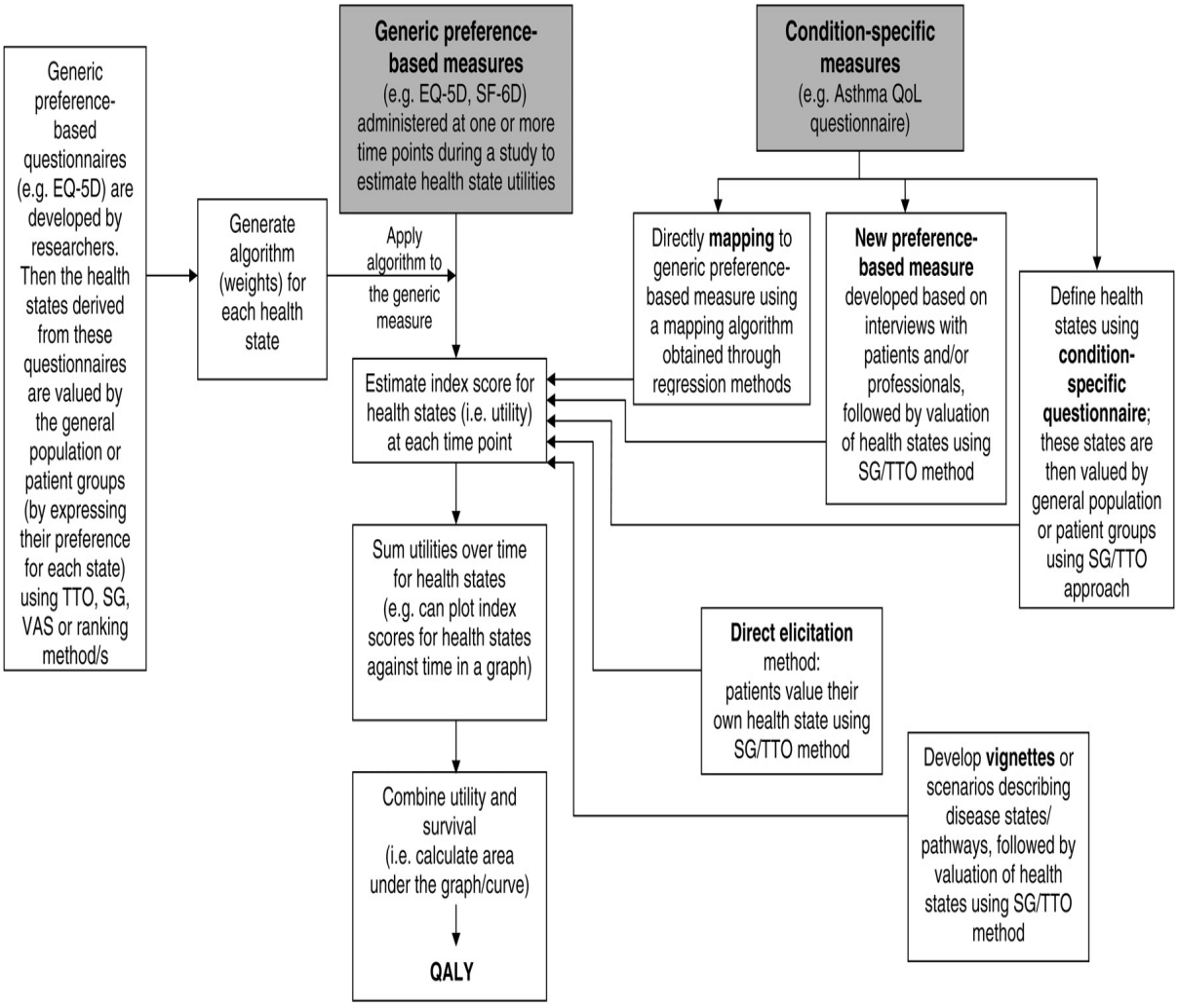
The value of Q in QALY is adjustment of life years to reflect the health states experienced during those years (quality of life).(74) The measurement of health utilities (health-related quality of life weights) is done by defining the health states of interest and valuing these health states. ADDIN EN.CITE (58, 74, 196) This is achieved by individuals assessing these health states and assigning a value on each health state. The methods to generate HRQoL weights are direct and indirect.(58) The direct elicitation techniques mainly include time trade-off (TTO), standard gamble (SG) and visual analogue scale (VAS). (22) The indirect techniques typically use the generic preference-based measures such as the EQ-5D etc to value the defined health states. The summary of the methods to generate health state values to calculate QALY is depicted in figure 4.1.

The different preference elicitation techniques are described in detail in the next section.

4.2.4 Techniques for valuing Health-related Quality of life weights

The measurement of health utilities (or HRQoL) includes defining health states of interest and defining in a 'vignette' and then carrying out valuation of these health states. (58) This involves assessment of different health states by individuals who place a value on them. There are direct and indirect methods to generate HQRoL weights.(58, 74) A summary of the different methods to generate health state values to calculate QALY is illustrated in figure 4.1 and these are discussed in depth in the following sections.

Figure 4.1: Summary of the different methods to generate health state values to calculate QALY(196)



4.2.4.1 (a) Direct elicitation methods

The most used direct elicitation methods include the visual analogue scale (VAS), time trade -off (TTO) and standard gamble (SG). ADDIN EN.CITE (58, 196)

4.2.4.1 (b) Visual analogue scale

The visual analogue scale is a simple direct elicitation method where an individual is shown a scale on a single line, with the top scale showing the 'best imaginable health' and the lowest scale the 'Worst imaginable health' .(196) The individuals are questioned to indicate on the scale according to their opinion where they prefer the health state of interest is to be. It is a simple technique and sometimes applied as a warmup exercise prior to other methods. However, there is a risk of scaling bias where the participants are more prone to indicating health states at extremes ends of the scale.(74)

4.2.4.2 (c) Time trade-off

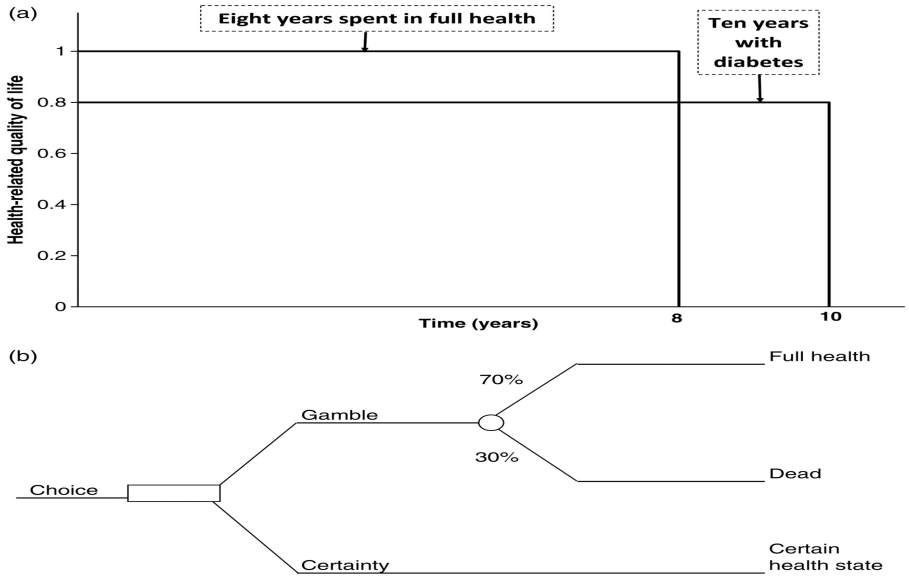
It is a choice-based method in which participants are questioned about their preference between two alternative scenarios. The choices include living in an impaired state of health for their remaining life or to live in full health but with a shorter duration of health. The time -period in a state of full health is varied until the individual reaches a point of indifference between the two states. (194) An example of TTO is given in figure 4.2a.(196)

In this example an individual with a chronic disease of type 2 diabetes is taken. The individual is given a choice to live with type 2 diabetes, for 10 years or an alternate state of full health. In this example the point of indifference is 8 years, and the participant is willing to sacrifice 2 years to avoid an impaired health state. Therefore, the point of indifference is 8 years and HRQoL can be deduced as 0.8 (8 years/ 10 years) for this example.

4.2.4.3 (d) Standard gamble

There is an element of risk involved in standard gamble in the decisions that the individuals are required to make. (196) The choices include either remaining in a fixed health state or taking a gamble of achieving full health or risking death. As shown in figure 4.2b there is a 30% chance or probability of death in the gamble. Therefore, HRQoL can be deduced as 0.7 (risk=0.3, hence utility=1.0-0.3=0.7) for this example. In this method the risk of death is varied till the participant is indifferent between the choice of certainty and gamble.(196)

Figure 4.2: Examples for TTO and SG(196)



4.2.4.4 Indirect elicitation methods

Indirect elicitation methods involve utilization of generic preference-based measures or condition specific measures. These measures cover different aspects of health dimensions. Generic based measures are formulated to be applied across a wide range of conditions, treatments and populations by involving a descriptive system encompassing common domains of health that can be generalized to everyone.(194) Examples of general preference based measures include EuroQoL (EQ-5D)(197), the short form 6D (SF-6D)(198)

and Health Utilities Index (HUI).(118) In contrast, condition specific measures primarily focus on the most important domains pertaining to the condition of interest and relevant symptoms.(58) Condition specific measures have greater sensitivity in context of picking up meaningful changes relating to the condition of interest. Details of different type of PROMs are already mentioned in detail in chapter 2 and 3.

4.2.4.5 Using discrete choice experiment to calculate QALYs

Another alternative technique embedded within health economics is utilizing ordinal tasks such as discrete choice experiment to generate QALY health state values. A discrete choice experiment (DCE) can be defined as 'quantitative technique for eliciting individual preferences'.(199) The technique allows researchers to explore how 'individuals value selected attributes of a programme, product or service by asking them to state their choice over different hypothetical alternatives.(199) However, evidence suggests that the health state values derived from ordinal data using such methods are prone to inaccuracies and not truly representative of values relating to health related quality of life.(200)

4.3 The applicability of the extra-welfarist approach for measurement and valuation of benefits associated with sexual health services for use in economic evaluation

Although the extra-welfarist approach has been criticized for being narrowly focused on health alone, it potentially offers the most in the context of the economic evaluation of

sexual health services.

There are several strengths associated with Extra-Welfarist approaches. These include the fact that the QALY provides a 'common currency' for comparison across interventions and other diseases or conditions, and is endorsed by many decision makers within OECD settings.(58) In addition, the Extra-Welfarist framework allows a consideration of outcomes beyond individual utility which can include a wide range of indicators of well-being as discussed in section 4.2. Moreover in recent times there have been attempts to expand the evaluative space.(163) Such approaches as will be discussed individually in section 4.4 allow consideration of a broader range of outcomes, and also allow the measures utilized to capture outcomes that are most important for patients and yet still be sensitive enough to detect meaningful changes. For example, if patients feel that reducing perceptions of stigma is an important outcome for them, then this would be considered for inclusion within the measure, alongside other factors (e.g., convenience). Such measurement tools could also help to capture the non-health aspects associated with having an STI including the stress pertaining to one's sexual health and impact on one's relationships with partner/s, family, and colleagues, and how well they are addressed by services (if the primary research finds that such issues are important for patients).

Furthermore, provision to sexual health services within the OECD, particularly UK settings is through publicly funded resource allocation. The objective of publicly funded healthcare is to improve population health.(58) Hence extra-welfarist framework is more feasible as it focuses on maximisation of health and cost per QALY analysis is more relevant to policy. Furthermore, it is more pragmatic in such healthcare systems to include the different stakeholders in the valuation of outcomes of interest which is permissible within the extra-

welfarist framework which focuses on technical efficiency.(69)

Having discussed the applicability of the Extra-Welfarist framework in a sexual health context the next section will examine the various techniques that are proposed in recent literature to expand the Extra-Welfarist evaluative space. These methods will be outlined and there will be consideration of which approaches could be utilised in a sexual health context.

4.4 Approaches to expand the evaluative space within Extra-Welfarism (QALY beyond health)

The four main techniques that have been recently proposed in literature(58, 75) to expand the Extra-Welfarist evaluative space (QALY beyond health) include:

i) Statistical mapping

ii) Valuing on a common scale using preferences

iii) Bolt- on dimensions

iv) Constructing a new sexual health services specific preference-based measure

Each strategy will now be discussed in detail with examples of application in different studies to weigh its significance and applicability in sexual health services context.

4.4. 1 Statistical mapping

In clinical studies various health status measures (non-preference based) are utilized to measure health related quality of life. Most of these measures cannot be utilized for cost

effectiveness analysis as mentioned earlier and discussed in detail in previous chapters (2 & 3). Statistical mapping allows the information captured by such tools to be 'translated' into health utility values for utilization in cost per QALY analysis. ADDIN EN.CITE (58, 75, 201) Mapping is endorsed by National Institute of Clinical Excellence (NICE) for generating utility information.(202) Statistical mapping can be categorized into two main types; 'mapping a non-preference based measure onto a generic preference based measure, and mapping a condition specific non preference based measure onto a generic preference based measure'. (201)

The utility values are predicted by developing an algorithm from economic models, other studies or clinical trials containing the predictive source measure, despite the fact that the target measure was not applied in the original source study of effectiveness.(203) This is achieved by estimating a relationship between a source measure (without utility information) of health and a target measure (providing utility scores) by regression and is presented as an algorithm or formula.(203) The algorithm that is generated is then applied to the source measure in the data set to calculate the predicted estimated score of the target measure.(194) There are various statistical techniques to deal with the distribution of variables included and specifications that can be fitted to the data set. ADDIN EN.CITE (201, 204, 205) Hence, the primary objective of statistical mapping is to help inform economic evaluation with the resulting prediction used to estimate utility values for health states being incorporated in cost effectiveness models and economic evaluation alongside clinical trials.(58)

The strength of the mapping function relies on the statistical association between the source and target measure. This is mainly determined by the following assumptions:

i) The two measures (preference-based target measure and non-preference-based measure) utilized for statistical mapping should have a conceptual overlap (75)

ii) All the essential health dimensions and aspects are entailed by the preference-based target measure which constitute the non-preference-based which was used as a start measure(75)

A systematic review was conducted to assess the validity, feasibility and applicability of the current practice of mapping between non preference based measures and generic preference based measures.(201) The review included 30 studies which reported 119 different models for statistical mapping. The findings of the review(201) revealed that there was variation in the performance of mapping functions with regard to estimating predictions and goodness of fit between the measures and cannot be generalized across instruments.(201) The review suggested that in situations where a generic measure was inadequate in capturing outcomes for a specific condition the technique of statistical mapping was not the right solution to address this issue due to its inability to predict reliable utility values for health states.(201)

The existing sexual health non-preference-based measures (which will be highlighted in chapter 5) capture health dimensions which are very different to generic preference-based measures (target measure) such as ED-5D and therefore have a low conceptual overlap and weak statistical association. Hence statistical mapping would be unlikely to produce reliable estimates of health utility values using data from non-preference based sexual health service measures. It is therefore not the most ideal technique in this context.

4.4.2 Valuing on a common scale using preferences

Another method suggested by literature to extend QALYs beyond health is valuing on a common scale, using preferences.(75) Different preference-based measures yield different utility values when used to calculate QALYs.(206) This is because of the variance in their descriptive systems, the valuation techniques applied and the sample selected to obtain these values. This technique allows comparison of different preference-based measures using a common scale.(206)

However, there is a concern with this method that participants can be fixated on certain aspects of health and they are not given the opportunity to broadly reflect on their lives to consider factors such as relationships, overall wellbeing, income etc making it unclear what they might imagine would happen to these aspects. (58, 75) Mixed methods can be applied by conducting in depth interviews to explore what respondents say they take into consideration while undertaking the task alongside empirical work pertaining to the impact of these factors in the valuation of states.(75)

This technique would have similar problem as statistical mapping of having a variation in the exchange rates between the dimensions encompassed with existing generic measures and a measure capturing outcomes pertaining to sexual health services. It would therefore be difficult to map between the measures using a common scale. Moreover, this method is in an exploratory stage and requires further research and would not be a feasible and pragmatic approach in this context.

4.4.3 Bolt-on dimensions

Another option is to use 'bolt-on' dimensions which is a technique designed to include additional (or 'bolt on') dimensions to a generic measure (EQ5D) to cover the dimensions not covered by the instrument. There are various examples of bolt-on dimensions that have been developed for ED5D including: cognition(207), sleep(208), energy, vision and hearing(209). A recent study also attempted to incorporate satisfaction.(210)

The main advantage of utilising this technique is that it allows researchers utilise the EQ-5D descriptive system as the core and then incorporate additional dimensions to strengthen the content validity of the instrument for a specific condition or area of interest.(75) In an economic evaluation the usefulness of this technique can be determined by the effect of the additional dimensions on the EQ-5D health state values.(211) For example, if the bolt-on dimensions have insignificant or no influence on the values, it will mean that the impairment described by the dimension/s is already encompassed by five EQ-5D dimensions or these additional dimensions have little or no impact on health-related quality of life.(75) For example, a study was conducted which developed bolt-on dimensions for vision problems, hearing problems and tiredness. The findings of the study inferred that the bolt-on dimensions influenced the health state values of EQ-5D but this was dependent on the severity of the core EQ-5D health state and the levels of the bolt-on dimensions.(211) Moreover, regression analysis to control the possible differences in socio-demographic characteristics between the groups demonstrated no significant difference between the health state values of the three bolt-on dimensions.(211) This is an under-researched area and literature suggests further research is needed to explore the impact of bolt-ons.

From the context of sexual health services, the bolt-on dimensions depicting other outcomes considered most important by patients could be added to EQ-5D. The impact of

these bolt-on dimensions on the health state values of ED-5D would help determine their impact on the health-related quality of life of patients. Moreover, this technique could be utilised to establish whether sexual health services offer additional unique dimensions which might exceed the limit of the dimensions that can be included in the descriptive system of EQ-5D to practically apply to valuation tasks.

Limitations of bolt-ons for capturing outcomes pertaining to sexual health services:

However, there are some limitations with this method which have been highlighted in recent literature which may restrict this technique from comprehensively capturing all the outcomes considered most important by patients while accessing the services. These limitations include:

i) *Evidence suggests that the addition of bolt on dimensions interferes with the value of other dimensions, where an addition of a dimension can reduce the coefficient of another dimension.(75)*

ii) *Bolt-ons may be useful within healthcare in situations where one or two dimensions are missing but there is also little conceptual similarity between the different generic measures (ED5D, ASCOT, ICECAP, WEMWBS etc.).(75) In our study nine important themes (important dimensions) were identified for sexual health services.*

iii) *there is a limitation of dimensions that can be included in a descriptive system to pragmatically apply to valuation tasks such as time trade-off and discrete choice experiments.(75) Furthermore there is also risk of double counting as dimensions in a one measure may be captured to some extent in dimensions in other*

measures.(58) For example the ability to meet personal care needs may be partially encompassed in the dimension of self-care in EQ5D.(75)

4.5.4 Development of new condition specific preference-based measures

There are certain conditions where generic measures like EQ-5D are inadequate to capture values truly reflective of patient preferences because of the generic nature of the domains and it may not be sensitive enough to pick meaningful changes pertaining to the consequences of the condition suffered by the patient. In such cases a condition specific preference-based measure can be constructed either from an existing condition specific measure or developed de novo. For example, the dementia-specific DEMQoL-U was developed from the DEMQoL(122) and the cancer-specific EORTC-8D was developed from EORTC-QLQC30(123). Examples of de novo condition specific preference based measures include the CAMPHOR tool for patients with pulmonary hypertension.(212)

It can be argued that condition specific descriptions are more sensitive to the implications of the condition suffered by the patient and allow greater precision and ability to differentiate between the severity of the condition and changes over time. This is because condition specific measures focus on important dimensions pertaining to the condition of interest which would be missed by a generic measure. (209) General preference-based measures were designed to cover more common dimensions of health and not all dimensions of health. This inadequacy has been increasing recognized in recent times and it has been

suggested that there has been a paradigm shift towards condition specific measures.(209) For example, a study was conducted to compare a generic measure (3 level EQ-5D) with condition specific preference based measures (AQL-5D for asthma, EORTC-8D for cancer and CORE-6D for mental health problems).(213) The 3 condition specific preference based measures were valued applying the same variant of time trade-off as the generic measure (EQ-5D).(213) The results of the study inferred that EQ-5D was insufficient in discriminating across patients in comparison to condition specific preference based measures, due to ceiling effects associated with EQ-5D. (213)

From a sexual health context, utilization of sexual health services specific preference-based measure would ensure that the specific descriptions are more sensitive to the implications of the outcomes considered most important by the patients and allow greater precision and ability to differentiate between outcomes and changes over time. This will be achieved because such a measure would focus on important dimensions pertaining to this area which would be missed by a generic measure.

However, there would be a trade-off between using a sexual health specific preference-based measure which is more relevant to sexual health services and its interventions, against the comparability allowed by using generic measures. The development of a new preference-based measure specific to sexual health services could be based on identifying important health outcomes by a review of existing literature, input by experts in sexual health and interviewing the patients. This could later follow by valuation of these health states by direct elicitation techniques such as standard gamble or time trade-off.

4.5 An assessment of the opportunities for applying these techniques to sexual health

There are various techniques that have been suggested to expand the QALY beyond a narrow focus on health alone. The summary above indicates that there are two approaches which seem most appropriate to the sexual health context, the method of (i) bolt-on dimensions and (ii) designing a de novo sexual health services specific preference-based measure. The other techniques such as statistical mapping have the issues of a low conceptual overlap and variation in the dimensions covered by existing generic measures and the dimensions relevant in a sexual health context. Similarly, valuing on a common scale for preferences will pose the challenge of having a variation in the exchange rates between the dimensions encompassed with existing generic measures and a measure capturing outcomes pertaining to sexual health services. (75)

Bolt-on dimensions that are relevant in sexual health could be added to ED-5D as a first step to allow us to focus more on outcomes that are important to patients. In addition, observing the impact of these dimensions on the health state values would provide useful information for the development of a new sexual health outcome measurement tool. A further approach would be the development of a standalone sexual health services specific preference-based measure which could specifically focus on the dimensions associated with the service, with increased ability to detect meaningful changes, making it more sensitive.

4.6 Conclusion

The overview of the evidence presented in this chapter suggests that the Extra-Welfarist approach is likely to be more appropriately suited for the evaluation of sexual health services. In a publicly funded healthcare like the NHS in the UK, the Extra-Welfarist approach allows 'extra' dimensions beyond individual utility to be considered, and several stakeholders can be involved in the valuation of these outcomes not just the affected individuals. The most widely used outcome within the Extra-Welfarist approach which allows comparison between programmes is the QALY. As discussed previously, generic preference-based measures used to calculate QALYs tend to focus on narrow health dimensions, and some are not relevant for a sexual health context. There are a range of strategies which have been proposed to expand the evaluative space within Extra-Welfarism. But strategies like statistical mapping or valuing on a common scale, for preferences to incorporate dimensions relevant to sexual health services, will not be a useful strategy to estimate accurate preference based single indices. This is due to the differences in the health dimensions of generic measures such EQ-5D and the dimensions constructed to capture outcomes relevant to sexual health services. There are two approaches that seem appropriate in a sexual health setting (i) bolt-on and (ii) a sexual health service specific preference-based outcome measure. The bolt-on dimensions pertaining to sexual health services can be added to EQ-5D to allow a broader range of dimensions to be included increasing the validity of the instrument in sexual health context. This would also allow us to observe the impact of these dimensions on the health state values. A standalone sexual health services specific preference-based measure would allow particular focus on the dimensions which are important to the service, with increased ability to detect meaningful changes in the status of patients. The evidence suggests that providing

services that are patient focussed is more likely to increase service uptake and engagement. This is important on economic grounds because untreated disease and lack of utilisation of services has health complications and additional costs directly affecting the patients, their families and health services.(177)

The assessment of existing tools utilized for capturing patient reported outcomes in sexual health services, identification of important themes (domains and items) through qualitative synthesis and meta-ethnography substantiated with further primary research (qualitative) can provide foundations for developing outcomes for a bolt-on for sexual health or sexual health services specific preference-based measure for cost per QALY analysis. This step of gathering information (through reviews and primary research) allow further investigation of whether a bolt-on would adequately allow coverage of what is important to patients (alongside EQ5D) or whether a de-novo outcome measurement tool is needed.

The next chapter is a systematic review which was conducted to assess the existing tools utilized to capture patient perceptions or reported outcomes while accessing sexual health services. Additionally, the review also aimed to identify the existing gaps in service and methodological issues in the existing evidence base.

CHAPTER 5: Measuring and assessing patient experience and satisfaction with sexual health services: A systematic review of literature

5.1 Introduction

One of the many key motivations for sexual health services in the UK and elsewhere is to educate people to take better care of their sexual health and to be more aware of the possible consequences of high-risk sexual behaviour, especially the young vulnerable people who are most at risk.(214, 215) Increasing access to sexual health services can be a potentially efficient strategy for achieving the aims of services and for reducing high infection rates, the additional costs associated with complications of STIs and unplanned pregnancies, as highlighted in Chapter 2.

A wide range of methods and approaches exist for assessing the barriers and facilitators of patient access to services. However, the use of patient derived outcomes is increasingly recognised as an integral component for the planning, delivery, and evaluation of clinical services. ADDIN EN.CITE (110-113, 216) Clinically relevant measures of performance can be developed based on patients′ perspectives which can allow services to be benchmarked, identifying, and sharing good practice. ADDIN EN.CITE (111, 113, 176) In addition, results of patient surveys can play a vital role in informing the future development of services and allow monitoring of performance against local or national priorities. ADDIN EN.CITE (33, 176)

Patient reported experience measures (PREMs) and patient reported outcome measures (PROMs) have been sought in a range of clinical areas to provide a benchmark by which to

judge services.(216, 217) A PROM is typically used to assess the effectiveness of care in reducing symptoms and improving quality of life(217) whilst a PREM is used to assess patients' experiences of care for example the information provided to them, timeliness or cleanliness of services.(114) PREMs will be discussed further in chapter 6 in context to capture patient experience dimensions pertaining to sexual health services. However, despite the widespread use of patient satisfaction surveys in healthcare settings, the literature reports issues with the validity and reliability of these instruments(218, 219) and there is an absence of a universal definition of patient satisfaction and its essential components.(77) A recent systematic review(84) of the determinants of patient satisfaction highlighted that the results of studies carried out in this area vary due to the lack of a universal construct of patient satisfaction and an agreed measurement system. Moreover, the instruments which have been developed over the years have had minimal patient input in the development process and had no clear information pertaining to the aspect of patient satisfaction measured by them. (77)

In Primary Care and hospital outpatients' clinics, a number of patient-based measurement tools have been tested to assess the quality of outpatient services in the NHS, for example, the 'Friends and Family', NHS Outpatient Questionnaire developed by the Picker Institute and introduced in English acute hospitals in 2013.(220) There have been discussion about the questionnaire since its inception and it has been argued in literature that this tool lacks a strong rationale and scientific evidence, and thus is a questionable measure of performance.(221) Additionally, such survey tools have not been validated within sexual health clinic populations. Moreover, the heterogeneity of patient characteristics within this group may limit the applicability and interpretation of the data tested on these instruments.

The British Association for Sexual Health and HIV (BASHH) developed the first validated patient satisfaction tool in 2010, specifically designed for sexual health clinic attendees.(222) It was tested in 12 sexual health clinics in the Southwest region of England. The measurement tool is a non-preference based type of PROM (without an associated preference-based scoring system) and therefore cannot be utilized to calculate a health outcome such as QALY (quality adjusted life year).(115)

As discussed in Chapter 2, the speed of change has been rapid in the way sexual health and contraceptive services are being delivered in the UK and OECD countries and there has been little patient input into the redesign of services. There is a need to work with patients to obtain their perspectives pertaining to the various components of sexual health services (considered most important them) which can help determine outcomes to evaluate the existing services. ADDIN EN.CITE (223) There is published literature which explores patients' views on different components of the service utilising various measurement tools in OECD settings.

Thus, the aims of this chapter are to systematically review the existing published literature concerned with patients' perspectives with regard to sexual health and contraceptive services. Additionally, the aim is to explore how such perspectives have been captured (assessment of the measurement tools utilised) and to identify the key gaps in sexual health services within OECD countries settings.

The main research question that the review aims to answer is 'what are the methodological and structural limitations of various tools utilized to capture patients' perceptions pertaining to sexual health services and the existing gaps in the service?'

5.2 Methodology

The review followed UK centre for review(224) and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) ADDIN EN.CITE (225, 226).

5.2.1 Initial Scoping Search

An initial scoping search was conducted to outline the research question of the systematic review. During the process search terms such as ‘sexual health services’, ‘contraceptive services’, ‘Sexually transmitted diseases’, ‘patient views’, ‘patient experiences’ and ‘patient reported outcome measures’ were searched through relevant search engines such as MEDLINE, EMBASE and PubMed. The initial scoping search provided an overview of the published literature pertaining to patient perspectives relating to sexual health services. The search indicated various types of studies capturing patients’ views as well as health provider perspectives about different aspects of the service, assessment tools and associated quality indicators. The scoping informed the final research question and helped to devise the Stage 1 criteria of the review.

5.2.2 Systematic research and screening

The research question for the systematic review was divided into key components utilising the SPICE framework (a generic model for question formulation). This was used to guide the literature searching(227):

Setting: sexual health centres, primary care, secondary care, online or general community settings in an OECD listed country

Perspective: male and female patients utilizing sexual health services or potential users

Intervention: sexual health services for STIs & contraception services

Comparison: other health concerns, accessing other types of services associated with sexual health

Evaluation: patient reported outcomes, attitudes, values, preferences, beliefs

Initially, papers were screened using the title and abstract to identify potentially relevant papers. Papers were then sorted into six groups according to the relevance of reporting of patients′ perceptions pertaining to sexual health or contraception services (Table 5.1). Papers which were labelled as reporting measurement or analysis of satisfaction, attitudes, experiences and opinions for those accessing or potential users of sexual health services or contraception services (category A) were analysed further. Those mainly concerned with describing patient views without analysis, those only reporting the views of clinicians and associated healthcare staff, or reporting views on specific STIs, prevalence etc. without mention of sexual health or contraception services, previous systematic reviews and studies with no relevance to sexual health services or patient reported outcomes were excluded (Categories B. C, D, E & F). In the next stage of screening full texts of potentially, relevant studies were read and were classified into 6 groups based on the methods utilized while conducting the research and whether primary or secondary data was reported (Table 5.1). Studies with a variety of aims were included and the approach taken was examined as part

of the analysis. Grey literature and studies that were not published in the English language were excluded from the review.

5.2.3 Search strategy

Search terms were created breaking the search question into fragments highlighting the key terms. Boolean operators were used to combine similar terminologies and linking the key terms by using 'OR' and 'AND'. Moreover, free text words, and subject headings/index terms were also combined. Furthermore, for a comprehensive literature search 'wildcards an asterisk and truncations were used with the specified terms. The search strategy with the detailed search term combinations used to retrieve relevant studies is included in Appendix 1. The electronic databases searched for this systematic literature review included:

- MEDLINE (R)
- Ovid MEDLINE (R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE (R)
- EMBASE
- CINAHL
- PsycINFO.

Relevant articles searched from the bibliographies of the retrieved research articles were also included. Google scholar was utilized to extract further web-based materials and for accessing full text articles. The initial searches were conducted between 23 March 2019 and 16 April 2019. The review was later updated between 21 June 2021 and 7 July 2021. The search was limited to the last 22 years (1999-2021) because the service delivery process has undergone a considerable change in the recent times as previously discussed in chapter 2 &

3 and the aim was to highlight patients' perspectives about various components of the service which are relevant at present.

5.2.4 Selection of studies

The titles and the abstracts extracted from the search strategy were exported into Endnote and all duplicates were removed both electronically and manually. The results of the search were individually screened in accordance with the Stage 1 criteria described below. MA screened all the records. LJ looked through a sub sample (30%) to substantiate inter-rater reliability. There was a high level of agreement (90%) between MA and LJ of the records screened. Full text articles were retrieved for the shortlisted categorised as 'A'. The full text articles were then comprehensively reviewed in accordance with the Stage 2 criteria. Full text articles were reviewed by MA initially and discussed with LJ for inclusion.

5.2.5 Data extraction and Analysis

Data were extracted from the final full text articles in relation to the tools used and patient groups involved utilizing pre-designed data extraction forms. The data extraction form required information on study characteristics, participant characteristics, study methodology and study tool and main study outcomes. The data were extracted within these broader categories as follows:

- Study characteristics: information pertaining to the author(s), year of publication of the research article, study design, aim of reported analysis, region of study, sample

size and sampling strategy, response rate and sponsorship and funding of the study.

- Participant characteristics and study methodology: data such as age of participants, sexual orientation of participants, gender of participants, ethnicity of participants, study tool or intervention, components of the study tool, development of the study tool, data collection techniques and ethical consideration while conducting the study
- Study results: included data such as main outcomes of the study, statistical analysis, limitations of the study identified by the authors and authors′ conclusions.

5.2.6 Synthesis & analysis

A narrative synthesis(228) was conducted in the study which comprised of description and assessment of the various tools utilized in the studies and presented the main findings of the various studies. The overall quality of the studies was reported but studies were not assessed and excluded on quality assessment criteria.

Table 5.1 Categories used to identify studies for inclusion

Initial categorisation criteria

A. A research study that reports on measurement/ analysis of satisfaction, attitudes, experiences, and opinions for those accessing or potential users of sexual health services/ contraception services (aged 13 years or above).

B. A research study that gives a description of patient views or experiences of sexual health services/contraceptive services but does not include measurement / analysis of views etc.

C. Research study that reports on opinions of clinicians and staff associated with sexual health services or contraceptive services but does not include measurement & analysis of users or potential users,′ satisfaction, attitudes, experiences and opinions.

D. A research study that discusses people′s views on specific STIs, screening, prevalence and associated behavioural issues but does not include views and opinions about sexual health services.

E. Systematic reviews of studies reporting on satisfaction, attitudes, experiences, and opinions for those accessing or potential users of sexual health services and contraception services.

F. The study does not have any relevance to sexual health services and associated patient reported outcome measures.

Further categorisation criteria

1. The study includes primary data on patient reported outcome measures or patient reported experiences pertaining to the sexual health services and contraception in clinic, primary care, and community settings or online/mHealth.
2. A research study that reports primary data on sexual health services/contraception and patient perceptions, which may be associated with a particular group of patients (adolescents/MSM/LGBT/BME etc.)
3. Study mainly discusses knowledge of the patients about STIs/Contraception and general awareness about provision of sexual health services
4. Study reports data on the various Pre-exposure prophylaxis or sexual risk reduction interventions pertaining to a specific STI
5. Study reports secondary data or broadly discusses sexual health services & contraception in a particular setting excluding primary data.
6. The study does not include relevant information to patient′s experiences to any type of sexual health services or contraception.

5.3 Results

The search process identified 8268 papers. The removal of duplicates and the initial screening of titles and abstracts resulted in 4701 papers being assessed for inclusion. A flow diagram (Fig. 5.1) illustrates the steps undertaken and the number of papers included and excluded at each stage. Further categorisation and analysis of the studies led to 47 papers being reviewed in full to determine their suitability for inclusion, and following this, 42 studies were selected for the synthesis. Data were extracted from all 42 studies included in the narrative review: 31 studies reported on general patient perspectives regarding sexual health/contraceptives and 11 studies reported on the perspectives associated with a particular group of patients (adolescents, MSM, transgender, sex workers etc.).

5.3.1 Key study characteristics

A summary of key characteristics of the papers included in the review is presented in Table 5.2. The majority of the papers were from the UK (64%) as illustrated in Figure 5.2. A significant percentage (52%) of studies applied a cross-sectional study design. Other study designs that were utilized included observational/evaluation studies, mixed methods, and qualitative study design (table 5.2). More than half of the studies were conducted in clinical settings either involving a specific STI clinic or Genitourinary Medicine department in a hospital (n=27). Other studies were conducted in community based pharmacies ADDIN EN.CITE (38, 39, 175), public health clinics & non-profit organisations(43), sexual health services within a rural outreach clinic(40), online outreach ADDIN EN.CITE (41, 42, 229),

multiple settings ADDIN EN.CITE (230-232) and integrated sexual health services(173) as reported in Table 5.2.

Most of the studies applied non-probability sampling techniques to recruit patients with the exception of 2 studies ADDIN EN.CITE (233, 234) which conducted random sampling to draw the sample. Most studies reported the findings with a gap of 2 to 4 years after data collection and 6 studies ADDIN EN.CITE (43, 170, 230, 235-237) did not include information about the date of the collection of data. The response rate of the questionnaires distributed among the patients varied from 21% to 96% among the reviewed studies, with 7 studies not providing information on percentage of patients responding (Table 5.2).

5.3.2 Study aims

The studies had a diverse range of aims which overlapped across studies (Table 5.2). Eight studies ADDIN EN.CITE (33, 35, 50, 222, 237-240) had an overall aim to assess patient satisfaction among attendees of various types and components of sexual health/contraceptive services (Table 5.2). Other aims of studies ranged from the assessment of patients' perceptions pertaining to various care pathways, preferences towards new models of care ADDIN EN.CITE (170, 171, 173, 229, 231, 236, 241-244), to identifying issues pertaining to the engagement (accessibility) and acceptability of services among particular groups of sexual health services attendees (for example sex workers, MSM, men, young people etc.) ADDIN EN.CITE (38, 41-43, 245). Details of the individual study aims are demonstrated in table 5.2.

5.3.3 Study participants

The demographic variables reported varied across the studies included in the review. The age of the participants across the studies ranged from 14 to 72 years of age (table 5.2). In a few studies (n=5) only the mean age was reported whereas in 6 studies ADDIN EN.CITE (41, 234, 236, 240, 241, 243) the age distribution of participants was not provided. With reference to ethnicity only 19 studies included information about the ethnicity of the participants, with 5 studies ADDIN EN.CITE (35, 40, 229, 242, 246) focusing specifically on ethnic minority groups within a population (table 5.2). Evidence suggests that the prevalence of STIs is much higher among ethnic minorities and lower socio-economic groups, particularly in the UK ADDIN EN.CITE (237, 247). With reference to sexual orientation, only 9 studies reported on the sexual orientation of the study participants (Table 5.2).

5.3.4 Development of study tools

Detail about the development of the instruments used to capture patient perspectives provides important information with regard to the validity of the assessment tools(217). This information was mentioned in only 18 studies (Table 5.3). In these eighteen studies the tools were developed by a range of techniques which mainly involved; utilising previously validated questionnaires ADDIN EN.CITE (33, 40, 175, 223, 229), developing tools based on previous published literature ADDIN EN.CITE (248, 249), input from clinical staff(238), service users(230), health educators(246) and key informants(43), generic PROM (SF-36) (35) & market research ADDIN EN.CITE (232, 235). Studies utilized different tools and a specific tool designed to capture patient reported outcomes for sexual health services was not identified. The frequency of the various sources utilized for development of study tools

in these studies are pictorially depicted in Figure 5.4. More than half the studies had no information about how the questionnaires were designed and the content validity of these instruments was not mentioned in these papers as shown in table 5.3.

5.3.5 Types of study tool design utilized in studies included in the review

The different type of study tools utilized (as reported in studies) is pictorially depicted by Figure 5.3. The study tools ranged from structured self-administered questionnaires ADDIN EN.CITE (40, 50, 238-240), interviews ADDIN EN.CITE (38, 43, 247) and FGD′s(171) to online surveys ADDIN EN.CITE (41, 42, 229) as reported in the studies. Approximately 12% (n=5) of the studies conducted only interviews to collect data as illustrated in Figure 5.3.

5.3.6 Attributes of the services assessed by study tools

The various attributes of the services assessed by the study tools are illustrated in figure 5.5 & 5.6. The main attributes of the sexual health services assessed by the study tools ranged from measuring overall patient satisfaction ADDIN EN.CITE (33, 35, 50, 222, 237-240), the feasibility of new models of care (27-29, 36, 39, 44, 45, 50-52) to determining quality indicators by incorporating patient feedback (for questionnaire development) ADDIN EN.CITE (250-252) as demonstrated in figure 5.5. The contents (questions or items included) of various tools utilized in individual studies are shown in detail in table 5.3.

5.3.7 Analysis of data

Most of the studies (n= 36) reported the descriptive statistics of the various responses provided by patients. Univariate and multivariate analysis of the quantitative data was reported by 5 studies (table 5.3). Thematic analysis was specifically reported by 5 studies ADDIN EN.CITE (43, 223, 237, 247, 251). However, there was no detail provided of steps involved in the qualitative analyses in these studies. Findings were presented narratively of patients views in such studies.

5.3.8 Main findings from studies

There were a range of conclusions due to the diverse aims of the studies. The main findings of individual studies are summarized in table 5.2. The main findings of the studies grouped according to the aims (overarching themes) of the studies were as follows:

a) **Patient satisfaction:** Studies assessing particularly patient satisfaction reported an overall high satisfaction level reported with existing services among patients. ADDIN EN.CITE (33, 35, 50, 222, 237, 238) However, the need for training of healthcare staff for efficiently delivering the service was suggested by patients in these studies (table 5.2).
b) **Evaluation of existing services:** Patients highlighted that continuous monitoring can ensure quality improvement and facilitate helpful evaluation of existing sexual health services and requires active involvement of patients and healthcare staffs. ADDIN EN.CITE (39, 40, 175, 223, 230) Moreover the findings suggested that current users of service are a useful tool for sexual health services evaluation and qualitative methods have a key role in measuring patient experience.

c) **New models of care:** Studies reported the potential for acceptability by patients, as well as the feasibility of newly planned care pathways, if services are carefully designed by incorporating patient suggestions and views. ADDIN EN.CITE (173, 229, 241-243)

d) **SHS services pertaining to specific groups:** The studies highlighted the unmet needs of specific patient groups (transgender, MSM, young people etc.) which should be addressed and acknowledged as potentially different to the general population. ADDIN EN.CITE (38, 41-43)

e) **STI testing and services:** The patients reported major concerns regarding confidentiality particularly when receiving test results for STIs. ADDIN EN.CITE (233, 246, 253) Furthermore their perception of the health risks associated with untreated STI was significantly associated with previous experiences (earlier attendance) as demonstrated in table 5.2.

f) **Questionnaire development:** The need to develop a nationally validated patient reported outcome measure tool for sexual health services was highlighted. ADDIN EN.CITE (248, 252)

g) **Service design:** Delivery of service by GPs and nurses was reported to be generally acceptable to patients although this varied by patient gender and ethnicity. Further development of SHS in primary care settings was suggested. ADDIN EN.CITE (36, 37, 232)

h) **Quality indicators:** The patients identified that maintaining confidentiality and incorporating continuous patient feedback were key quality indicators to improve service (as shown in table 5.2).

5.3.9 Quality of studies included in the review

The studies included in the review broadly captured patients' perceptions pertaining to various aspects of sexual health and contraceptive services. A minority of studies ADDIN EN.CITE (36, 41, 170, 239, 240, 242, 250, 254) had a large sample size strengthening the external validity of the findings. Overall, the studies referred to a variety of settings. Studies with multiple settings particularly acknowledged the limited generalisability of the reported findings due to the differences in care pathways in use in a service setting ADDIN EN.CITE (222, 233, 235). Participants were mostly recruited by convenience or purposive non-probability sampling techniques. There is a bias associated with such methods as it can be argued that the sample included may not be representative of the true population.(234) Specifically, non-probability sampling techniques and small sample size was mentioned as a limitation in some studies ADDIN EN.CITE (175, 223, 229, 234, 245, 251). Therefore, it can be argued that due to the reliance on a self-selected sample, there may be misrepresentation of the views, experiences, or opinions of diverse group of patients, limiting the external validity of the findings.

The age of the participants in the studies varied with only the mean age reported in some studies. ADDIN EN.CITE (41, 234, 236, 240, 241, 243). Age is an important indicator in accessing the perceptions of the patients pertaining to the sexual health and contraceptive services due to higher prevalence of STIs among younger age groups (46). Disproportionate age groups of patients and missing information on age distributions can affect the inferences drawn from the studies, as reported findings may be representative of a certain

age group and not applicable to all age groups of patients within a region or general population.

The participants in most of the studies did not include a representative sample of the general population (disproportionate mix of patients in terms of ethnicity) as demonstrated in table 5.2. Evidence suggests that the prevalence of STIs is much higher among ethnic minorities and underprivileged segments of the community particularly in the UK ADDIN EN.CITE (47, 237, 250). Therefore, not properly addressing or excluding this important variable while designing the sampling framework and collecting data weakens the reliability of the conclusions drawn by such studies. Similarly, information about the sexual orientation was reported by only 21% of the studies ADDIN EN.CITE (36, 41, 43, 170, 171, 223, 229, 244, 252).

There were also structural limitations observed in the study tools utilized in the reviewed studies, and little or no information was provided about their development process as previously mentioned in section 5.3.4. Some questionnaires were brief with a few structured questions.

Most studies reported the findings with a gap of 2 to 4 years after data collection whereas a few studies ADDIN EN.CITE (43, 170, 230, 235-237) did not include information of collection of data (table 5.2). The data collection may have also varied among the different settings. It may raise issues about the data management and potential bias which may result in synthesising findings due to a long delay in data collection and publishing results. Moreover, the data were collected mostly by research staffs that were a part of the service which may lead to bias of reporting positively and only recruiting patients with good compliance. The

response rates also varied among the studies and those with low response rates missed out the views of patients which might have been different from the ones that participated in the study. The studies that reported interviews did not mention details of how the data was analysed and presented findings as narrative description of patient comments. The statistical analysis was limited to descriptive statistics in studies in studies utilizing structured questionnaires (table 5.3).

Figure 5.1 PRISMA flowchart showing the study selection process

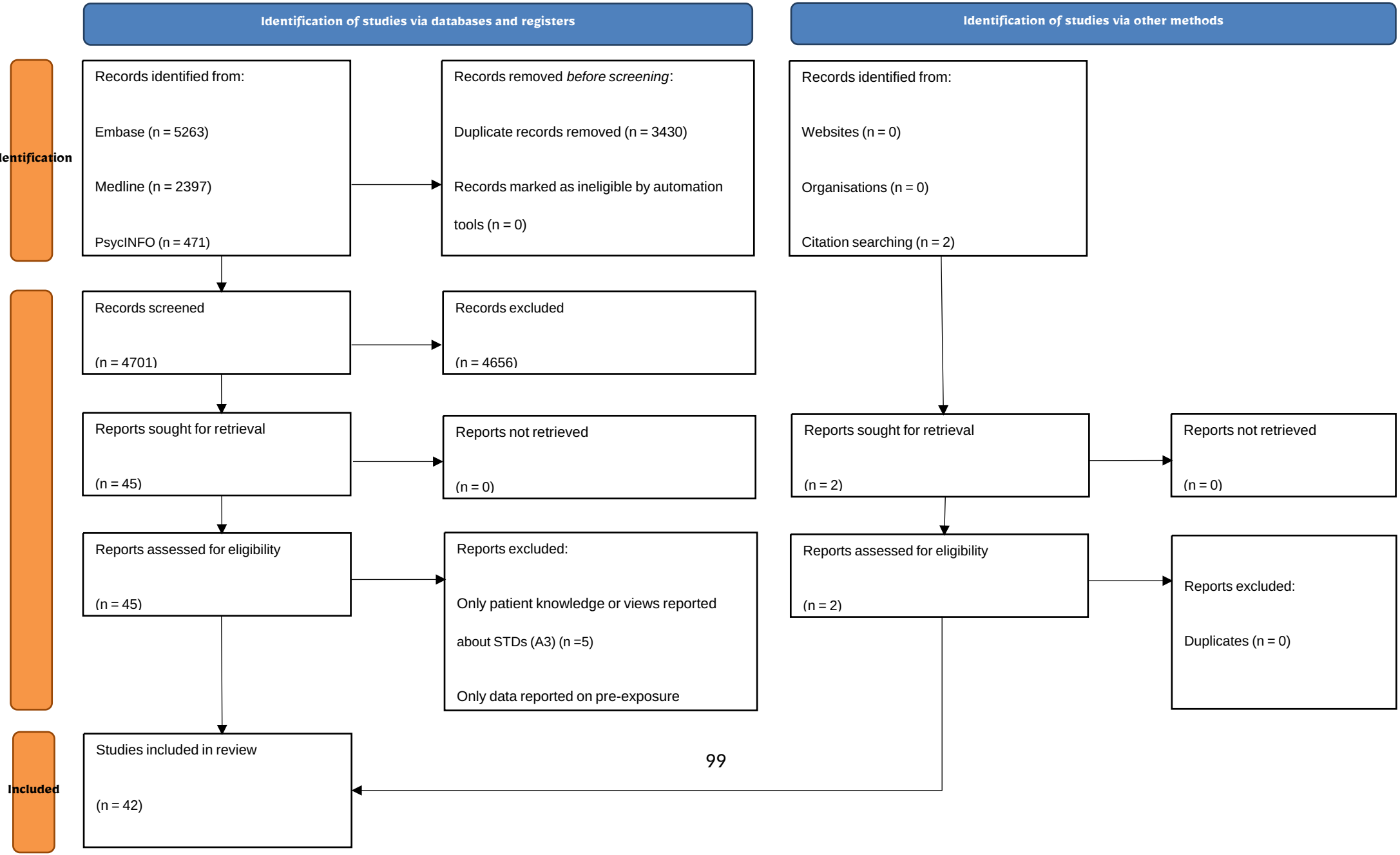


Figure 5.2: Country of origin of study

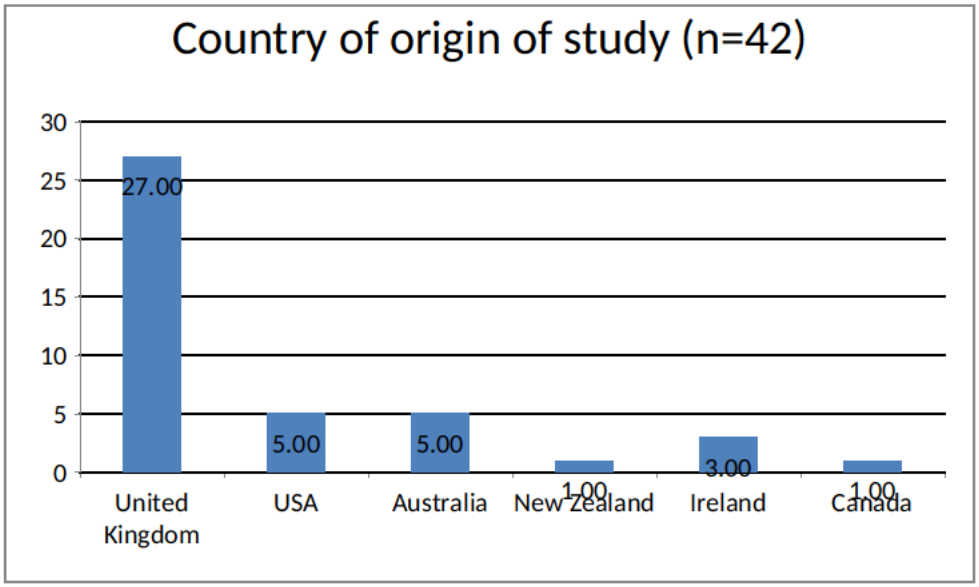
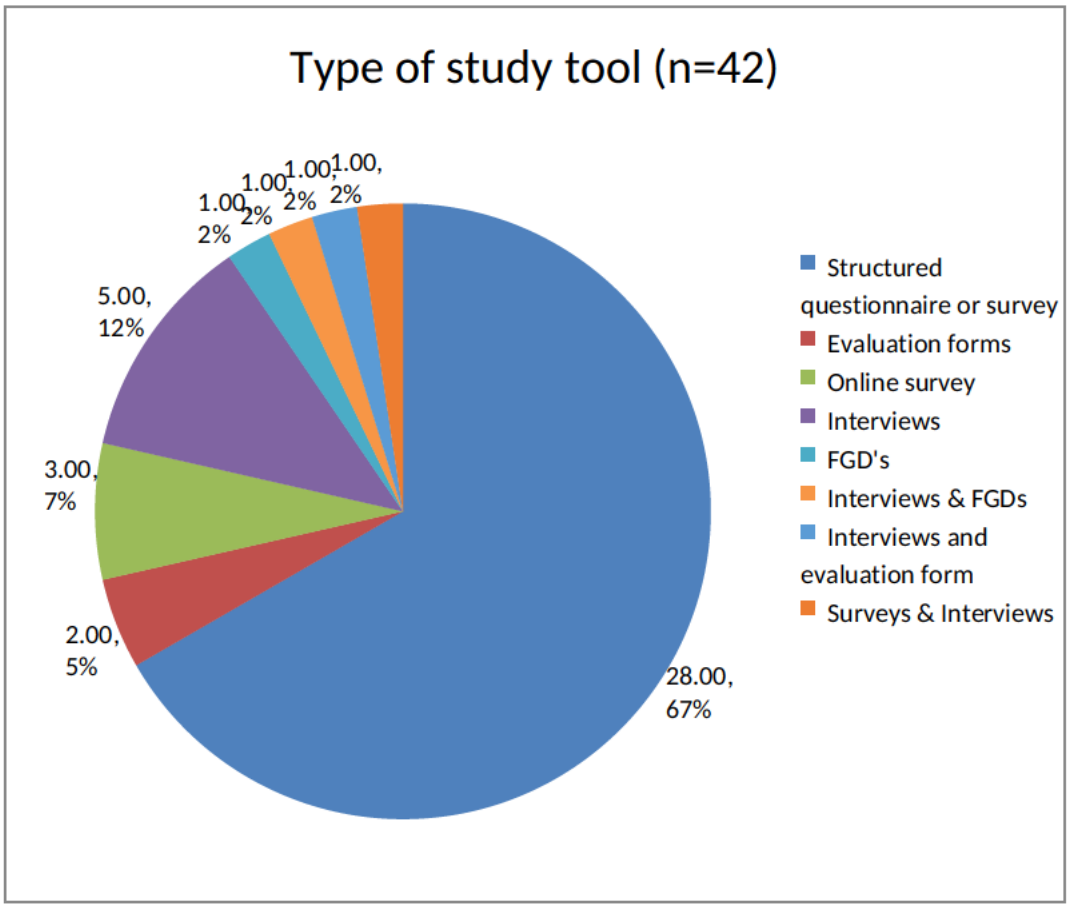


Figure 5.3: Type of study tools reported in the reviewed studies (n=42)



*FGDs Focus group discussions

Figure 5.4: Source of development of study tool design (n=42)

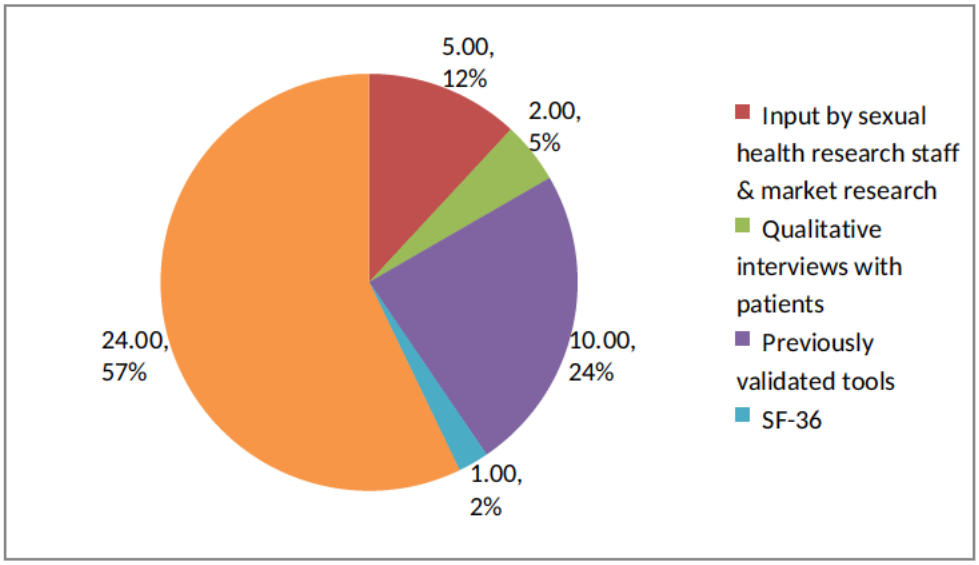


Figure 5.5: Main components of service addressed by study tools (n=42)

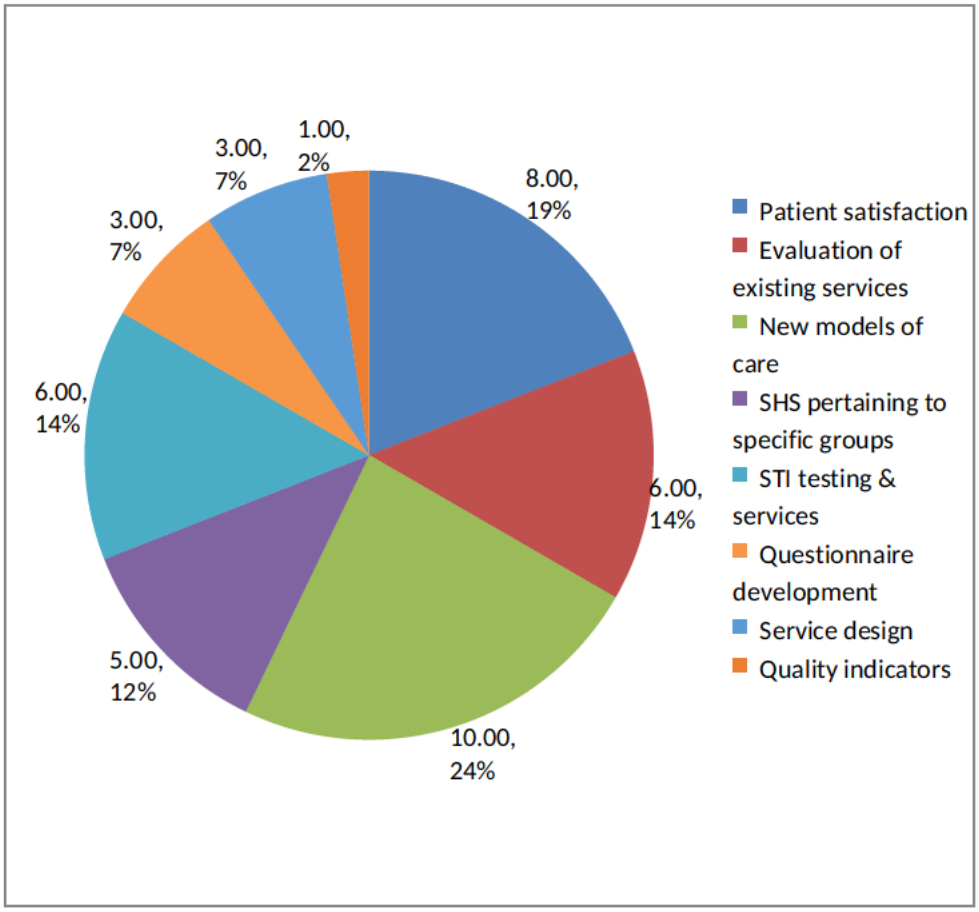


Figure 5.6: Types of study tools utilized to address different studies aims (assessing different attribute of service) included in the review (n=42)

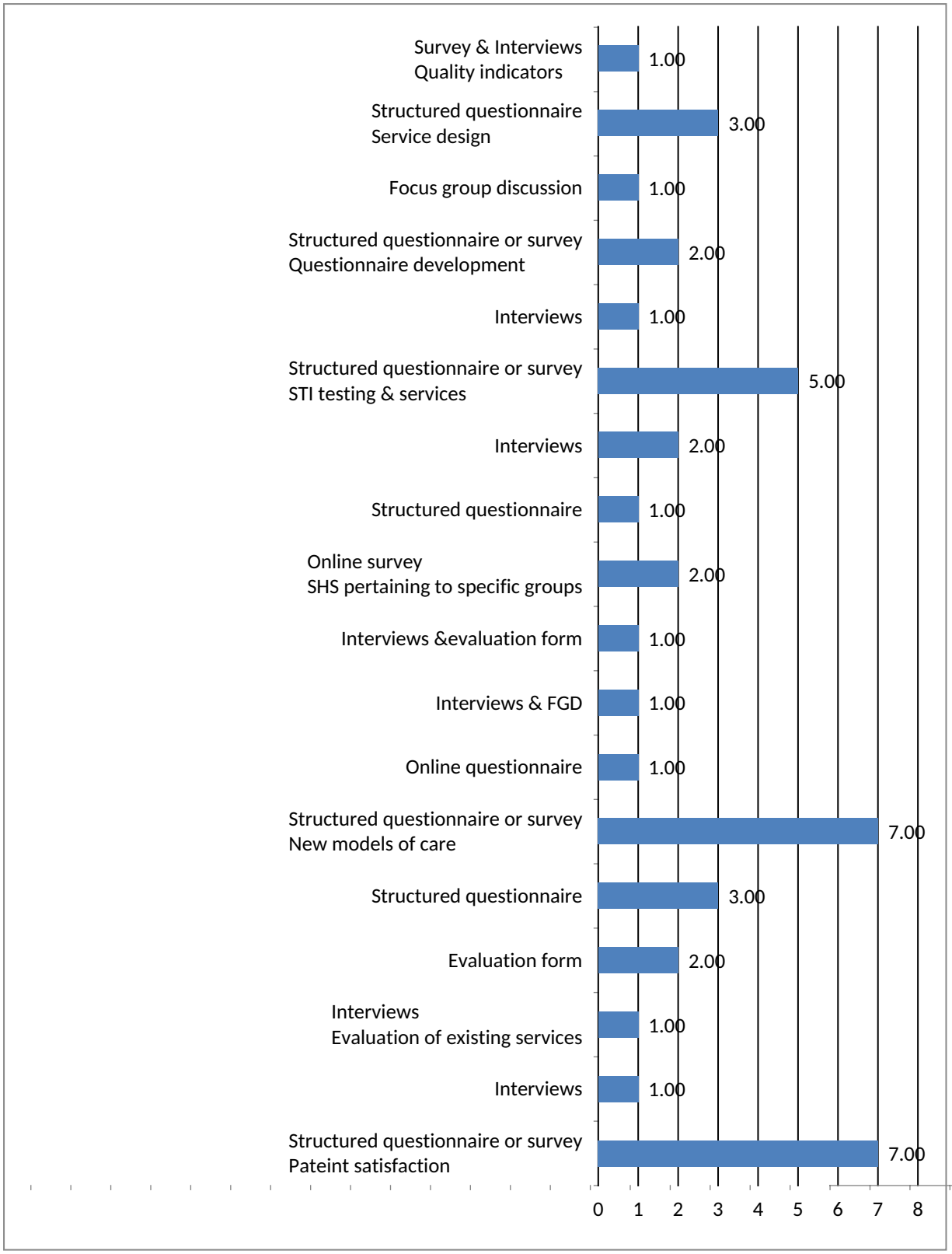


Table 5.2 Summary description of the 42 studies included in the review (grouped according to main overall aim of the studies)

Main Author	Study objective	Country; Population; Ethnicity	Sexual orientation of participants	Study settings	Study type	Sample size; Sampling strategy; Year of data collection	Response rate	Main findings of the study	Authors main conclusion
Measuring patient satisfaction									
Harrison et al., 2016(33)	To assess patient satisfaction with existing services and gauge interest in an express service option	Australia (Sydney); Male and Female mean age 31; NG	Not Given	SHC (Express clinic)	Cross sectional survey	443; Purposive non-probability sampling; 2013	Not given	A high level of satisfaction was reported in those who had used the express service	The express service was well received by clients and has potential to improve service.
Challenor et al., 2012(222)	To assess patient satisfaction among attendees of sexual health clinics	UK (Southwest England); Male & Female aged 14-72; WB, BA, A, BB, CH, OEG	Not Given	GUM/SH Clinics (12 Clinics)	Cross sectional survey	593; NG	Varied among clinics	High level of satisfaction with overall quality of care.	Medical revalidation for professional practice approaches requires all doctors participating in collecting quality improvement data.
Duffy et al., 2011(50)	Assess patient satisfaction with community based SHC and reasons for attending it	Ireland (Dublin); Male and Female aged 15-44; NG	Not Given	Community based SHC	Cross sectional survey	80; convenience non - probability sampling; 2009	NG	98% satisfaction level was reported.	Attendees to the clinic expressed a high level of satisfaction with the overall services provided.
Arkell et al., 2006(237)	To explore factors associated with anxiety in patients attending STI clinics	UK(London); Male and Female mean age 32; WB, WNB, BA, BB, AA	Not Given	STI Clinic	Qualitative study	20; Purposive non-probability sampling; not mentioned	n/a	Staff attitudes and location of clinic, emotional difficulties, stigma, substance misuse were factors associated with anxiety.	The origin of anxiety in STI patients are multifactorial and difficult to identify in brief appointments
Mehta et al., 2005(35)	To assess patient satisfaction with public STD Clinics	USA(Baltimore); Male & Female mean age 30.5; 96% B	Not Given	STD clinic	Cross sectional survey	499; Simple random sampling; 2002-2003	82%	Overall, patients at both clinics were satisfied with the service.	Patient satisfaction was associated with modifiable provider and clinic characteristics.

Bockting et al., 2004(239)	To compare satisfaction of transgender and other sexual medicine patients with SHS.	USA(Minneapolis); Gender not specified aged 35-42; NG	Not Given	SHC	Cross sectional study	1017; Convenience non-probability sampling; 1993-2002	72-86%	The study few significant differences between transgender & other SH patients.	The findings of study put individual complaints in perspective.
Challenor, 2003(240)	To determine patient satisfaction with quality of care at GUM clinics	UK (multiple cities of England); Gender and Age not specified; NG	Not Given	GUM Clinics	Cross sectional survey	1747; convenience non-probability sampling; 2002	NM	Most patients were very satisfied with the standard of care in southwest GUM clinics.	The physicians should be actively involved in patient surveys as a part of monitoring process.
Hope et al., 2001(238)	To understand patients' opinions and experiences with SHS	UK(London); Male & Female aged <30; Majority W	Not Given	GUM clinics	Cross sectional survey	389; convenience non-probability sampling; 1999		Most of the GUM patients were satisfied with their care. Waiting time was highlighted as important quality indicator.	Most GUM patients were satisfied with the service, but differing experiences and opinions need to be addressed when planning services.
Evaluation of existing services									
Howarth et al., 2017 ADDIN EN.CITE (223)	To explore patients views about Sexual Health Services	UK(London); Male and Female aged 25-35; W, A & B	HS, BS & Gay	SHC	Qualitative study	17; Purposive non-probability sampling; 2012	n/a	All interviewees were positive about their experiences	Qualitative methods have a key role in measuring patient experience and ensuring their involvement in service improvement.
Bell et al., 2014(39)	To assess male access to emergency contraception in pharmacies	USA (New York); Male aged 19-28; NG	Not Given	Pharmacies	Observational study	158; Purposive non-probability sampling; 2012	n/a	73% of pharmacies created barriers to get emergency contraception (EC)	Overall, the males had a 20% probability of not being able to access EC.
Hunter et al., 2014(40)	To investigate patients' attitudes, knowledge and perceptions pertaining to SHS	New Zealand: Male & Female aged 16-25; NZE, MAO	Not Given	SHS with rural outreach clinic	Cross sectional survey	216; Convenience non- probability sampling;2009	87%	Outcomes showed that confidentiality remains a significant concern among patients.	It is necessary to keep clinic visit details confidential for some patients attending SHS.
Parsons et al., 2013(175)	Evaluation of a community pharmacy delivered OC service	UK(London); Females, age not mentioned; NG	Not Given	Community pharmacies	Observational study	99; Purposive non-probability sampling; 2009-11	n/a	Most clients were satisfied or very satisfied with the service.	Clients were largely satisfied by the OC service provided by trained pharmacists.

Baraitser et al., 2008(230)	To test feasibility of professional patients as a tool for SHS evaluation.	UK(London); Male &Female aged 16-50; WB, BB, BA, ME & BO	Not Given	Multiple settings	Observational Study	40/ convenience Non-probability sampling; not given	N/A	Less than 50% patients were satisfied with the quality of services.	Professional patients are a useful tool for SHS evaluation
Sheriff, 2007(234)	To improve SHS provision by incorporating patient perceptions	UK(Chesterfield); gender and age not mentioned; NG	Not Given	GUM Clinic	Cross sectional survey	50; simple random sample; 2006	n/a	Waiting times, accessibility to appointments, information about results and chaperones for patients and staff were identified as areas for improvement.	Continuous patient enquiry through satisfaction surveys will lead to overall improved SHS.
Assessment of new models of care									
Fairley et al., 2013(241)	To evaluate changes in efficiency and quality of SHS after induction of purpose built EMR system	Australia (Melbourne); age & gender not mentioned; NG	Not Given	SHC	Mixed methods study	624(paper record patients) 790(EMR patients); convenience non-probability sampling; 2011	44% (PMR) 31% (EMR)	Patient satisfaction was high both with paper and electronic medical records	The Introduction of EMR improved efficiency while maintaining the quality of the patient record.
Martin et al., 2013(242)	To determine acceptability of express model of SHS among CLAD patients.	Australia (Sydney); Female aged 15-44 and above; CH, TH, KO	Not Given	SHC	Cross sectional survey	366; convenience non-probability sampling; 2012	94.3%	There were significant differences in acceptability of different components of express model between language groups.	The components of the express model are not favourable to CLAD client base.
Garrett et al., 2011(229)	To investigate young people's pre-use views on telephone and webcam consultations for SH	Australia; Male &Female aged 16-24; AUS, AB, TSI	HS & HMS	Online	National online survey	662; Convenience sampling; 2009-2010	21%	Majority of patients indicated of willing to have a in-person consultation with doctor.	Although only 29% respondents were willing for webcam consultation such service might benefit youth who may not have otherwise access to SHS.

Baraitser et al., 2011(173)	To describe client experience with SM within SHC	UK(London); Male & Female aged 16-50; NG	Not Given	Integrated SHS	Mixed methods study	43; Purposive non-probability sampling;2008-2009	n/a	Users valued self-manage because of reduced waiting times, autonomy & privacy	SM is acceptable option with SHS if informal support is available.
Hitchings & Barter, 2009(243)	To describe the implementation of self-triage in SRHC	UK(London); age & gender not mentioned; NG	Not Given	SRHC	Prospective study	193; Purposive non -probability sampling; 2004-2005	72%	Self-triage significantly reduced waiting times for patients.	Self-triage can effectively reduce waiting times &allow better organisation of resources.
Griffiths et al., 2008(171)	To assess acceptability of different one-stop shop models for SH among community groups	UK(England); Male & Female aged 16-21; WB, AB, BC& SA	HS & MSM	Community settings	Qualitative study	122; Purposive non - probability sampling; 2005	n/a	Different groups highlighted different themes. Common themes included; convenience, anonymity, addressing cultural barriers, increasing awareness & addressing confidentiality	Integrated training for providers across clinical specialities is a realistic way forward to meet client preference for one provider/session for their SH needs.
Osmond et al., 2007(170)	To identify patients' opinions about chaperones in SHS	UK(London); Male & Female aged 15-69; W, B, A, OE	HS, BS & MSM	GUM Clinic	Cross sectional study	627; Convenience non- probability sampling; not mentioned	84%	Women patients accepted chaperones when offered when examined by man, and least accepted by MSM	Most of the patients do not chaperone for intimate examinations.
Jones et al., 2007(244)	To investigate attitudes of patients towards virtual chaperone in SHC	UK(London); Male & Female aged 20-29; 65% W & NS	85% HS	SHC	Cross sectional survey	180; Purposive non - probability sampling; 2005	90%	Only 40% respondents felt VC was acceptable in GUM clinics	GU medicine patients do not favour introduction of virtual chaperone.
Hamil & Goldmeier, 2005(236)	To evaluate patient opinions on alternative models of care	UK(London); Age and gender not specified; NG	Not Given	Recurrent genital herpes clinic	Cross sectional survey	74; Convenience non-probability sampling; NM	NM	62% of patients supported the idea of nurse led clinic.	The findings of the study suggest initiation of nurse led RGH clinic.

Doherty, 2000(231)	To inform future development of SHS for population of rural health board by incorporating views of clients	UK (Northern Ireland); Male & Female (age not specified, 69% < 30; NG	Not Given	Multiple settings	Cross sectional survey	137; Convenience non- probability sampling; 1998		Majority of the patients were satisfied with the service. Confidentiality was the most important factor affecting the choice of service provider.	Significant training needs in SH was identified for PC professionals and new models of service were proposed.
Sexual Health Services pertaining to specific groups									
Thng et al., 2018(42)	To investigate sex workers satisfaction with SHS and its accessibility	Australia (Sydney); Male, Female &Transgender aged 18-50; NG	Not Given	Online	Online Survey	53; Purposive non-probability sampling. 2015	20%	Participants attending GPs were less likely to disclose sex work & were less satisfied	Better awareness of sexual health needs of sex workers is important in GP services.
Brennan et al., 2015(41)	To investigate MSM experiences and self-perceived impacts of online outreach	Canada (Ontario); Male age not mentioned; NG	MSM	Online outreach	Online survey	1830; Purposive non-probability sampling;2013-2014	Not given	Of the men who assessed online outreach, their experiences were mostly favourable	Online outreach services are promising health promotion strategy to provide self-referrals and engage diverse groups in SHS.
Boyce et al., 2012(43)	To identify barriers to accessing SHS among patients with different sexual orientations	USA (Guatemala City); Male & Female aged 18-59; NG	BS, HS & Gay	Public Health Clinics & NGOs	Qualitative study	29; purposive non-probability sampling; NG	n/a	The most prominent barriers to SHS included fear of discrimination, fear of having HIV, cost and lack of social support.	There is need of strengthening existing public STI clinics to address multiple layers of stigma & discrimination against MSM and transgender persons.
Perry et al., 2008(245)	To assess SHS specifically set up for young people	UK (Northwest England); Male &Female mean age 14; NG	Not Given	SHC for young people	Observational study	36; Convenience non - probability sampling; 2002	64%	The young people reported high satisfaction with services received.	Young people can be engaged in SHS if it is modelled according to their needs.
McAllister et al., 2002(38)	To determine acceptability and	UK(Glasgow); Females aged 14-39; NG	Not Given	Pharmacy	Prospective qualitative	98; convenience non - probability	67%	Clients were satisfied or very	Clients reported high level of satisfaction

	accessibility of SHS for young people in city centre pharmacy				survey	sampling; 1999		satisfied with the clinic location, timings and environment.	with the service; timing and location were mostly commonly quoted reasons for attendance.
STI testing and services									
Brugha et al., 2011(254)	To investigate young patients' preference to receive STI screening test results	Ireland (Dublin); Male & Female aged 18-29;	Not Given	GUM clinic & PC settings	Cross sectional survey	5685; convenience non- probability sampling; 2009	93%	Mobile call was more preferred way of receiving positive results followed by email.	Young patients prefer to be called on mobile phone to receive positive test results compared to other ways of communication.
Holloway et al., 2011(246)	To evaluate men's preference on SHS in community clinic	USA (New York); Male aged 18-53; LH, AFA, CAU, A, OE	Not Given	Community clinic	Cross sectional survey	199; Convenience non- probability sampling; 2007	63%	Respondents preferred learning of positive STI result by phone.	Multiple options for STI testing, notification & treatment are recommended to maximise service use among men.
Brown et al., 2010(233)	To assess acceptability and efficacy of non-invasive STI testing among asymptomatic patients	UK(Birmingham); Male &Female aged 16-62; WB, CA & MR	Not Given	GUM Clinic	RCT	331; stratified random sampling; 2006	87%	Patients randomly assigned to NIT were more likely to disagree with longer waiting times than expected.	NIT for STI in asymptomatic can reduce the time patients spend in clinic.
Steedman et al., 2009(253)	To assess patient perception of STI related factors associated with accessing SHC	UK(Chester); Male and Female aged 15-60; NG	Not Given	SHC	Cross sectional study	253; Purpose non-probability sampling; 2008	96%	Patient perception of health risk associated with untreated STI was significantly associated with earlier attendance.	Increased public education regarding STI increases appointments within 48 hours.
Brown et al., 2008(235)	To determine patient's preference of SHS pertaining to obtaining STI screening results	UK(Birmingham); Male & Female aged 16-25; WB, BC, BO	Not Given	STI Clinic &household; not mentioned	Cross sectional Survey	744; not specified	92% Clinic; 43% CM	40% patients preferred telephone and 41% face to face	The patients preferred face to face or telephone route to receive

								consultation for receiving STI results.	results despite options of new technology.
Evans & Cross, 2007(247)	To explore the experiences of clients accessing community STI service	UK (Southeast London); Male &Female aged <25-40; W, B, BC, BB, OE, U	Not Given	Community STI service centre	Qualitative study	16; Purposive non-probability sampling; 2002-2003	n/a	Access was easier at community centre, environment of SHC is important to patients, clients were generally satisfied with the services received.	More research is needed to determine whether community STI service would be acceptable to client groups currently not using it.
Questionnaire development for assessment of sexual health services									
Weston et al., 2010(250)	To design and validate a specific STI patient satisfaction survey	UK(Birmingham); Male and Female aged 18-45; W, AB, B, BB, MO	Not Given	STI Clinic	Cross sectional survey	936; Convenience non- probability sampling; 2009	53%	Most patients were satisfied with overall clinic, and all would attend clinic if required & recommend to friends.	There is a need for a nationally validated PROM to assess patient satisfaction within SHC for service improvement.
Lichtenstein & Bachmann 2005(251)	To evaluate develop tools for assessment of client satisfaction at STD clinics.	USA(Alabama); Male and Female mean age 41; NG	Not Given	STD clinic	Evaluation study	15; Purposive non-probability sampling; 2003	n/a	Clients were concerned with visibility, being stigmatized, or disrespected and about breach of confidentiality.	Staff-client interactions are an important element of STD care.
Miles et al., 2003(252)	Development of patient satisfaction questionnaire to compare satisfaction of women attending nurse led or doctor led clinics	UK(London); Females aged 16-60; WB, AB, BC & SA	HMS, HS & BS	SHC	Cross sectional survey	282; convenience non -probability sampling; 1999	90%	Female patients were more satisfied with care provided in nurse led clinic than doctor led clinic.	Study demonstrates that nurse led clinics with SH are an acceptable alternative to existing doctor-led clinics.
Assessing service design									
Fernando et al., 2008(36)	To ascertain patient attitudes towards data management in GUM	UK(Edinburgh); Male and Female aged <18≥18; NG	HS, BS & MSM	GUM Department in Hospital	Cross sectional survey	527; Convenience non- probability sampling; 2006	67%	Factors significantly associated with agreement to GP	Mode of referral and concerns about implications

	settings							contact included; heterosexual orientation, initial GP referral & perceptions of HIV testing not to have negative implications.	of HIV testing affect patient preference on patient sharing.
Hambly & Luzzi, 2006(37)	To determine patient's preference for seeing GP for SHS	UK(Buckinghamshire); Male &Female aged <24-34; WB	Not Given	GUM department at Hospital	Cross sectional study	209; NG; 2004	94%	62% patients would accept appointment with a GP	There should be development of SHS in primary care settings.
Ross et al., 2006(232)	To determine patient's acceptability to options available to GUM clinics in UK	UK(Birmingham); Male and female aged 16-25; WA, BC & BO	Not Given	GUM clinics & Households	cross sectional study	542(community) 202(clinic attendees); convenience non-probability sampling; 2005	43% (CM survey) & 92% (clinic survey)	Delivery of SH care by specialist nurses was acceptable to 81% community participants and 72% of clinical patient interviewees.	Delivery of SHS by nurses and GPs was generally found to be acceptable although varied by patient sex and ethnicity.
Exploring key quality indicators									
Challenor et al., 2010(176)	To develop quality indicators for STI services by incorporating patients' views	UK (Plymouth & Taunton); Male &Female aged 17-63; NG	Not Given	GUM Clinics	Mixed methods study	40; Purposive non-probability sampling;2009	n/a	High satisfaction levels among patients. Maintaining confidentiality & continuous feedback of patients suggested	Quality indicators need to be challenging yet achievable and it is difficult to set standards.

Abbreviations (W: White, WB: White British, B: Black, BB: Black British, BO: Black Other, SA: South Asian, OE: Other Ethnicity, U: Unknown Origin, NG: Not Given, CA: Caribbean, BC: Black Caribbean, AUS: Australian, AB: Aboriginal, TSI: Torres Strait Islander, CH: Chinese, A: Asian, B: Black, AB: African Black, AA: Asian American, WNB: White Non British, TH: Thai, KO: Korean, MO: Mixed Origins, NEW: New Zealand Europeans, MAO: Maori, LH: Latino Hispanic, AFA: African American, CAU: Caucasian, SM: Self-Management, SHS: Sexual Health Services, STI: Sexually Transmitted Infections, NM: Not Mentioned, SHC: Sexual Health Clinic, SRHC: Sexual & Reproductive Health Clinic, STD: Sexually Transmitted Disease, N/A: Not Applicable, SHS: Sexual Health Services, NG: Not Given, NGO: Non-Profit Organisation, MSM: Men who have sex with Men, EC: Emergency Contraception)

Table 5.3: Details of development and components (questions or items) of study tools of the 42 studies

Main Author	Study tool	Main components of study tools	Development of study tool	Analysis of data	Ethical considerations	Funding
Theme: Patient satisfaction						
Harrison et al., 2016(33)	Structured questionnaire	Waiting times, satisfaction with pre and post express service	Not Given	Descriptive statistics	Ethics received by LEC	Not Funded
Challenor et al., 2012(222)	Patient satisfaction survey (PSS)	Pre-appointment, Performance of HCP, facilities and privacy, communication, information provided & overall experience	Modified from BASHH PSS	Descriptive statistics	Not Given	BASHH
Duffy et al., 2011(50)	Questionnaire survey	Reasons for attendance, referral route, satisfaction rating	Not Given	Descriptive statistics	Ethics received by GP EC	Not Given
Arkell et al., 2006(237)	Interviews	Exploring psychological aspects of SH among patients, anxiety factors of SHP	Not Given	Thematic analysis	Ethics approval received by LEC	Grovelands's Priory Hospital
Mehta et al., 2005(35)	Structured questionnaire	Patient characteristics, healthcare service	SF-36 & CAHPS Study 2.0	Descriptive statistics, Univariate & Multivariate analysis	Approved by IRB	NIH grant
Bockting et al., 2004(239)	Structured questionnaire	Distress at intake & present, satisfaction levels among patients of various aspects of SHS (appointments, handling problems etc.)	Not Given	Descriptive statistics univariate analysis	Not Given	Not Given
Challenor, 2003(240)	Structured Questionnaire	Experience of consultation, quality of service, information provided, informed decisions, revisiting clinic, Overall satisfaction	Pre-piloted/validated questionnaire among 20 GUM patients	Descriptive statistics	Not Given	Not Given
Hope et al., 2001(238)	Questionnaire survey	Patient profile, clinic attendance & care, clinic facilities, availability of appointment & overall satisfaction	Input from staff	Descriptive statistics	Ethics clearance not required	GlaxoSmithKline UK Ltd.
Theme: Evaluation of existing services						
Howarth et al., 2017 ADDIN EN.CITE (223)	Interviews	Patient experiences with the service	Pre-tested topic guide	Thematic analysis	Ethics approval by LEC	ICH charity
Bell et al., 2014(39)	Evaluation form	Availability to EC	Not Given	Descriptive statistics, univariate analysis	Not Given	Not Given

Hunter et al., 2014(40)	Structured questionnaire	Patient demographics, motivation for clinic attendance, clinic referral pathway, access to computerised test results & discharge	Previous survey (pre-test and piloted before administration)	Descriptive statistics	Ethics approved from central regional EC	No funding received
Parsons et al., 2013(175)	Structured questionnaire	Patient satisfaction pertaining to pharmacy delivered OC	Adapted from PCT Chlamydia testing questionnaire	Descriptive statistics	Not Given	The Guys & St Thomas Charity
Baraitser et al., 2008(230)	Evaluation form	confidentiality, waiting time, information provided	FGD with 93 service users	Descriptive statistics & narrative description	Ethics approval by LEC	The Guys & St Thomas Charity
Sheriff, 2007(234)	Structured questionnaire	Waiting times, preference of obtaining test results, preference of chaperone	Previous PSS & input from multidisciplinary staff	Descriptive statistics	Ethics not required	Chesterfield Royal Hospital NHS Trust
Theme: Assessment of new models of care						
Fairley et al., 2013(241)	PSS	Comfortability of patients during consultation, effect of EMR on quality of SHS	Not Given	Descriptive statistics & narrative description	Ethics received by Alfred Hospital EC	Not Given
Martin et al., 2013(242)	Structured questionnaire	Satisfaction with CASI, preference for healthcare assistants & self-testing	Not Given	Descriptive statistics, multivariate analysis	Not Given	No Funding
Garrett et al., 2011(229)	Online questionnaire	Demographics, accessibility, Communication, IT information, sexual behaviour	Validated Questionnaires from published research	Descriptive statistics	Ethics approved by University of Melbourne	Melbourne International Research Scholarship
Baraitser et al., 2011(173)	Interviews & Evaluation form	Uptake of self-management of patients and attitudes & experiences associated with it	Not Given	Descriptive statistics & Thematic analysis	Ethics approval received by Multiple EC	Guys & St Thomas Charity
Hitchings & Barter, 2009(243)	Patient Satisfaction Survey	Patient satisfaction with care, waiting times	Not Given	Descriptive statistics, Univariate analysis	Not Given	Not Given
Griffiths et al., 2008(171)	Interviews & FGD	Awareness of SHS in local area, patient preferences of SHS	Not Given	Thematic analysis	Not Given	Department of Health, UK
Osmond et al., 2007(170)	Structured questionnaire	Present visit, patient preferences for future visit	Not Given	Descriptive statistics, univariate analysis, multivariate analysis	Not Given	Not Given
Jones et al., 2007(244)	Structured questionnaire	Attitudes of patients to VC, overall acceptability of VC during examination & consultation	Not Given	Descriptive statistics	Not Given	Not Given
Hamil & Goldmeier, 2005(236)	Structured Questionnaire	Patient acceptance of new methods of clinical management (Nurse led clinics & group therapy for psychological support	Not Given	Descriptive statistics	Not Given	Not Given
Doherty, 2000(231)	Structured questionnaire	Information sources, reasons for attending, satisfaction levels, preferred options for future SHS, choice of service provider	Not Given	Descriptive statistics	Not Given	Not Given
Theme: SHS pertaining to specific groups						

Thng et al., 2018(42)	Online survey	Access to care, confidentiality, types of services available, satisfaction with care	Not Given	Descriptive statistics	Ethics approval received by LEC	Not Given
Brennan et al., 2015(41)	Online survey	Demographics, patient experience of online outreach	Not Given	Descriptive statistics	Not Given	Not Given
Boyce et al., 2012(43)	Interviews	Patient experiences with SHS, perceived barriers to access, HIV risk behaviours, Social and sexual network characteristics	Input from research team & Key informants	Thematic analysis	Ethics approved from 3 different review boards	US CDC & Prevention
Perry et al., 2008(245)	Structured questionnaire	Demographics, history of clients, frequency of use and overall satisfaction (waiting times, efficiency of care, confidentiality, attitude of staff)	Not Given	Descriptive statistics	Ethics approval received by LEC	Not Given
McAllister et al., 2002(38)	Interviews	Demographics, attendance factors, previous experience SHS, alternative services, consultation outcome, future services	Not Given	Descriptive statistics, narrative description	Not Given	Not Given
Theme: STI testing and services						
Brugha et al., 2011(254)	Structured Questionnaire	Partner notification, registration preferences	Irish study of SH & Relationships, case Performa's & exploratory qualitative research	Descriptive statistics	Ethics approved by Irish Health Research Board	The Irish Health Protection Surveillance Centre
Holloway et al., 2011(246)	Structured Questionnaire	Socio-demographics, SH history, preferences for STI testing and results, experience and preferences for partner notification	Input from clinicians and health educators	Descriptive statistics	IRB from Columbia University	William & Flora Hewlett Foundation
Brown et al., 2010(233)	Patient satisfaction survey	Anxiety & comfortability about STI tests, waiting times, experience of visit, satisfaction with care, revisiting clinic	Not Given	Descriptive statistics and univariate analysis	Ethics approved by Solihull LEC	Heart of Birmingham PCT
Steedman et al., 2009(253)	Structured questionnaire	Demographics, appointment times, factors affecting attendance, alteration of SHS	Not Given	Descriptive statistics Univariate analysis	Not Given	Not Given
Brown et al., 2008(235)	Standardized questionnaire	Options for test results, Labelling of infection	Input by SHRS &Market research	Descriptive statistics, Univariate Multivariate analysis	Not Given	Heart of Birmingham tPCT
Evans & Cross, 2007(247)	Interviews	Experiences of clients using community STI service	Not Given	Thematic analysis	Ethics received by LEC	The Department of SRH, Lewisham PCT
Theme: Questionnaire development						
Weston et al., 2010(250)	Structured questionnaire	Before/after arrival in clinic, waiting times, appointment quality, information provided, overall impression	Systematic review and semi-structured interviews	Descriptive statistics	Not Given	Not Given
	Focus group interviews	Quality of STI care & patient satisfaction	Not Given	Thematic analysis	Not Given	

Lichtenstein & Bachmann 2005(251)						CDCP Alabama department of Public Health
Miles et al., 2003(252)	Patient satisfaction survey	Interpersonal relationship, quality of care, information provided, service attributes, overall satisfaction	Previously validated questionnaire adapted with input from further qualitative interviews	Descriptive statistics, Univariate and Multivariate analysis	Ethics approval by LEC	Not Given
Theme: Service design						
Fernando et al., 2008(36)	Structured questionnaire	Demographics, motivation for clinic attendance, clinic referral pathways, patient preferences of referral letters to GP	Not Given	Descriptive statistics, univariate analysis	Not Given	Not Given
Hambly & Luzzi, 2006(37)	Structured questionnaire	Information provided, preference for STI factors influencing screening and treatment	Not Given	Descriptive statistics	Not Given	Buckinghamshire Hospitals NHS Trust
Ross et al., 2006(232)	Questionnaire	Acceptability of different models of care (GP and Nurse-led care)	Internal workshop (input from CRS & Market research company	Descriptive statistics. Univariate and multivariate analysis	Ethics received from South Birmingham LEC	Heart of Birmingham Trust
Theme: Quality indicators						
Challenor et al., 2010(176)	Interviews & Survey	Confidentiality, communication, quality of care, accessibility to STI testing	Quality measures based on BASHH & Dept of Health Targets	Descriptive statistics & thematic analysis	Not Given	Not Given

Abbreviations (NG: Not Given, HMS: Homosexual, HS: Heterosexual, BASHH: British Association for Sexual Health & HIV, BS: Bisexual, LEC: Local Ethics Committee, NIH: National Institute of Health, PCT: Primary Care Trust, PSS: Patient Satisfaction Survey, SHS: Sexual Health Services, EC: Ethics Committee, CDC: Centre for Disease Control, IRB: Institutional Review Board, EMR: Electronic Medical Record, MSM: Men who have sex with Men, SH: Sexual Health, SHP: Sexual Health Patients, CDCP: Centre for Disease Control & Prevention, CASI: Computer assisted self-interview, VC: Virtual Chaperones, NM: Not Mentioned)

5.4 Discussion

5.4.1 Principal Findings

The systematic review was conducted to investigate how patient perceptions have been captured pertaining to the various components of sexual health and contraceptive services and to identify any potential gaps in services as perceived by them. The systematic review provides the first synthesis of how patient's perspectives in this area within OECD countries. The review found that there was evident heterogeneity in the study participants, study settings and aims of the studies.

The assessment of the various tools utilized in the reviewed studies suggest the lack of a standardized validated tool (preference-based PROM) to comprehensively capture patient reported outcomes relating to sexual health and contraceptive services. This tool should be inclusive and representative of all types of patients accessing sexual health or contraception services, with careful consideration of assessment of the various components of the service. Additionally, the tools utilised in the studies (included in the review) demonstrated methodological limitations. For instance, out of the total 42 studies included in the review only 18 studies reported information on the development process of the tools utilised (table 5.3). Information about the tool development process is important to determine instrument validity and reliability of the findings of the study. The review also highlighted that there was minimal patient involvement in the development process of the tools in most of the studies. These tools were mostly developed by published literature, market research and based on feedback from associated sexual healthcare staff. Most of the study tools were brief and the domains (of the aspects of care) and items included in the instruments were not clearly

defined. Most of the tools utilized in the studies were non-preference based PROMs which cannot be utilized in an economic evaluation. Only one study utilized a generic preference-based PROM (SF-36).(35) It can be argued that this generic PROM (SF-36) cannot capture wider health outcomes which are truly representative and specifically associated with sexual health services. The most detailed study tool(250) identified by the review was a structured questionnaire which was a non-preference based PROM. It was developed by conducting a systematic review (including studies from developing countries) and semi-structured interviews. However, it was developed more than a decade ago and has structural and methodological limitations which were acknowledged by its developers in the study limitations. (250)

Despite, the objective and methodological variance in the reviewed studies these data are consistent with the notion that service delivery mechanisms and the quality of care can be considerably improved by comprehensively incorporating patient derived experiences to promote patient centred care which has been increasing recognized as an essential component of service planning, implementation and evaluation ADDIN EN.CITE (33, 176, 216, 217).

5.4.2 Generalisability of the findings of the review

The studies reported have heterogeneity in the study settings, components of the service assessed, the type of the study tools utilized, socio-demographic characteristics of patients and period of data collection. These factors limit the generalisability of the overall findings of the review which cannot be applied over a larger population or a specific service setting. The variance in the structure of study tools (and lack of following standard procedures of

PROM development process in their development) makes it difficult to select a comprehensive study tool which can applied over a wide range of settings and patient groups to effectively capture outcomes associated with the service. These tools cannot be utilized in an economic evaluation as they are non-preference-based type of PROMs as discussed in chapter 2 and 3 of the thesis. Another limitation in the generalisability of the findings is that the participants were mostly self-selected which may have different characteristics than patients recruited randomly. Given the nature of the assessment to capture patient's perspectives it is possible that self-selected patients may be more motivated to respond positively and report outcomes which may be different from general population and not a true representation.

Additionally, considering the specific aim and objectives of the study it can be argued that the content and construct validity maybe be affected due to non-specialised background of the healthcare staff in academic research. It can be argued that given the potential for limited research skills among the healthcare staff, important themes and components may have been overlooked or under-represented which could otherwise have been helpful in drawing specific conclusions from the findings. Incorporating such indicators and associated responses from a patients' perspective may have more comprehensively answered the research question in some studies. For example, a study assessing the different one-stop shop models for sexual health services among community groups included limited aspects of service for integration and did not include questions (items) relating to broader components of sexual health services. (171) With regard to the quality of analysis of data, the studies which reported conducting interviews did not mention details of the qualitative synthesis and presented findings as narrative description of patient comments. ADDIN EN.CITE (43,

223, 237, 247, 251) Moreover, the disproportionate distribution of samples (in the reviewed studies in which some patient groups were excluded or underrepresented) further weakens the generalisability of the findings. The above-mentioned factors, the inherent deficiencies of the study designs (cross-sectional study design) and applied methodological limitations of the measurement tools utilized to achieve desired objectives of the studies may have led to polarization of responses, which may be region, specific patient-group and setting specific, thus jeopardising the overall generalisability of findings.

5.4.3 Strengths and limitations of the review process

The main strength of the review process is that a robust systematic search was conducted applying two stage criteria. The search process was managed carefully at every stage to ensure the review is clear, thorough, reproducible, and transparent. A considerable amount of time was spent devising a comprehensive search strategy, formulating an inclusion/exclusion criteria and discussion and agreement on extracted data between MA, TR, LJ, JS and NT. The piloting of search strategy, supplementation of the electronic search with hand searching and searching of the reference lists of included studies also strengthened the review.

The limitations of the review include the fact that studies are only from OECD countries, but this was because the demographic characteristics of patients and mode of service delivery may differ in other regions. Only published original research articles were included in the review excluding conference abstracts, reports, and theses. This may also be a limitation of the review. This is mitigated by the fact that a significant number of studies were identified encompassing a range of settings and addressing various components of the service. It is

unlikely that excluding unpublished studies affected the overall research findings. The studies identified provided a rich pool of data and themes and allowed various aspects of service to be considered and a diversity of settings were included. Another potential weakness was that the only one reviewer (MA) conducted the review. However, at all stages (screening, decisions regarding inclusion and exclusion of studies, data extraction, analysis etc.) of the review process double checks were conducted by TR, LJ, JR & NT (PhD supervisory team).

5.4.4 Implications of the review & recommendations for future research

The methodological limitations of existing instruments which aim to capture patients' perspectives on sexual health services mean that research needs to be undertaken to develop more robust tools. The developers should prioritise to follow the standard scientific procedures of PROM development process (as mentioned in chapter 2) with the aim to develop a validated instrument which can yield reliable results and holistically capture patients' perspectives relating to the various components of the service. The various economic theories and its applied methodologies should also be considered for developing a preference-based PROM which can be utilized in an economic evaluation in this area.

Moreover, it is important to consider representativeness of the sample recruited in the study which should reflect on the sexual health care needs of the population. For instance, the sample drawn in the studies could have been more representative of the true population accessing sexual health services or patients who are at high risk with unmet needs. The prevalence of STIs is higher among ethnic and sexual minorities and such patients are classified as high risk, often report of feeling victimised and have greater

anxiety issues while seeking sexual health care and advice ADDIN EN.CITE (41, 170, 171). The various economic theories and its applied methodologies should also be considered for developing a preference-based PROM which can be utilized in an economic evaluation in this area.

The studies documenting a qualitative design without clearly describing a strategy for systematic collection, organisation and interpretation of textual information or studies primarily reporting quantitative data with primarily non-probability sampling techniques suggest weaknesses in data management, analysis plan and qualitative research techniques utilized in the reviewed studies.

The following methodological recommendations are summarized for future researchers planning to design measurement tools to determine outcomes considered most important by patients while accessing sexual health services:

- the study tool selected or designed for any research assessing sexual health services and capturing patient reported outcomes should have both a strong theoretical basis and ideally should be constructed in accordance with the standard criteria for PROM development process
- the data management, collection and analysis plan should be carefully designed applying robust techniques following strict protocols
- the researchers involved in formulating the study design, data collection, data analysis and drafting of the research manuscript should be sufficiently trained in basic principles of conducting scientific research and ideally not be directly related to the service

- existing economic theories and its applied techniques should be explored to consider the need for preference-based PROM specifically for sexual health services for conducting an economic evaluation in this area

5.5 Conclusions

Patient perceptions pertaining to various aspects of sexual health services within OECD settings have been captured by a range of different measurement tools, data collection techniques and among different patient groups. There is a lack of preference-based validated PROMs in this area which can holistically capture patient reported outcomes pertaining to all the important components of the service and can be utilized in an economic evaluation to ensure that the service is cost efficient and patient-centred. Hence, there is a need to further explore the important patient experience dimensions to gather information (synthesize important themes) that can provide solid foundations for the development of a future preference-based PROM in this area.

5.6 Chapter summary

This chapter analysed how patient perceptions and satisfaction have been measured and reported in literature for various aspects of the sexual health services in OECD settings. This is the first ever analysis of the various tools utilized in assessment of sexual health services and provides useful insight into the validity and reliability of these instruments. The next chapter presents the findings of a qualitative synthesis and meta-ethnography which was conducted to further explore and highlight important patient experience dimensions

pertaining to the service to establish important themes relating to the various components of the service delivery process.

CHAPTER 6: Patient experience dimensions pertaining to sexual health services: Qualitative synthesis and meta-ethnography

6.1 Introduction

Recently there has been a paradigm shift towards recognizing patient experiences of healthcare as one of the essential indicators for assessing quality. ADDIN EN.CITE (114, 216, 255-257) Across the UK NHS patient and public involvement and engagement (PPIE) is a major indicator of quality alongside clinical effectiveness and patient safety. ADDIN EN.CITE (223, 258, 259) It has been proposed that clinical indicators and mortality rates only provide a partial value of healthcare and what is of true significance is what patients want which is closely associated with their wellbeing and ability to play an active role in society. ADDIN EN.CITE (114, 255, 256)

Importantly the significance of capturing patient experiences for improving the quality of care is now increasingly recognized by policy makers from various Organisation for Economic Co-operation and Development countries.(114) A term with broader context 'patient-based evidence' has more recently been proposed which encompasses a range of information based on patient input on different aspects of care.(255) It mainly includes, patient narratives, data on health related quality of life and patient experience survey data.(255) The introduction of this concept is based on the philosophical perspective relating to the significance of incorporating patient experiences to improve healthcare delivery process.(255, 260) The principle emphasizes that providing services that are not wanted by patients is meaningless even if they are clinically effective and economically efficient.(260) Additionally, evidence suggests that patient input has thus far been minimally included in development of tools to capture health outcomes.(255)

Patient experience surveys primarily focus on the process of care rather than the associated outcomes. ADDIN EN.CITE (223) The key issues that are highlighted through these tools are 'communication with healthcare staff, information provision, patient involvement in

decisions relating to care, emotional support, physical comfort and care transitions′.(114) Evidence suggests that patient experiences in particular, are better captured by qualitative research design which facilitates an in-depth inquiry and can explore various issues which are deeply embedded which cannot solely be contextualized by quantitative survey. ADDIN EN.CITE (223, 256, 261)

There a number of established generic frameworks to capture patient experiences namely; The Warwick Patient Experiences Framework, Institute of Medicine framework and the Picker principles, Picker principles and the National Health Council and International Alliance Patients′ Organisation. ADDIN EN.CITE (133, 134, 255, 257, 262) However, there are limitations in the existing frameworks due to uncertainty about the background research in designing the framework and representativeness of the experience dimensions in reflecting patient-identified experience.(255) Moreover, patient reported experience measures (PREMs) and indicators may vary across different disease conditions and healthcare settings.(255) To achieve desirable outcomes from this resource it is essential to formulate well designed questionnaires tailored for specific diseases substantiated with high quality research and a commitment to act on its findings. (114, 255)

Exploring patient experience dimensions can provide in-depth information and highlight important themes pertaining to the various aspects of the sexual health and contraceptive services and its delivery processes.(114) Capturing patient experiences by conducting qualitative research can comprehensively describe different dimensions of care and a broad range of patient priorities. ADDIN EN.CITE (223)

The literature suggests that there are various issues in capturing patient experiences for sexual health services. ADDIN EN.CITE (114, 223, 250) The factors identified in national

surveys and studies, which may pose as a challenge in collecting generalizable information about patient experiences, include; the complex nature of the sexually transmitted diseases particularly the undiagnosed asymptomatic patients, difficulty in recruitment in research due to issues of confidentiality because of the stigma associated with STIs and complex diversified characteristics of patient groups accessing care in terms of age, gender, sexual orientation, ethnicity and various socio-cultural indicators. ADDIN EN.CITE (1, 43, 46, 47, 49, 242, 263) Hence, it is worthwhile to systematically search the qualitative studies conducted in the UK and within OECD countries exploring the various experience dimensions of patients accessing sexual health services and to assess the methodological quality of this evidence base as well as highlighting important themes associated with service delivery process.

The aim of this chapter (qualitative synthesis and meta-ethnography) is to explore patient experience dimensions to develop a better understanding of the various components of the service considered most important by them building on the information gathered by the systematic review (chapter 5). Therefore, the main study question for the review is ‘what are the important patient experience dimensions for people accessing sexual health services?’

6.2 Methodology

There are several approaches that can be applied for qualitative synthesis with no gold standard technique or agreed guidelines as it is relatively new research method.(264, 265) For this research, a meta-ethnographic approach was applied as adapted to health research. ADDIN EN.CITE (264-267) It is an interpretative approach based on translation of studies into each other.(264, 267) The process involves a comparative analysis of concepts and interrelationship between studies whilst acknowledging the original interpretations and context of studies.(264) As a result of the process, new theoretical perspectives are generated which is the primary aim of the approach. (264) This helps to understand the 'whole (organisation, culture etc.) based on selective studies of the parts'.(266)

The qualitative synthesis was conducted in 3 stages:

i) Systematic search and screening

ii) Critical appraisal

iii) Translating and synthesising studies using techniques of meta-ethnography(266)

6.2.1 Systematic research and screening

The research question for the systematic review divided into key components utilising the SPICE(S) framework (a generic model for question formulation). It was used to guide the literature searching(227):

Setting: sexual health centres, primary care, online or general community settings in an OECD listed country

Perspective: male and female patients views utilizing sexual health services or potential users

Intervention: sexual health services for STIs & contraception

Comparison: other health concerns, accessing other types of services associated with sexual health

Evaluation: attitudes, values, experiences, beliefs, emotions, views

Social science method: Qualitative

A two stage process was used to identify studies for inclusion.(268) Initially, papers were screened using the title and abstract to identify the potentially relevant papers. Papers were then sorted into five groups according to the relevance of reporting of patients' perceptions of sexual health or contraception services (Table 6.1). Papers which were labelled as describing views, attitudes, experiences, and opinions of patients accessing or potential users of sexual health services/ contraception services (category A) were analysed further. Those mainly concerned with reporting on opinions of clinicians and staff associated with sexual health services or contraceptive services, studies discussing people's views on specific STIs, screening, prevalence and associated behavioural issues, systematic reviews of studies reporting on satisfaction, attitudes, experiences and opinions for those accessing or potential users of sexual health services and contraception services and studies that did not have any relevance to sexual health services and associated patient views pertaining to services were excluded (Categories B, C, D & E). In the next stage of screening, full texts of potentially, relevant studies were read and were classified into 7 groups based on the

methods utilized while conducting the research and whether primary or secondary data was reported (table 6.1). We included studies with a variety of aims and examined the approach taken as part of our synthesis.

6.2.2 Search strategy

Search terms were created breaking the search question into fragments highlighting the key terms. Boolean operators were used to combine similar terminologies and linking the key terms by using 'OR' and 'AND'. Moreover, free text words, and subject headings/index terms were also combined. Furthermore, for a comprehensive literature search 'wildcards an asterisk and truncations were used with the specified terms. The search strategy with the detailed search term combinations used to retrieve relevant studies is included in Appendix 2. The electronic databases searched for this systematic literature review included:

- MEDLINE (R)
- Ovid MEDLINE (R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE (R)
- EMBASE
- CINAHL
- PsycINFO.

Relevant articles searched from the bibliographies of the retrieved research articles were also included. Google scholar was utilized to extract further web-based materials and for accessing full text articles. The searches were conducted between 23 March 2019 and 16 Oct 2019 and updated between 25 June 2021 and July 16 2021. The search was limited to the last 22 years (1999-2021). The search was limited to the last 22 years (1999-2021)

because service delivery processes have undergone considerable changes in recent times as previously discussed in Chapters 2 & 3 and the aim was to highlight patients' perspectives about various components of the services which are relevant at present.

6.2.3 Selection of studies

The titles and the abstracts extracted from the search strategy were exported into Endnote and all duplicates were removed both electronically and manually. The results of the search were individually screened in accordance with the Stage 1 criteria described below. MA screened all the records. Full text articles were retrieved for the shortlisted categorised as 'A'. The full text articles were then comprehensively reviewed in accordance with the stage 2 criteria and discussed by MA & LJ.

6.2.4 Critical appraisal

The potential studies for inclusion, when identified were appraised utilizing a modified version of CASP (Critical Appraisal Skill Programme) Checklist. (264) The approach described by Dixon-woods(269) was used which assesses the relevance and value of papers to the synthesis rather than excluding papers based on reporting quality. Hence, a double review was conducted using this method. The papers were evaluated independently and a paper was assessed as to whether it was a Key paper (KP),(KP, meaning a paper that was conceptually rich and valuable to the synthesis), a Satisfactory Paper (SAT) (SAT, when the paper was not very conceptually strong but still potentially relevant to the synthesis) and Unsure (unsure, when there was ambiguity of the relevance and value of the paper to the synthesis).(264) The critical appraisal process was not utilized to exclude papers before

synthesis but to assess the contributions of the papers at a later stage. (270)

6.2.5 Translating and synthesising studies using techniques of meta-ethnography

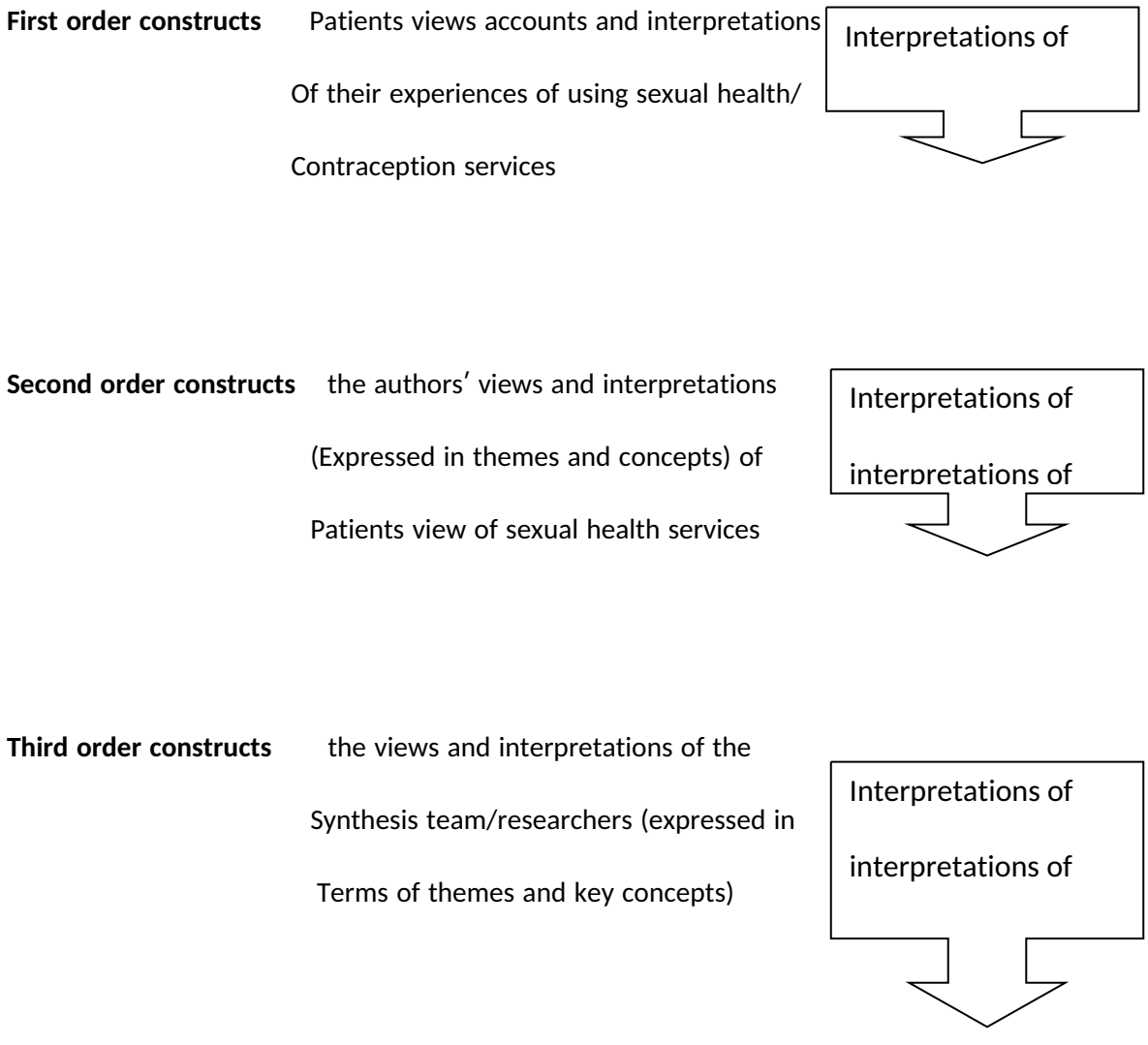
The working definitions of 1st, 2nd and 3rd order constructs ADDIN EN.CITE (264, 267, 271) are presented in figure 6.1. The first order constructs represent the direct quotations of patients pertaining to their views and interpretations of their experiences of using sexual health and contraceptive services. The second order construct refer to authors views in individual papers and the third order construct encompass the views and interpretations of the research team pertaining to themes and key concepts as shown in figure 6.1. The included papers were read and re-read in a chronological order and important details about the studies were recorded in data extraction tables.(264, 267) The second order constructs were extracted from individual papers illustrated with first order constructs in two separate columns. In the third column concepts were noted that came along while reading the papers which helped in development of third order constructs. ADDIN EN.CITE (264, 267, 270) The second and first order constructs were discussed among MA, LJ and JR for individual papers. This was followed by translating the second order constructs across the final papers included in the synthesis.(270) The word translation refers to the idea of each researcher using their own 'interpretive language' to compare the conceptual terms across studies which are interpretive readings but not further conceptual development.(270) The final stage of meta-ethnography was the synthesis of the translations.(270) This led to the development of third order concepts using 'line of argument' approach in which translations of studies are amalgamated to synthesize an overarching interpretation. ADDIN EN.CITE

(264, 265, 267) This process was led by MA and facilitated through discussion with LJ and JR.

Table 6.1 Categories used to identify studies for inclusion

Initial categorisation criteria	Further categorisation criteria
A. A research study that includes description of views, attitudes, experiences, and opinions for those accessing or potential users of sexual health services/ contraception services (aged 13 years or above). B. Research study that reports on opinions of clinicians and staff associated with sexual health services or contraceptive services but does not include description of users or potential users,' satisfaction, attitudes, experiences and opinions. C. A research study that discusses people's views on specific STIs, screening, prevalence and associated behavioural issues but does not include views and opinions about sexual health services. D. Systematic reviews of studies reporting on satisfaction, attitudes, experiences, and opinions for those accessing or potential users of sexual health services and contraception services. E. The study does not have any relevance to sexual health services and associated patient views pertaining to the service.	1. The study includes primary qualitative data on patient experiences pertaining to the sexual health services and contraception in clinic, primary care, and community settings or online/mHealth. 2. The research study that reports primary qualitative data on patient experiences pertaining to sexual health services and contraception but focus on a particular group. (Adolescents/MSM/LGBT/BME etc.) 3. The study includes only quantitative data pertaining to on patient experiences pertaining to the sexual health services and contraception in clinic, primary care, and community settings or online/mHealth. 4. Study mainly discusses knowledge of the patients about STIs/Contraception and general awareness about provision of sexual health services 5. Study reports data on the various Pre-exposure prophylaxis or sexual risk reduction interventions pertaining to a specific STI 6. Study reports secondary data or broadly discusses sexual health services & contraception in a particular setting but does not include primary data. 7. The study does not include relevant information on patient's experiences to any type of sexual health or contraception services.

Figure 6.1: Working definition of 1st, 2nd and 3rd order constructs (drawing on work of Noblit and Hare, 1988, Britten et al., 2002 and Jackson and Roberts 2015 ADDIN EN.CITE **(264, 267, 271))**



6.3 Results

The search process identified 529 papers. The removal of duplicates and the initial screening of titles and abstracts resulted in 101 papers being assessed for inclusion. A flow diagram (Fig. 6.2) illustrates the steps undertaken and the number of papers included and excluded at each stage. Further analysis and categorization of studies led to 44 papers being read in full to determine their suitability for inclusion. Out of these studies only 17 studies were included for critical assessment (qualitative synthesis and meta-ethnography). The studies were mainly capturing patients' experiences of accessing sexual health services on various aspects ranging from reporting their perspectives on quality indicators, potential gaps in service, to preferences for STI testing and receiving results.

6.3.1 Critical Appraisal

The included studies were judged to be of at least 'satisfactory' quality. However, several studies did not provide sufficient information to fully satisfy the requirements of the critical appraisal tool. The critical appraisal tool was utilized to highlight the potential limitations in papers and to extract information to enrich the synthesis.(269) No paper was excluded on the basis of quality.(264)

6.3.2 Synthesis findings

Seventeen studies were selected for synthesis. The main study characteristics of the included studies are shown in table 6.2. Regarding patients' experience dimensions

pertaining to various aspects of sexual health services, six over-arching concepts were developed (based on the synthesis of key concepts discussed in individual studies as depicted in table 6.3 and 6.4). The findings of the qualitative synthesis and meta-ethnography are summarized in table 6.5. The main concepts that were identified include; issues of confidentiality, quality indicators important for patients, perceived barriers to accessing care, preferences for STI testing, support mechanisms, and gaps in service.

i) Issues of confidentiality

The synthesis of studies highlighted that confidentiality was of paramount importance for patients accessing sexual health or contraception services. Studies highlighted how many patients felt self-conscious during visits and were afraid of being identified by their relatives, friends, or their community members. The comfort level of patients during a visit depended on their individual perceptions of confidentiality as well. Such perspectives were sometimes associated with the behaviour of the staff as reported in some studies. ADDIN EN.CITE (34, 167, 171, 174, 176) Some patients felt they were looked down upon and judged because of the stigma associated with STIs and reported that healthcare staff were not discrete enough to make them feel comfortable. One study specifically mentioned the discord between the patients and healthcare staff about maintaining confidentiality during visits.(251)

Most studies reported that maintaining confidentiality during visits was one of the main factors leading to patients′ overall satisfaction with their visit. The clinics which observed strict confidentiality reported high satisfaction which was reported by patients themselves: *'Having used the service before leaves me quite happy to feel everything's confidential and the system they have in place is good, so it make me feel safe to use the service' (Howarth et al., 2017.P.4).* ADDIN EN.CITE *(223)*

ii) Quality indicators reported by patients

There were a few quality indicators which were mentioned by patients in the studies which they felt were associated with the quality-of-service delivery.

The initial contact with the staff prior to consultation was particularly mentioned by patients in most of the studies. The attitude of the reception staff affected how the patients felt about their attendance at the clinic (whether they felt welcomed or judged). It was emphasized by patients that overall body gestures & the tone of the speech of healthcare staff and how they were referred to by the staff influenced how they felt about the service. Other quality indicators identified by patients included; waiting times, referral methods for their consultation, the information provided during visits, the environment of the clinics and the accessibility of the service.

Patients considered clinics to be efficient if they had to wait for a lesser time for appointments, there was a clear referral procedure, sufficient information was provided about their health and treatment during their visit, the clinic had a friendly environment and the clinic was accessible and within reach. However, waiting times and the accessibility of the clinic were more commonly mentioned by patients in studies than other quality indicators: '*They just said I could go either to see my GP or I could come to family planning or I could go to walk-in but that would mean I would have to sit and wait for hours and hours to be seen I could go to X [GUM clinic] but again I have been there before onetime and I was sitting there for 5 hours so I just thought, no I'm not doing it' (Evans & Cross; 2007.P.260).* *(247)*

iii) Perceived barriers to accessing care

Among the perceived barriers to accessing care, the stigma associated with STIs, and HIV and the associated clinics were reported by most patients in the studies. Patients felt strong anxiety with feelings of shame and guilt when visiting sexual health services. They felt that they would be judged while discussing their health-related issues and had difficulty in openly discussing STIs during consultations due to the strong stigma associated with such infections: *'In a certain clinic…. They did some tests and from that, someone opened their mouth and told everyone that certain friends were living with HIV and certain friends had sexually transmitted infections. So because of this, there are many people who don't get tested or go for a check-up' (Boyce et al; 2012.P.320).(43)*

Additionally, two studies ADDIN EN.CITE (43, 151) from a US setting reported of patients having no health insurance coverage which prevented them from accessing sexual health services.

iv) Preferences for STI testing

The key aspects pertaining to preferences for STI testing as highlighted in the studies was the demand for an efficient testing service and timely confirmation of results whether negative or positive. The patients themselves emphasized the need for receiving results quickly: ′I can′t handle anything but a rapid test. *Waiting a week is like putting me in a coma' (Koester et al; 2013.P.7)*.(151) A study which explored patients′ views about self-booking and testing reported that patients were happy with this model of care and preferred being in charge of the process : *'You come in; you face a computer; you do everything yourself, so everything's personal. Everything is between you and yourself' (Baraitser et al; 2011.P.25)*.(173) In another study patients preferred the option of point of care tests compared to conventional practice due to shorter waiting times to receive the

result: *'So I'd rather just sit an hour and a half one day and not have to waste the time travelling to the clinic…if I can just travel one time and can be seen in one to two hours rather than over two days [that] is, I think, better' (Fuller et al;2019.P.6)(9)*

v) Support mechanisms

The two main aspects of support mechanism highlighted in studies to strengthen satisfaction and engagement with the service was (i) the ongoing support and supervision of sexual healthcare staff and capacity building of patients to take control of their treatment and (ii) health-related decisions. The patients themselves emphasized the need for ongoing support from sexual health staff particularly in practicing contraception: *'But she still messaged me as well after she'd put it in, she were still texting me to like you know remind me and that which were really good because I've got a very bad memory' (Hayter et al; 2016.P.292).* ADDIN EN.CITE *(172)*

vi) Gaps in service

Several studies reported that patients felt that there was a need for improvement in the healthcare provider interaction during consultation. The patients felt more assured when they were listened to with consideration and given proper time. The sense of connection with the healthcare provider, particularly the communication process during the consultation, increased their trust and satisfaction with the service: *'I've had like situations where… well, like the doctor that I see regularly, he always is like if there's something wrong like I'll call you. And I guess I have a relationship with him, that way so I don't mind waiting in that way '(Cassidy et al., 2018.P.6*). ADDIN EN.CITE (167) Studies exploring Gay and MSM patients' experiences of interactions with the healthcare provider reported that they felt discriminated and not properly respected. It was highlighted by these patients that there

should be an increased sense of awareness among sexual healthcare professionals about issues pertaining to sexual orientation: *'It's not different and it doesn't have to be embarrassing, if you [clinician] want to know something, ask…. It would be nice to be asked and not assumed' (Munson & Cook., 2016.P.3503).*(152) In some studies patients also suggested greater input of patients through regular feedback to improve the quality of service and felt it wasn't the case at present.

Figure 6.2: Flow diagram of studies included and exclude at each stage of the review

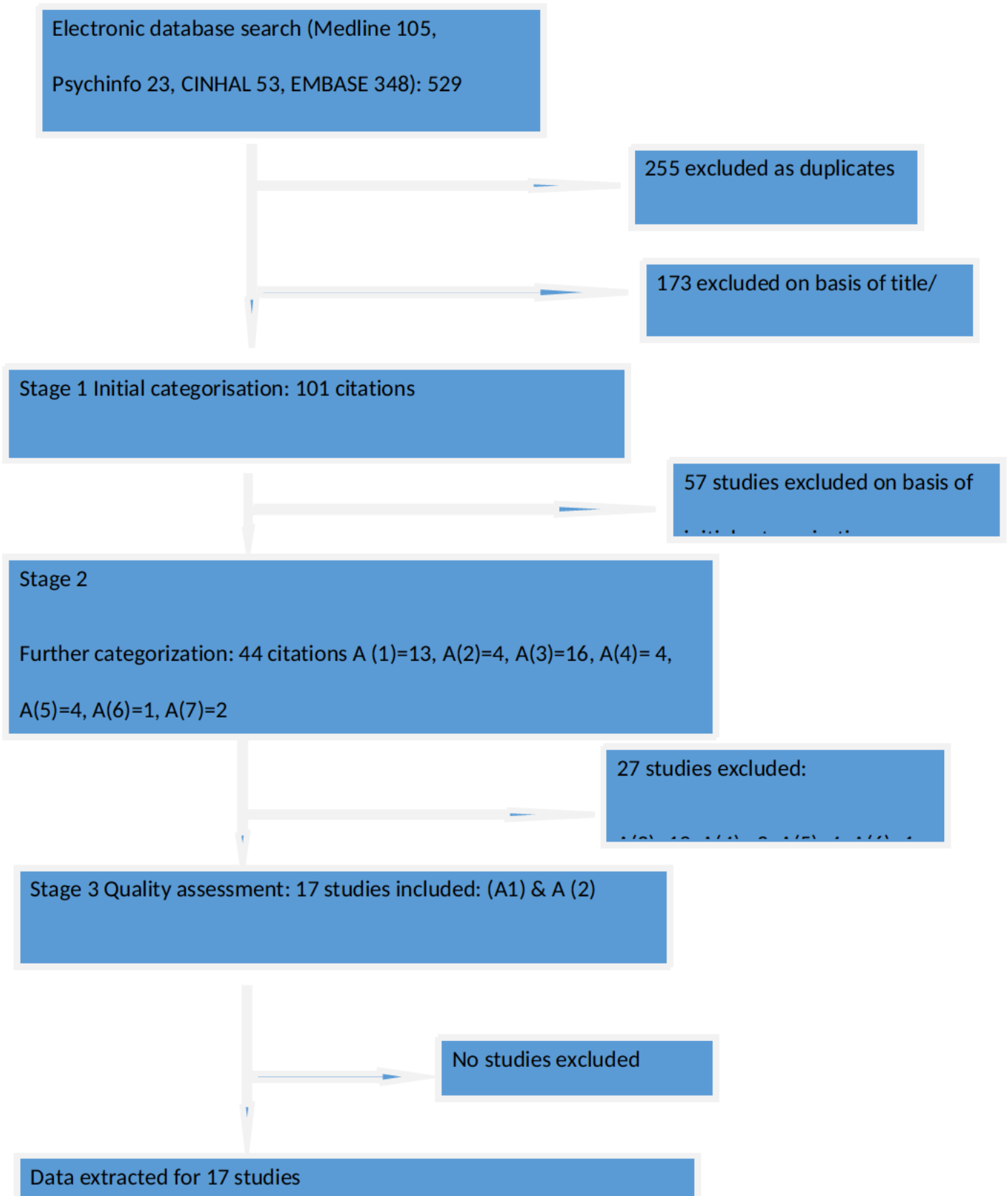


Table 6.2: Study characteristics of the papers included in qualitative synthesis

No	Lead author	Year	Country; setting	Participant details (age, gender, ethnicity & sexual orientation)	Sample size & sampling technique	Methods; analysis	Aim of the study	Main study findings
1	Fuller	2019	UK; Sexual health clinics	16-44 years of age; male and female; majority white; Heterosexual, & MSM	9; Purposive sampling	Content analysis approach	Explore patients' opinions and expectations for implementing point of care tests (POCTs) for STIs	Patients may accept PCOTs if they are given information to these changes prior to attending service.
2	Cassidy	2018	Canada; University SHS	18-25 years of age; male & female; not provided; heterosexual and LGBTQ	56; stratified purpose sampling with snowball sampling techniques	Focus group discussions; content analysis	To identify the perceived barriers and enablers to SHS use among university undergraduate students	Key linkages between students' social opportunity and motivation were found influencing access to SHS
3	Howarth	2017	UK; Sexual health clinic	29 years or less to 30 years or more, male & female, white, South Asian, Black, Chinese, and mixed ethnicity; heterosexual, gay & bisexual	17; purposive sampling	In-depth interviews; framework analysis	To explore patient preferences to care and understanding of survey questions	All Interviewees were positive about their experience.
4	Hayter	2016	England: nurse-led home-based contraception service	17-21 female; not provided; not provided	40; purposive sampling technique.	Semi-structured interviews; framework analysis	To explore experience of teenage mothers using nurse-led home-based contraceptive service	Aspects identified contributing to effectiveness of service were privacy, convenience, flexibility, easy access, staff attitudes and ongoing support.

5	Munson	2016	New Zealand; community settings	23-47 years of age; female; not provided; lesbian or bisexual	7; snowball sampling	Semi-structured interviews; General inductive approach	To develop insight into the experiences of lesbian and bisexual women accessing sexual health services	The patients highlighted the difficulties that lesbian and bisexual women face while seeking sexual healthcare.
6	Koester	2013	USA; sexual health centre	20-67 years of age, male & female to male transgender, not provided, gay and bisexual	32; purposive non-probability sampling	In-depth interviews' framework analysis	To explore sexual healthcare preferences among gay and bisexual men	The study identified a continuum of sexual healthcare seeking practices and their associated drivers.
7	Boyce	2012	USA; Public health clinics, NGOs & Public spaces	18-59 years of age, male and male to female transgender; not provided	29; purposive sampling	Semi-structured interviews; thematic analysis	To identify barriers to accessing SHS among gay, bisexual and heterosexual identifying men	The most prominent barriers to SHS included fear of discrimination, fear of having HIV, cost, and lack of social support.
8	Baraitser	2011	UK; sexual health clinic	18- 40 years, Male and female; not provided; not provided	24; purposive sampling	In-depth interviews; thematic analysis	To describe client experience of self-management within a busy walk-in SHS	Self-management is a acceptable option within SHS among patients if informal support is available.
9	Sutcliffe	2011	UK; GP practices and GUM clinics	16-43 years of age; 20 male and 29 females; not provided	49; purposive sampling	Semi-structured interviews; framework approach	To explore the expectations and experiences of patients availing SHS to improve service delivery.	Absence of formal referral, lack of information and perceived avoidance of sexual health matters by practitioners were commonly cited as reasons of

								disappointment by patients.
10	Challenor	2010	UK; GUM clinics	Not provided; male and female; not provided; not provided	20; consecutive random sampling	Interviews; not mentioned	To explore patient views regarding service quality measures	Patients were overall satisfied with the service.
11	Shoveller	2009	Canada; STI services	15-25 years of age; 33 male & 37 females; Aboriginal, Black, Chinese, South Asian, South-East Asian, Latin American, White; heterosexual & sexual minority (lesbian, gay, bisexual, transgender)	70; purposive sampling technique	Semi-structured interviews; thematic analysis	To analyse the experiences of youth accessing STI services	Structural and socio-cultural factors were identified by clients
12	Evans	2007	UK; Community STI service	Aged <25->40 years of age; male & female; black, white, mixed race, unknown ethnicity; not provided.	16; purposive non-probability sampling	Semi-structured interviews; framework analysis	To explore the experiences of clients utilising community STI service for testing and treatment.	The environment of STI clinic and easy accessibility were important themes identified.
13	Arkell	2006	UK; STI clinic	Mean age 32 years of age, male and female, White, Black African, Black British, Asian America; not provided.	20; purposive sampling	Unstructured interviews; thematic framework approach	To explore factors pertaining to anxiety among patients attending STI clinic.	The origins of anxiety in STI patients are multifactorial and difficult to identify in brief appointments.
14	Lichtenstein	2005	USA; STD clinic	Median age 41, Male & female; black, white, biracial; not provided.	15; convenience sampling	Focus group discussions; constant comparison process	To evaluate and develop tools for assessment of client satisfaction at STI clinics	The clients most concerned about privacy and confidentiality
15	Ziebland	2005	Scotland		22; not provided			

			UK; patient home and postal survey	Not provided; female; not provided; not provided		Semi-structured interviews; not mentioned	To describe women's use of emergency contraception packs and views of advance supplies.	EC has an anomalous role in contraception
16	McAllister	2002	UK; Sexual health clinic	14-39 years of age, female, not provided, not provided	66; convenience sampling	Interviews; not mentioned	To determine the acceptability and accessibility of a SHS for young clients in a pharmacy.	Patients reported high satisfaction with service and location.
17	Griffiths	2008	UK; GUM clinic & Community contraception service	16-21 years of age, Male & Female, White British, African Black, South Asian, Black Caribbean; Heterosexual and MSM	122; purposive non - probability sampling	Semi structured interviews and Focus groups; framework thematic analysis	To assess acceptability of different of different one shop models of sexual health provision among patients	Respondents expressed preference for one provider/one session to provide GUM & contraception care.

Table 6.3: Grid of Key concepts in studies included in qualitative synthesis n=17 (studies numbered from 1-17)

Key concepts	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
STI testing	✓		✓			✓		✓	✓	✓							
Receiving results	✓	✓				✓		✓	✓	✓							
Healthcare provider interaction		✓		✓	✓		✓		✓		✓	✓		✓	✓		
Confidentiality		✓	✓					✓		✓	✓	✓	✓		✓	✓	✓
Waiting times	✓	✓	✓			✓		✓		✓						✓	
Anxiety & fear among patients while visiting STI clinic		✓	✓		✓		✓				✓			✓			
Lack of understanding of health concerns of sexual minorities (LGBT)				✓		✓	✓				✓	✓					
Stigma			✓	✓	✓		✓				✓			✓	✓		
Accessibility					✓			✓	✓		✓		✓	✓		✓	
Ongoing support																	
Fear of monitored by insurance companies						✓											
Discrimination of patients based on sexual orientation				✓			✓				✓	✓					
Self-management								✓									
Communication with healthcare provider					✓				✓						✓		
Significance of clinical environment					✓						✓			✓			
Staff attitude and behaviour							✓		✓			✓		✓	✓		
Access to emergency contraception																✓	

Cultural barriers																	✓
Information provided					✓				✓			✓				✓	

Table 6.4: Description of Key concepts of individual studies including 2nd Order constructs

No	Lead author /year	Main themes of individual papers	Summary description of key findings of individual papers	Interpretation of key concepts
1	Fuller (2019)	'Acceptability of point of care tests by patients', 'turnaround time and willingness to wait for results'	Patients may accept new point of care pathways if they are given information prior to attending services and was more preferred by those experiencing symptoms and are anxious about their infection status.	Efficient STI testing preferred by patients Receiving quicker results more desirable by patients
2	Cassidy (2018)	Capability, visibility of sexual health services, opportunity, health care provider interaction, peer influence, campus culture, accessibility of services, motivation, normalizing sexual health matters, stigma, privacy, and confidentiality	The psychological capability, clarity of information provided, accessibility and visibility of service, healthcare provider interaction and issues of stigma, privacy and confidentiality were identified as key factors influencing accessing SHS	Psychological capability of patients influences seeking care Healthcare provider interaction influences patient compliance to seeking care Waiting times matter to patients Maintaining confidentiality during visits is of key importance to patients
3	Howarth (2017)	Making patients feel comfortable, waiting times & confidentiality issues	Patients expressed fear of being judged by visiting SHC, extended waiting times caused distress among patients, patients reported preference of receiving results by text, maintaining confidentiality in clinic led to higher satisfaction among patients	Patients feel anxious of visiting clinics due to fear of being judged Prolonged waiting times causes distress among patients Increased confidentiality in clinics leads to higher patient satisfaction
4	Munsun (2016)	Heteronormativity, the conundrum of safer sex, implied and overt homophobia, engagement with health promotion and resilience	Lesbian and bisexual female patients felt excluded due to heteronormativity in clinics and lack of understanding among healthcare staff of their sexuality, prejudices misconceptions and homophobia reported by patients among healthcare providers	Lack of understanding and prejudices against homosexual patients among healthcare providers

5	Hayter (2015)	Privacy, convenience, flexibility, ease and speed, facilitative attitudes, ongoing support, taking control, developing understanding beyond contraception, preventing repeat pregnancy	Among the aspects of home-based contraception and sexual health care for teenage mothers which contributed to its effectiveness were according to patients were privacy, convenience, flexibility, easy access, non-judgemental behaviour of staff and ongoing support	Fear of patients being judged in clinic and open settings Patients prefer easy accessibility to service Patients expect adequate information provided by healthcare provider Patients desire ongoing support, contact, and advise with healthcare provider
6	Koester (2013)	Fear of being monitored by insurance companies, employers or the government, desire for specialization in sexual health services, desire for rapid and/ or highly sensitive and or comprehensive screening technologies, desire for services to be convenient, lack of healthcare insurance coverage	Gay and bisexual patients had mixed views of seeking sexual health services within primary care settings or seeking a specialized sexual health service. The factors for desiring fragmented service included efficient screening and testing service and lack of health insurance coverage in a US setting.	Demand for efficient screening and STI testing service Fear of being monitored by insurance companies therefore seeking fragmented care
7	Boyce (2011)	Participants experiences to SHS, barriers to SHS (fear of discrimination related to sexual identity and behaviour, STI/HIV stigma and discrimination, lack of social support, cost)	Transgender and gay/bisexual identifying participants preferred clinics where they felt a sense of belonging. The most prominent barriers to sexual health services included fear of discrimination, fear of having HIV, cost, and lack of social support.	Perceived barrier of stigma and discrimination for MSM and transgender patients for accessing care Lack of understanding and empathy of healthcare providers
8	Baraitser (2011)	Advantages of self-management, issues of confidentiality	Self-management is an acceptable option by patients within sexual health services if informal support is available.	self-management ensure confidentiality self-management and booking increases efficiency
9	Sutcliffe (2010)	Accessing general practice, patient expectations and experiences, expectations, and preferences for future STI-related care	Patients approaching their GP practice typically expected written referral. Absence of formal referral, lack of information and perceived avoidance of sexual health matters by practitioners	Accessibility issues in accessing SHS Weak communication between healthcare provider and patients Lack of information provided to patients Demand for HIV/STI testing within service

			were commonly cited reasons for disappointment.	Expectation to receive quicker results
10	Challenor (10)	Friendly and non-judgemental staff, good communication, the paramount importance of confidentiality, keeping self-referral of patients, easy availability of appointments, confirmation of results, regularly taking patient feedback	Patients highlighted the significance of maintaining confidentiality. They suggested easy availability of appointments, receiving quicker results of STI testing and regularly taking patient feedback to improve service.	demand for confirmation of results increased confidentiality during visit and consultation ensures higher patient satisfaction
11	Shoveller (2009)	Social and physical features of community (issues of privacy and confidentiality), fear of breach of confidentiality by family doctor, clinics described as 'Feminised' spaces, lack of knowledge relating to STI testing	Patients identified geographical location of clinic, confidentiality issues, clinic décor and difficulty of disclosing sexual behaviour to clinicians by LGBT patients particularly in contexts that are perceived to be homophobic.	Accessibility issues of receiving care Fear of stigma associated with STI while accessing care Issues of confidentiality while accessing care Lack of understanding of sexual health concerns of LGBT patients Gender biased clinical environment
12	Griffiths (2008)	Young men's perception of one-stop shops (convenience is the most important factor, Preference for young person's one-stop shop, anonymity of mainstream one-stop shops, general practice one-stop shop should be provided by nurse) MSM's perceptions of one-stop shop (reason for one-stop shop visit obvious for men, family planning a 'happy time' versus STI- testing an 'anxious time', GP reluctance to do sexual health, GUM staff acceptance of MSM issues) Black African and South Asian men and women's perceptions of one-stop shops (Mainstream shops could improve	Patients expressed preference for one provider/ one session to provide GUM and contraception service.	Confidentiality is of prime importance to patients Lack of understanding and acceptance of MSM issues by GUM staff Cultural barriers to accessing care among certain ethnic background patients particularly south Asian patients

		awareness of service, Mainstream shop more relevant/appropriate for women, perceptions of confidentiality of general practice, convenience of general practice for sexual health, cultural barriers to sexual health/one-stop shops		
13	Evans (2007)	Easier access at community centre, environment of sexual health clinics is important to patients, high patient satisfaction with service	The environment in sexual health clinics is important in determining the degree of stigma experience by patients. Easy access to a STI service is an important factor in determining client's choice of services.	Accessibility of the service Maintaining privacy during consultation Getting familiar with the service with consecutive visits Environment of the clinic considered important for patients
14	Arkell (2006)	Factors related to possible STIs and to clinic function (anxieties about HIV, fertility, waiting times, staff attitudes, waiting areas, clinic location, painful examinations, awkward questions) Factors unrelated to clinic (social, occupational, and financial issues or previous emotional difficulties) Issue of stigma, embarrassment, and shame about STIs	Stigma and embarrassment were highlighted by patients during visits. Anxieties related with STI testing and staff attitudes and clinic location were reported as factors associated with anxiety while attending a STI clinic.	Importance of clinic location Staff attitudes and behaviour Stigma and embarrassment associated with STI
15	Lichtenstein (2005)	Friendliness and respect, privacy, and confidentiality	Clients were concerned with visibility, being stigmatised, or disrespected and about breach of confidentiality	Staff attitudes and behaviours (judgemental which make patients uncomfortable) Fear of breach of privacy by staff (staff being too loud) Distrust among patients of maintaining confidentiality by staff Rude and inconsiderate behaviour of staff
16	Ziebland (2004)	Effects of easy accessibility to EC, increased confidentiality, concerns for younger	Patients were generally satisfied with receiving advance supplies of emergency	Easier accessibility to emergency contraception ensured increased confidentiality as perceived by

		women	contraception	women receiving supplies
17	McAllister (2002)	Overall satisfaction with service & suggestion for increased service timing	The patients were overall satisfied with the service particularly due to the anonymity maintained at the service.	Maintaining anonymity of patients at service leads to greater satisfaction among them.

Table 6.5: Qualitative synthesis: themes, subthemes and inclusion in papers

Third order concepts	Sub theme (second order constructs)	First order constructs (Direct quotations)	Studies that included second order constructs (study number)
Issues of confidentiality	Fear of breach of confidentiality	In a clinic I feel intimidated because there's a lot of people sitting there and 'oh, I wonder what they think I'm sat here for? I don't want them to judge you or anything like that··· (Hayter et al., 2015. P.290) I don't like seeing other students, especially if I am there for sexual health reasons. And I've had bad experiences where they would say out loud that like I'm there for a pap test. So like people in the waiting room could hear that. And it just made me uncomfortable. (Cassidy et al., 2018.P.9 I was forced to communicate with the client support worker about the reasons that I was there and how to use the swab very close to the waiting area, which they were not being discrete about and was talking quite loud. (Baraitser et al., 2011.P.26) The clinic was the most nerve-wrecking part-I knew people in room. It's like some peoples' voices carry. And the receptionist could talk a little quieter about why I'm there (Shoveller et al; 2009.P.400)	2, 3, 5, 8, 9, 11
	Significance of maintaining confidentiality	Having used the service before leaves me quite happy to feel everything's confidential and the system they have in place is good, so it make me feel safe to use the service (Howarth et al., 2017.P.4	1, 2, 3, 9,13,15 10,12,13,15

	Demand for increased confidentiality during visits Perceptions of confidentiality	The privacy at the reception desk I think there could be a bit more privacy to be honest, like giving your details there and then sometimes you need a bit more privacy… you don′t want anyone else to know (Evans & Cross., 2007.P.261 I don′t know how they do their work because they work in packs. If one of them sees something interesting everybody is coming to look. If you come in with a female they think you are bisexual (Lichtenstein et al., 2005. P.283) You know they are smirking, when they look at you like that. I′m embarrassed, and they′re smirking. (Lichtenstein et al.,2005. P.283) I didn′t want to go (for testing) in my area because I didn′t want people to know me, because I′m scared of people who are going to be going to be like, ′oh what are you doing? (Shoveller et al., 2009.P.398)	1, 8, 9, 11, 12, 15
Quality Indicators important for patients	Staff behaviour & communication	They have got an attitude. Like when they come to the door and call your name. They stand there and roll their eyes. I have a couple of them do that to me (Lichtenstein & Laura., 2005.P.283) They just don′t look at you, they just look at the computer… she should tell me because she is my GP and I don′t know about these diseases, she knows (Sutcliffe et al., 2011.P.133) Very good professional, open minded and non-judgmental and easy to talk to staff (McAllister et al., 2002.P.205)	2, 3, 7,8, 9, 11, 12, 14, 15, 17

		I prefer coming here [FPC]···. because the people are friendly. They are friendly here and don't look intimidating (Evans & Cross., 2007.P.261)	
	Waiting times	It's been a very quick service considering it's a walk-in centre, And I have not felt rushed (Howarth et al., 2017.P.5)	3, 6, 7, 8, 9, 16
	Referrals	She just give me the number for ···. (GUM clinic) and said you have to go to a special clinic (Sutcliffe et al., 2011.P.133)	2, 9, 10, 11, 12
	Providing information	I thought they'd give me more advice or- I don't know I went there and they just, she was so well you need to go to the GUM clinic we can't do it here, which I thought was like-because my friend had been to the same doctor as me and she had it done there (Sutcliffe et al., 2011.P.133)	6, 7, 9
	Environment of sexual health clinics	It's very relaxed, very casual; you know they have signs up saying, 'it's a phone=positive zone.' And they have magazines and lots of information pamphlets and the receptionist is young and so she looks very approachable (Shoveller et al.,2009. P.400)	2, 6, 7, 9, 10
	Easy access to care	This one [family clinic (FPC)] is better [than GUM] 'cos you can just walk in any time you want and it closes late as well (Evans & Cross., 2007.P.260)	1, 6, 3, 8, 10, 11, 13

Perceived barriers to accessing care	Stigma associated with STIs & HIV	You feel as if you have done something wrong and you will be judged (Arkell et al., 2006.P.302) Because there is awful lot of personal anxiety around sexual health. Clearly there are barriers to conversation and communication (Cassidy et al., 2018.P.9)	1, 2, 3, 4, 5, 9, 11, 12, 13
	Clinic location	I found the way this clinic is situated encourages stigma somehow. It's like dark alley ways to enter here you know? (Arkell et al., 2006.P.301	1, 5, 8, 9, 11, 13, 14
	Lack of social support	Yes, because I know many people who have had···sexual relations without condom. They feel they are incapable, or because of the fear that they have AIDS or some bad illness, but they feel incapable of getting checked (Boyce et al., 2011.P.321)	4,5
	Lack of healthcare insurance coverage	I didn't have insurance at the time and I also felt more comfortable going to a place that was specifically centred around sexual health, as opposed to seeing a primary care physician ((Koester et al.,2013. P.8)	4, 6
Preferences for STI testing	Self-booking	You come in; you face a computer; you do everything yourself; so everything's personal. (Baraitser et al., 2011.P.25)	8
	Self-management	It was more comfortable doing the test by myself than having to see a professional to do it··· means	6, 8

		you don't have to go through all the rigmarole (Baraitser et al., 2011.P.27)	
	Confirmation of results	I like the confirmation of results, whether positive or negative-really important to get closure. Two weeks seems like an OK time limit (Challenor et al., 2010.P.330)	4,8, 10
	Desire for more efficient screening technologies	I can't handle anything but a rapid test. Waiting a week is like, put me in coma (Koester et al.,2013. P.7) No, that's long, my friend. That's very very long. Yes, if it is possible to get it within an average of 15 minutes, now we're fine (Fuller et al., 2019.P.8)	1,4,6,5, 17
Support mechanisms	Ongoing support	You've got someone to turn to when you need to know something and they are always there for you to contact as well which is good (Hayter et al.,2015. P.292) It were just, I were knackered, never got round to it so it were nice for someone to just be there (Hayter et al., 2015. P.293)	3, 5, 13,14
	Taking control	It's hard. I didn't realise how hard it'd be having him, and then after having him, I realised that I need to start taking control (Hayter et al., 2015 P.292)	3,5
Gaps in service	Healthcare provider interaction during consultation	I had a bad experience with one particular doctor, and if I didn't know which days they would be working, and if I needed to go that day, and there were the only one working, then I wouldn't want to go there. (Cassidy et al.,2018.P.6)	1, 2, 5, 6, 15

	Discrimination towards patients with different sexual orientations	I've had like situations where··· well, like the doctor that I see regularly, he always is like if there's something wrong like I'll call you. And I guess I have a relationship with him, that way so I don't mind waiting in that way… (Cassidy et al.,2018. P.6) The poor attention they can give to a person, because you know, not everyone sees us as human beings, but rather we are sometimes we are viewed with disgust··· (Boyce et al., 2012. P.318) The doctor asked him [friend] if he was gay and he said no, so he told me that the doctor asked again, 'Why do you say you're not gay if it is obvious that you are?' So he told me that he told the doctor that he had no reason to tell him if he was gay or not. (Boyce et al.,2012. P.318) What is most embarrassing to them is if [the doctors] examine your penis or anus and say 'Ay! How uncomfortable it would be if they were to stick something in there or examine you! (Boyce et al., 2011.P.319) [He] discussed everything related to heterosexual sex, all the things, not even considering that it might not be a factor (Munson & Cook.,2016. P.3502)	4,7
	Incorporating patient feedback	Is it not possible to treat 100%, at the first visit, and you can't go for 100%, but 70% seems quite low. (Challenor et al.,2010. P.330) In an ideal world the general practitioner would be an expert in everything which I think you know isn't	9, 10, 14

		possible, but that would be my ideal, for me personally, although the awkwardness is still there it kind of takes away the stigma, which is probably really old fashioned, but yeah it's just that thing you know it's embarrassing to you know…(Sutcliffe et al.,2010.P.133)	
	Increase service timings	Good to keep the Thursday and Sunday opening times but it would be good to have one on Saturday (McAllister et al., 2002.P.205). It's the only one open on a Sunday and I think a lot of people would be frantic if this wasn't open (McAllister et al., 2002.P.205).	17

6.4 Discussion

6.4.1 Principal findings

The study highlighted key concepts which have been highlighted in the qualitative literature in relation to patient views and experiences of sexual health and contraceptive services. The analysis resulted in the development of six overarching concepts namely issues of confidentiality, quality indicators important for patients, perceived barriers to accessing care, preferences for STI testing, support mechanisms and gaps in service. There was some overlap between these concepts, for example, the synthesis showed that issues of confidentiality were closely associated with staff behaviour and healthcare provider interactions with patients. This association was dependent on developing a relationship of trust and respect between patients and healthcare providers from on the initial point of contact.

The results of the synthesis demonstrate that there are individual (patient oriented) and societal factors which act as barriers to accessing care and can affect patient satisfaction. Societal factors mainly included stigma, anxiety and the embarrassment associated with contracting STIs. Individual factors were mainly associated with waiting times, STI testing options, staff attitudes, specific needs of different patient groups, communication skills of healthcare staff and the overall service delivery mechanisms which can affect patient experiences of the service.

One of the important gaps identified by the study was the lack of understanding and recognition of needs of specific patient groups (for example based on sexual orientation)

among healthcare providers of sexual health services.

6.4.2 Comparison with other literature

The review highlighted several factors which patients associated with their overall satisfaction while using the sexual health services. These mainly included feeling that their confidentiality was maintained throughout the consultation process, shorter waiting times and the quality of the interactions with healthcare staff. These findings are supported by a systematic review which was conducted to explore factors associated with patient satisfaction during visits to STI clinics.(272) The review(272) included both quantitative and qualitative evidence to report the indicators associated with overall patient satisfaction. However, that review(272) had some limitations as studies were only included which were conducted in STI clinic settings and also reported findings of quantitative surveys (including studies other than OECD countries) rather than focusing on exploring patients′ experiences in depth.

Moreover, another review ADDIN EN.CITE (273) explored school based sexual health services for young people in the UK, and synthesized evidence from quantitative and qualitative studies. Similarly, its findings indicated patients concerns about confidentiality and the stigma associated with STIs. This review ADDIN EN.CITE (273) was limited to sampling a specific age group and study settings and analysis. Additionally, the review encompassed a wide range of factors associated with sexual health, with a focus on various components of the service, the role of sexual healthcare staff and the service delivery mechanisms or processes.

The current synthesis is the first study which adopts a meta-ethnographic approach to explore patients' experiences of accessing different types of sexual health services within OECD settings to highlight the key aspects that are important to patients when accessing services, solely from the patient perspective.

6.4.3 Methodological considerations

The findings of this study underline the potential advantages of meta-ethnography as a method to inform the identification of components of sexual health services that matter the most to patients, as well as highlighting potential barriers to engaging with the service.(264) The main strength of the approach and the review presented here is that it comprehensively examines patients' perceptions pertaining to the various factors associated with service with consideration of various models of care and diverse patient characteristics. The study had a broad and systematic search and inclusion strategies. The meta-ethnographic approach provided a useful method for synthesising qualitative evidence leading to the development of overarching concepts encompassing various aspects of patient experiences of the service. The results of the study further substantiate that meta-ethnography can be utilized as a technique to bring together findings from various studies to develop a comprehensive understanding of the various issues associated with service delivery of sexual health services from a patient's point of view. In this study mete-ethnography was utilized to synthesize qualitative research in a reductive manner with the aim to develop overarching concepts pertaining to all the aspects of the service delivery process which are considered important by patients accessing the service.(264)

6.4.4 Theoretical implications

An issue with qualitative synthesis which has been stated in literature is the challenge of amalgamating data grounded in different theoretical or methodological perspectives.(270) An argument which is forwarded by writers holding a relativist perspective is that synthesising qualitative studies with different 'epistemological underpinnings' is not pragmatic or a feasible approach as each individual study reports a unique view which is determined by the variations in theory or method that influences the study.(270, 274)

Only one study(152) explicitly stated the theoretical perspective while in others the information was not provided. For example, studies which did include sexual minorities may have ideally adopted 'Queer theory' which 'allows the social positions and perspectives of sexual minorities to be 'read' from a standpoint that enables them to be viewed inclusively'.(152)

6.4.5 Strengths and limitations

The systematic identification of papers applying a two stage criteria and critical appraisal and discussion of individual papers among three different reviewers arguably enhanced the robustness of the synthesis. Each paper was read and re read for second order constructs by MA. The second and third order constructs were discussed in detail among MA, LJ and JS and revised several times as a part of iterative process. No study was removed based on quality in the critical appraisal process, but the process enabled to test the contributions of the studies to the synthesis based their quality.

The limitations mainly included the heterogeneity in patient characteristics, study settings and the variance in the models of care involved. Only published papers were included and relevant work reported in book chapters, or 'grey literature' was not included. It is also acknowledged that the process of synthesising translations is basically an interpretative process therefore a different research team may have formulated a different conceptual framework. The epistemological view of the researchers MA & LJ may have also influenced formulation of 3rd order constructs.

6.4.6 Policy implications and recommendations for future research

The results of the synthesis have some broader policy implications. The findings emphasize that it is important for healthcare providers to acknowledge that the needs of patients vary according to their age groups, ethnicities, and sexual orientation. There is a need to devise measures and strategies that makes patients feel safe, non-judged, welcomed, and understood while accessing services in different settings. It can be helpful to incorporate patient feedback while designing services with due consideration of patients with different characteristics (e.g., ethnicity, sexual orientation, age groups etc.). Recognizing patients or potential clients as an important stakeholder in the evaluation of services or its design and re-design can lead to higher satisfaction levels among patients, increase overall efficiency and engagement with services as well as ensuring they are patient centred. There is need for further exploration of the views and opinions of patients or potential clients. This can be achieved by designing a primary study (qualitative investigation) to explore the various factors and aspects of sexual health services that are considered most important by patients

or potential clients while accessing sexual health services. This study can help to determine which themes are most essential from a current or potential users' perspective which can help determine outcomes which can be potentially incorporated in a preference-based measure which can also be possibly utilized in an economic evaluation in this area.

6.5 Conclusion

The qualitative synthesis and meta-ethnography, to some extent conceptualized patient experience dimensions pertaining to sexual health services. The study suggests that there are potential gaps that exist in the level of understanding of patient needs by healthcare staff which need to be addressed.

The issues of confidentiality among patients are complex and vary according to settings and their sexual orientation which suggest social constructs and other factors which need to be explored further by adopting a relevant theoretical framework for conducting high quality qualitative research in this area. Moreover, there is need for further exploration through empirical work to understand the various indicators relating to service delivery highlighted by patients in the review. Additionally, there is a lack of specific designed framework to capture patient experiences pertaining to sexual health services. This finding suggests the need to develop a framework to specifically capture patient experiences with sexual health disease or those seeking sexual health care. There is a need to further strengthen the existing evidence base by conducting primary research (qualitative study). The primary research should be conducted with well-defined theoretical frameworks to holistically capture what truly matters to patients with in-depth exploration of all the key components of the service from their perspective.

6.6 Chapter Summary

This chapter has highlighted important patient experience dimensions pertaining to sexual health services and highlighted some key areas which need further in-depth exploration by conducting primary research. The next chapter will present the findings of the qualitative study which was conducted to further explore these key aspects.

CHAPTER 7: Capturing outcomes considered most important by current or potential users of sexual health services within UK settings: a qualitative study

7.1 Background

This chapter will outline the methodology and report on the results and discussion of the primary research conducted to capture outcomes considered the most important by current or potential users of sexual health services. In the previous chapters it has been discussed in detail that there are various potential benefits of PROM assessment in research and clinical practice with regard to 'clinicians and individual patient care, healthcare management teams, regulators and commissioners and policy makers'.(111) PROM assessment within healthcare can generate evidence which can facilitate doctor-patient communication, substantiate patients input to their care and can help inform commissioners how services can be designed or redesigned.(110, 114)

It has been emphasized previously in the thesis that PROMS should be developed with substantial patient input to ensure that the outcomes, within the instruments, measure what truly matters to patients, so they are sensitive to detect meaningful changes.

Qualitative research methods were adopted for this element of the PhD research as they allow detailed exploration of the issues and outcomes that are relevant to the current or potential users of sexual health services .(275, 276) A semi-structured interview format was adopted to allow systemic coverage of key areas as well as flexibility to focus on issues highlighted by current or potential service users.(277, 278) This primary research was conducted to explore various current or potential users' experiences and views to determine important health dimensions to be analysed.

7.1. 2 Aim and objectives of research

The main research question of the primary research was, 'what are the outcomes (components, pathways and results of care) that are considered most important by current or potential users accessing sexual health services?' The aim of the study was to inform the development of a measurement tool for the assessment of sexual health services as part of an economic evaluation. It is essential to incorporate input from patients to ensure that any future designed instrument will be appropriate to detect meaningful changes which are truly representative of patients' preferences.

The main objectives of the study were:

- To explore the various factors and aspects of sexual health services that are considered important by patients or potential clients while accessing sexual health services;
- To determine which themes are most essential from a current or potential users' perspective which can help determine outcomes which can be potentially incorporated in a preference-based measure designed to be utilized in an economic evaluation.

7.2 Methodology

7.2.1 Study settings

All the participants were recruited from the Birmingham area. Birmingham city offers a diverse ethnic population with the highest percentage of Black, Asian and Ethnic minority (BAME) communities in the UK with significant challenges associated with and sexual health

services.(279, 280)

There have been major changes in how sexual health services are being delivered in Birmingham since 2013, with the commissioning of a city-wide sexual health system with services being provided by 'Umbrella'. (280) It is a new partnership led by University Hospitals Birmingham integrating community-based organisations, charities, and health service providers. The major changes in the delivery of care over the last few years mainly include; shift from centralised clinics to greater use of Family Doctors (GPs) and community based pharmacies, and facilitating the screening process through usage of the internet.(280)

7.2.2 Study participants

The study aimed to recruit participants who were either current or potential users of sexual health services within UK settings, falling within the 18-24 age groups. This age group was selected as evidence suggests that the prevalence of STIs is reported to be highest among young individuals as mentioned in chapter 2.

7.2.3 Eligibility criteria

The eligibility criteria for recruiting participants who were either current or potential users of sexual health services are highlighted below.

Inclusion criteria

Current or potential user of the service who were:

- able to provide informed consent
- aged between 18 to 24 years of age

- able to understand and speak in English
- willing to provide their name, email or phone number and willing to be contacted by researcher

Exclusion criteria:

The following were not eligible for inclusion: those who were:

- under 18 years of age or over 24
- unable to provide informed consent
- were unable to understand or speak in English

7.2.4 Sample size and sampling technique

It was anticipated that participants would be recruited to take part in semi-structured interviews until saturation of data was approached (when additional emerging data is not shedding additional useful light on the research question). ADDIN EN.CITE (281-283) This was based on the evidence from previous studies. ADDIN EN.CITE (284-286) This was a qualitative study and so no formal sample size calculations were appropriate. ADDIN EN.CITE (284-286) Participants were recruited in the study by non-probability convenience sampling.(287)

7.2.5 Participant recruitment strategy

The current or potential users of the service were recruited to the study by the following steps.

i) Identification of participants

Participants were recruited from the University of Birmingham and via Birmingham City Council's Youth Service.

ii) Approaching the participants and recruitment into the study

The participants were approached through different electronic methods including, social media, email communication and electronic newsletters. The strategy for approaching participants through each medium is described briefly below.

a) **Email communication:** Youth workers from Birmingham City Council used their contact list to send details of the research to young people aged 18-24. Young people who were interested in taking part were asked to contact the main researcher via email (Muslim Syed). The researcher then contacted the participant to send further details about the study and arrange a convenient date and time for the interview. For University students, the communication leads of various departments/colleges in the university were approached and requested to send a group email with an advertisement about the research so interested students might approach the researcher to be recruited in the study. The undergraduate admission tutors and programme leads were also requested to circulate details of the study. The contact information of the administrative staff and programme leads was accessed through the University website to make the initial request to circulate details of the research to students.

b) **Social media:** Different social media forums namely; Twitter, WhatsApp and Facebook were utilized to tag various colleges of the University of Birmingham to advertise the research and request for recruitment in the study. Interested participants emailed the researcher to find out more information about the study.

c) **Snowball sampling technique:** Participants who participated in interviews were requested to identify other potential participants who might be interested in the research. They were requested to pass on the details of the researcher to these new potential participants.

7.2.6 Topic guide

The systematic review and qualitative synthesis (chapters 5&6) were used to develop a list of topics and questions. This was used to inform the development of a topic guide to be utilised for conducting semi-structured interviews. Moreover, the interview guide was reviewed by clinical sexual health consultants (JR & NT) and senior academics (TR & LJ) who have published substantial research in this area.

The topic guide was used to stimulate discussion about the characteristics of the sexual health services focusing on various aspects of the service delivery processes. The topic guide encompassed important themes with a subset of questions (Appendix 2). The areas included in the topic guide were expectations of the service, concerns about confidentiality, pathways of care, quality of medical care, direct and indirect costs associated with service, suggestions to improve services & outcomes.

7.2.7 Qualitative data collection

The participants were given the option whether to participate via face to face online interviews (via Zoom or Microsoft Teams) or over the telephone. The participants all asked to participate by telephone. This method was largely chosen because participants felt more comfortable and felt their confidentiality was maintained through this medium due to the sensitivity of the topic. The interviews were recorded with the permission of participants. . Personal reflection notes were taken during interviews to aid reflection and to inform subsequent interviews. Once the interview had taken place all contact information about the participants was securely destroyed and all the data collected was anonymised. All participants were reimbursed with a £10 gift voucher to cover the time for the interview.

7.2.8 Analysis of qualitative data

The qualitative interviews were transcribed verbatim and then analysed using thematic analysis.(288) The approach mainly encompasses 'interpreting, exploring, and reporting patterns and clusters of meaning within the given data'.(289) One of the key advantages of thematic analysis is the flexibility it offers as it is not tied to any particular discipline or set of theoretical constructs.(289) Therefore, it is a very widely utilized approach for analysis of qualitative data. However, the approach is also criticized of being a generic method as this approach (thematic coding) is applied in various analytic traditions such as content analysis and grounded theory.(290)

The analysis was initiated by reading and re-reading the transcripts for a full familiarisation. This was followed by application of open codes to four transcripts to identify emerging

themes of relevance by two researchers (MS & LJ).(291) A Computer Assisted Qualitative Data Analysis (CAQDAS) package (NVivo 12 for Windows) was utilized for this process. This was followed by agreement of researchers (MS & LJ) on a set of codes which could be used with the rest of the transcripts. During this stage categories were constructed and defined by grouping of codes. This led to the development of a working coding framework which was utilized with the rest of the data. The framework was used to code the remaining transcripts. The coding framework was amended by researchers during this process as necessary. The coding framework was then applied to all transcripts. The data was managed and summarized by a framework method matrix.(292) The matrix was composed of cases (rows), codes (columns) and cells of summarised data. The matrix was utilized for comparison and contrasting the data across and within cases. (292) Connections and differences between codes were analysed to identify the factors that are meaningful and relevant to the current or potential users in context to service delivery processes while accessing sexual health service. (292)

The results of the study were reported in accordance with *'Consolidated criteria for reporting qualitative research'* (COREQ) (293) and *'Standards for reporting qualitative research'* (SRQR) (294) guidelines to ensure good qualitative research practice (Appendix 5).

7.2.9 Ethical considerations

a) Consent

Verbal consent was obtained by the researcher prior to the start of the interview and was recorded on the digital audio recorder with the participants' permission.

b) Sensitive or embarrassing topics

The interviews questioned participants about various domains pertaining to clinical consultations while attending a sexual health clinic. This might have involved some consideration of sensitive topics. However, this was minimised by asking participants not to share details of their own visits to SHS but to reflect on what would be important to patients like them.

At all stages it was emphasised that participation is voluntary and that the data generated will be anonymous. We made it clear that participants could withhold any information that they felt was too sensitive or withdraw from the study at any time. We did not anticipate that there would be unacceptable psychological discomfort associated with participating in the study, but should the need arise; participants were given the option to cancel the call and withdraw from the study.

c) Storage of information

No personal information about respondents was held by the study team after the interview had taken place. Respondents who wished to take part in the interview were asked to provide a first name and telephone number to allow them to be contacted and to obtain some basic demographic information. The electronic data was stored on the University's secure servers. The contact details for respondents were securely destroyed as soon as the interview had taken place. Data collected in the interviews was anonymised by the study team. Interviews were recorded with the permission of respondents. The interviews were transcribed and anonymised soon after the interviews and the digital recordings of the interviews were removed from the digital devices. The anonymised transcripts and digital recordings were stored securely on a server within the University. The anonymised

transcripts and digital recordings will be stored for 10 years in line with the University's Code of Practice for Research. This data will then be securely destroyed in line with university guidelines.

The next section of the chapter will outline the findings of the study highlighting the various themes that emerged from analysis of the data.

7.3 Results

Demographic details of the participants

A total of 15 participants were interviewed from July to August 2021. The interviews were conducted until saturation of data was approached. The interviews ranged from 30 to 45 minutes duration. Sixty percentage (n=9) of the participants recruited in the study were

current users of sexual health services whereas 40% (n=5) were potential users. The age group of the participants varied between 18 to 24 years of age. The participants recruited in the study were from different ethnic background within UK settings (details of individual participants is summarized in Table 7.1).

Table 7.1: Demographic details of participants (n=15, sample recruited by non-probability convenience sampling)

Participant no	Gender	Age	Ethnicity	Current or potential user of sexual health services
1	Male	21-22	White (Swedish)	Potential user
2	Female	23-24	African Black	Current user
3	Male	23-24	African Black	Potential user
4	Female	21-22	White (South African)	Current user
5	Male	18-19	White (British)	Current user
6	Female	22-23	White (Romanian)	Current user
7	Male	23-24	Asian British (Pakistani)	Potential user
8	Female	23-24	Asian British (Pakistani)	Potential user
9	Male	20-21	Asian British (Indian)	Current user
10	Female	20-21	Asian British (Indian)	Current user
11	Female	21-22	Black British	Current user
12	Female	19-20	White British	Potential user
13	Male	21-22	Asian British (Indian)	Current user
14	Female	19-20	British Black	Current user
15	Male	20-21	White (Australian)	Current user

There were no major discrepancies found in the study between the opinions of service users and potential clients pertaining to the various aspects of services. Nine main themes were identified by the thematic analysis: involvement in decision-making; clear and comprehensive diagnosis and treatment; being seen and getting results quickly; having a choice of appointment type; feeling respected and put at ease; non-judgemental and friendly staff; feeling reassured about confidentiality; having support with partner

notification & being able to find & get to services. There was also an underlying theme relating to the stigma associated with accessing sexual health services. The sub-themes and direct quotes associated with the broader themes are summarized in table 7.2. The direct quotations are included to demonstrate the heterogeneity within some themes.

Being involved in decision-making

Most of the current users of the service believed that it was vital for them to be involved in decision making processes pertaining to the various treatment options and sharing information about the possible side effects of the prescribed treatment so they could better understand how it would affect their health and general wellbeing. Moreover, they emphasized the need to make informed decisions and to feel empowered in the decision-making *process:*

'I would say feeling, the understanding what is going on, so as adult you feel that you are involved in the care and the decisions are not being made for you, they are made with you, I would probably say that is most important for me' [P 2, female, age 23, African Black ethnic group]

'I just what to be in control, if I go to a sexual health clinic I want to be in control of my own decisions' [P 4, female age 21, White ethnic group]

'If all my points are taken into account, and you know a collective solution is reached, medication is given, all the tests are done, instead of simply brushing something of like, oh it's not that serious but if it persists, come back, you know, dealing with it at that, you know at that minute.' [P 10, female, age 21 years, Asian British ethnic group]

In contrast, a minority of participants believed that they were confident in the expertise of the clinician in diagnosis and treatment and had no expectations to be included in the decision-making process. For example, a potential client of the sexual health services commented:

'I think personally, the doctor knows their job and have been doing it for a long time, I am confident in the treatment given and trust their judgement, so I wouldn't bother in asking unnecessary questions and waste their time' [P 8, female, age 24, Asian British ethnic group]

Clear and comprehensive testing, diagnosis and treatment

Most of the participants emphasized that the information provided pertaining to their condition should be communicated in a clear and comprehensive manner so their sexual health issues were better understood and they would be assured that a right diagnosis had been made by the clinician.

For example, a female patient elaborated on the significance of communicating to patients in a clear and concise manner while making comparison with other type of health services:

'I think it's about being thorough. So sometimes when you have a problem you'll explain what your problem is, but in science terms when a GP or a doctor tries to explain it back to you it's not something that we might understand. Sometimes the GP, they don't really pay much attention. They just scribble notes down and then they say, 'Okay, go to the pharmacy, this is what you need.' Sometimes they don't take enough time to actually explain what the route cause or what the problem is, do you know what I mean? Just the general conversation, so yeah, that's probably the most important thing I would say when it comes to sexual health service' [P 14, female, age 20, Black ethnic group].

Similarly, a male patient stated:

'Well, it'd be going there and then feeling like they've helped my issue. So feeling like I've got the right answer that I need or that feeling like I've been heard or feeling that, okay, I've got these results and they've told me the proper ways to care for myself' [P 13, male age 21, Asian British ethnic group]

There were expectations of a comprehensive clinical assessment during the clinical consultation. They expected the clinician to carefully consider all aspects of their health issue while recommending diagnostic tests and treatment plan:

'I would say that a good outcome would be being able to identify the root of the problem or whatever issues you may have and also being able to provide the right services and the ease of the patient as well because a lot of patients come in and they may not really get on well with people so I would say that being able to understand the patient, being able to understand exactly what the problems are they are facing and trying to mitigate those problems according to you know the patient's emotions or any other underlying background' [P 15, male, 20 years, White ethnic group]

In terms of being tested for STIs, more than two thirds of the participants expressed their desire to be tested for all STIs during their visit to the sexual health clinic:

'I would say people first of all would have the immediate ones like HIV is the most common one that they would want to be tested for, if I was to think about any other ones they would probably be… the ones that are usually the most common, like syphilis or maybe gonorrhoea, some people who are actually not sure what type of STI they have would want to take as many tests as possible just to be able to you know narrow it down but like I said earlier, HIV AIDS would be the most common test that people go for' [P 2, Female, 23 years, African

Black ethnic group]

Similarly, a current user of the service recommended:

'I would say it's good to be tested for everything, as there are so many STIs, there are diseases like gonorrhoea and chlamydia, so you want to be tested for everything that you don't have any of them' [P 9, male, 20 years, Asian British ethnic group]

Being seen and getting results quickly

In context to waiting times, two thirds of the participants interviewed expected to get an appointment within 2 weeks. Once in the clinic the acceptable waiting time for consultation was reported between 30 minutes to 1 hour. The acceptable waiting time to receive test results was documented between 3 days to 1 week. Most of the participants emphasized the need to receive a quicker STI test result as they associated a delay in receiving the result with increased anxiety and stress:

'Being time efficient, so from the minute I'd booked the appointment, I know my appointment's going to be at this time, I'm seen quite efficiently, the clinic was easily accessible, I didn't have to waste a long time travelling to and from it, so just being time efficient in general would make me feel like it was successful' [P 4, female, 21 years, White ethnic group]

Most participants reported 1-2 weeks as acceptable waiting times to receive a STI result and explained that a delay can create a lot of anxiety among patients while waiting for results and they should be notified timely:

'a…so I don't think I didn't get the results of my STI test when I last visited I need to check about that. If you get your results within a week that is really helpful and put someone waiting for the result at ease, as it is really stressful waiting for the results. It should not be more than 2 weeks I would say' [P 2, female, 23 years, African Black ethnic group]

Having a choice about appointment type

Nearly all participants wanted to have a choice over their appointment type. Interestingly, face to face consultation was preferred over online consultation by the majority of the current users of the sexual health services, particularly in the context of the Covid 19 pandemic which was being experienced at this time. This was particularly reported by male and female participants with Black or Asian ethnic backgrounds:

'Umm.. a….i would probably say face to face, as there are a lot of questions, that I guess are more easy to ask face to face, I would probably say, that there is more human contact which can make the patient comfortable, so if I have a option a face to face is much better than online, I would probably say, yea, and there might be issues which need to be solved there and then, for example an examination is always better face to face, if a physical examination is needed, or there is such a problem' (P 2, female, 23 years, African Black ethnic group]

Similarly, a current user of the service quoted:

'I would rather have a face to face consultation so that if there were any testing they needed to do immediately, it could be done immediately instead of having a phone consultation and then still having to go back into the clinic for some tests. So, I think I would pick a face to face consultation' [P 6, female, 22 years, White ethnic group]

On the contrary, a few of the potential users of the service suggested an online consultation option, considering it safer option during Covid 19 pandemic:

'I would probably say online, as it's more safe' [P 12, female, 19 years, white ethnic group]

Feeling respected and put at ease

Most of the participants documented the need to be treated with respect and put at ease by the healthcare staff during the visit to the sexual health clinic:

'Probably respect. Coming out and feeling respected … my views and opinions and my sexual health is respected and me as a person as well' [P 2, female age 23, African Black ethnic group]

'One can really feel vulnerable while visiting a sexual health clinic… self-respect is important, I guess to everyone, and when you visit a sexual health clinic, one can feel that it can be compromised, I mean if they are made to feel that way while in the clinic. It is very important for the clinic staff to consider this and give the respect that a patient deserves, that is what I believe' [P 10, female age 21, Asian British ethnic group]

The significance of a clean and calm environment in a sexual health clinic to make patients feel relaxed and relieve their anxiety was discussed by most of the participants. The perceptions of a good environment included; soft music, magazines and other forms of entertainment to keep patients calm while waiting for the appointment in the waiting room.

A potential client suggested an ideal clinic environment to reduce stress levels while waiting for appointment:

‘a..umm…like I have been, if there is something as simple as music in the waiting area like magazines to look at, if you are nervous and embarrassed about attending, you have got something whilst you are waiting for appointment., something that will keep you occupied. The main thing is I would say is welcoming, ummm…something private and a safe place to go to’ [P 12, female, 19 years, White ethnic group]

Non-judgemental and friendly staff

Most of the current and potential users highlighted the significance of staff attitudes and behaviours which substantially influenced their satisfaction with the service and overall comfort levels while visiting the clinic. Most of the participants′ general expectations from the healthcare staff were for them to be friendly and approachable, non-judgemental and someone they could relate to. These expectations were also similar among the different ethnicities and genders of participants.

A current user of service, while discussing his expectations of staff attitudes and behaviours commented:

‘And I would say a friendly personality and someone you can relate to can be really helpful. As the people that walk in are stressed and worried and a friendly face or a warm personality can really help and go a long way…’ [P 13, male, 21 years, Asian British ethnic group]

Moreover, some participants felt that additional support for patients would be helpful. These participants elaborated that such support would lessen their anxiety and feel more assured during the visit:

'Yeah so like somebody who picks you up and takes you, like someone who can answer your questions because it's quite alarming to go like it's something new for most people and sometimes traumatising so they want to open up to someone they trust. So if somebody picks you up and actually guides you through the process, tells you what's happening and then you are more confident as the patient to go there, it might be better if there was say like a chaperone system to take you one way and like you don't really see other people as much because you want to like keep it private, most people want to keep it private' [P 2, female, 23 years, African Black ethnic group]

Feeling reassured about confidentiality

Confidentiality was one of the major concerns of the potential and current users of the service. It was mentioned in various parts of the interviews and was strongly linked with other aspects of the service. The participants discussed the significance of maintaining confidentiality at every stage of the service delivery process starting from the point when the patient approaches the reception desk. The significance of confidentiality varied among the ethnic minority groups, and was of extreme importance particularly among male and female participants with Asian ethnic backgrounds:

'I have got a mixed group of friends, you see, we as Asians have more problem and are more concerned about the confidentiality aspect while visiting the clinic, whereas the white friends I have are more relaxed and discussed matters of sexual health with their family more openly I guess, something that we Asians can't do. …if there is some staff from Asian background would really help specially for me, a Asian face would help and would make me feel comfortable' [P 10, female, 21 years, Asian British ethnic group]

Importantly, the significance of confidentiality among LGBT groups was acknowledged and mentioned by male and female participants:

'I think the levels of confidentiality would differ because some of them might be a part of the LGBT community, but it's not out yet, so they would not want everyone to know about their sexual preferences….'[P 15, male, 21 years, White ethnic group]

'Absolutely they (significance of confidentiality) will differ. They will be different from one person to another because as you because of race, because of gender, because of sex, just because every person's way of thinking. So yeah, absolutely everyone will experience this in a different way' [P 1, male, 21 years, White ethnic group]

Different suggestions were provided by the participants (current and potential users) pertaining to addressing confidentiality issues in clinical settings. The most common suggestions were staff training, discretion at the reception desk, reassurance about confidentiality by staff, offering and signing a confidentiality agreement form and overall reassuring behaviour by the healthcare staff:

'The staff should be trained and should be capable, and I mean they should be spot on when it comes to giving instructions and reassuring the patients that everything that they share will be confidential. There can be a form; I think…a agreement that can be signed. That will make the patients feel protected. If it's possible' [P 12, female, 19 years, White ethnic group]

'a…..the behaviour of the staff, if they can reassure that it is a confidential service, if the young people can be convinced, a…. it's the kind of trust that is build up which is very important, so I would say the initial conversation at the reception is important, and I guess, I would probably say that if they are reminded about the protection of their personal information that they will share, …I guess it will really help them and put them at ease. This

is what they can do in terms of putting the people at ease' [P 13, male, 21 years, Asian British ethnic group]

Having support with partner notification

Regarding partner notification there was mixed views among the participants and the challenges associated with it were mentioned. Participants believed that a phone call would be more appropriate means of communication whereas majority of participants from Black or Asian backgrounds in the study preferred a text message or email as an appropriate route.

For example, a potential user commented on the question pertaining to the appropriate route of partner notification:

'I think probably through a phone call as it's such a sensitive issue. A text message will be really problematic because they get a very very very difficult situation without a explanation about it' [P 1, male, 21 years, White ethnic group]

In contrast to the above-mentioned view, a current user of the service, said:

'Umm… I am not sure; I think I was also asked about partner notification when I visited. It would be the same I guess a text message and email will be better as well. A call can actually make them angry, imagine if they are no longer in a relationship, it can create a bit of drama, so I would say a text message or email would be better' [P 11, female, 22 years, Black British ethnic group]

Being able to easily find and get to services

There were various aspects which were discussed in context to accessibility to sexual health services which ranged from finding the service initially, costs associated with making a visit to suggestions to increase accessibility of sexual health services.

Most of the participants believed that it is easier to finding the sexual health service initially especially for younger generation due increase access to internet and online booking options:

'Well now I don't think it's been that difficult, I mean depending on the people attending, I mean for example young people would find it very easy as they could easily log into… it could be an app or a website and trying to book an appointment because now appointments could be booked online but I don't know, maybe back in the day or with the older generation they actually had to go to the place so I would say that it's slightly easier, it's not as difficult as it used to be' [P 5, male, 18 years, White ethnic group]

However, a few participants were of the view that finding the service initially can be challenging and better signposting is need in GP services and pharmacies about local sexual health services. For example, a potential user of the service suggested:

'I don't think it's that easy. Better signposting at GP, maybe pharmacies, maybe some adverts at the TV, so people know that there is special care available for sexual health rather than going to a GP' [P 8, female, 24 years, Asian British ethnicity]

Accessibility to the service was associated with the location of the clinic and flexible opening times by most of the participants. They were of the view that the closer it is for patients the greater the accessibility to the service:

'Umm….for me it would the one which is more easier to get to within my local area, which one is easier to get to, quicker to get to, and yes the opening times as well, if someone has to go in evenings, and also the location of the clinic if it is in a area that is obvious, like why are you there and why are you walking into,umm, also the kind of services they are offering as it may be different for different clinics' [P 10, female, 21 years, Asian British ethnicity]

Various suggestions were given by both current and potential users of the service to increase accessibility of services, which mainly included: increasing awareness and acceptability among the general public about sexual health services and utilising social media to engage young people with the service. For example, a current user of the service suggested:

'*To engage young people you can use social media like 'Instagram' or 'Snapchat', where young people can join, a live stream for general information can really help, you know what I mean. Make youngsters aware through such social media groups, it can be discreet, no one will get to know and they can get all the information and that will really help as we are always on the phone' [P 14, female, 20 years, British Black ethnic group]*

Reduction of stigma

The majority of the participants believed that when compared to other illness and related health services, there was more stigma attached with accessing sexual health services:

'Yea… I would say that perhaps…ummm…maybe more stigma when going to sexual health services rather than for example to other services like going to a GP, ummm.. you would be like, like, like more embarrassed to go, to access sexual health support, ummm…yea..I would

say it is different in that aspect, I would say, ummm..maybe it's not that much talked about, if you feel unwell you might feel ok sharing about it with friends or family... that you have a appointment with the GP, umm… if it is for example something to do about sexual health you can't be that open about it with people that I have an appointment with umbrella about sexual health as compared to other health problems' [P 14, female, 20 years, British Black ethnic group]

',….. but for some young people, I would probably say it can be difficult to let your family know. For example some young people might not get the support from their family and I guess they would, probably make the visit without letting them know. There is this embarrassment that is there with sexual diseases and that can weaken the family and social support you see, as people are afraid to reach out…so...yea there can be those issues' [P 6, female, 22 years, White ethnic group]

The social and family pressure associated with visiting a sexual health clinic was a major issue for the current and potential users of sexual health services from Black and Asian ethnic backgrounds:

'Yeah I think stigmatisation is a problem these days as you know when people hear that someone has a sexually transmitted disease people tend to you know either make fun of them or mock them or you know just avoid them or stay away from them, I would say there are issues like that but that's also dependent on the type of background that you have, some people have very supportive backgrounds trying to help them with whatever problems they have whereas other people may say that oh what if I get this thing from being around you, that kind of thing, so yes there are issues' [P 3, male, 23 years, African Black ethnic group]

Table 7.2: Key themes and sub-themes identified based on the interviews

Key themes	Sub-themes
Being involved in decision making	• Making informed decisions about treatment • Feeling empowered in decision making process
Clear and comprehensive diagnosis and treatment	• Information provided • Comprehensive clinical assessment • Being tested for STIs
Being seen and getting results quickly	• Acceptable waiting time for consultation • Acceptable waiting time to receive STI result
Having a choice about appointment type	• Face to face consultation • Online appointment
Feeling respected and put at ease	• Role of healthcare staff • Clean and calm environment
Non-judgemental & friendly staff attitudes and behaviours	• Desirable attributes of healthcare staff • Additional support
Feeling assured about confidentiality	• Significance of maintaining confidentiality • Confidentiality issues among different patient groups • Suggestions to address confidentiality issues
Having support with partner notification	• Route of partner notification • Challenges among different patient groups
Being able to easily find and get to services	• Finding service initially • Costs associated with making a visit • Suggestions to increase accessibility

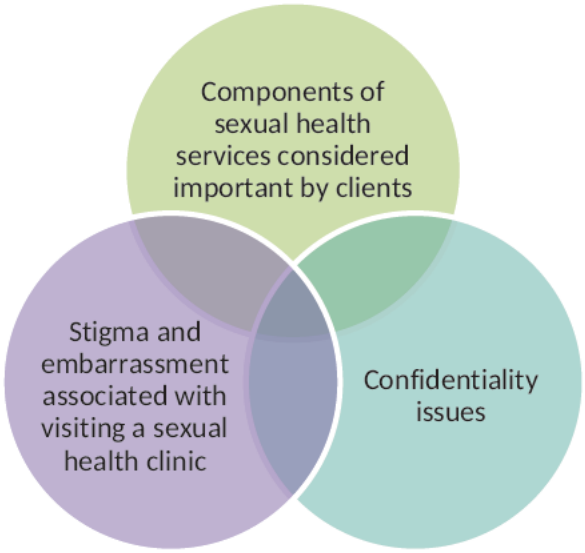
7.4 Discussion

7.4.1 Principal findings

The main aim of the study was to explore the factors and aspects of the sexual health services which are considered most important by current and potential users to help identify key themes that potentially can be utilized to develop a preference-based PROM specifically designed for economic evaluation in this area. The broader themes identified were: involvement in decision-making; clear and comprehensive diagnosis and treatment; being seen and getting results quickly; having a choice of appointment type; feeling respected and put at ease; non-judgemental and friendly staff; feeling reassured about confidentiality; having support with partner notification & being able to easily find and get to services. There were no major discrepancies found in the study between the opinions of service users and potential clients pertaining to the various aspects of service.

Evidence from the interviews suggests that a concern about confidentiality is one of the key issues that causes distress and anxiety among patients accessing sexual health services and is closely interlinked with their expectations from other components of the service (Figure 7.1). Patients and potential clients, who participated in the study, strongly emphasized the significance of maintaining confidentiality at every stage of service delivery process.

Figure 7.1: Venn diagram depicting the overlap of confidentiality issues, stigma and embarrassment associated with visiting sexual health services with different components of service considered important by clients (current or potential users)



The participants (current or potential users of sexual health services) reported various components of the service considered important by them and judged the quality of the services based on various aspects of the service delivery process. The study indicated that the quality of care was mainly judged by clarity of communication pertaining to the diagnosis, treatment options and the associated side effects. Similarly, the study reported that the perception of quality of care was also closely linked with staff attitudes and behaviours with the participants expecting friendly, non-judgemental and sympathetic attributes from the healthcare staff. Another important aspect of service that was considered important by participants was waiting times. Perceived efficiency of the service was associated with getting timely appointments, lesser waiting time in the clinic for consultation and receiving the test result of a STI without any unnecessary delays. Additionally, a clean and calm environment of the sexual health clinic was associated with relieving the anxiety of patients.

7.4.2 Comparison of the study with previous published literature

The study included a young cohort of participants who were either current or potential users of sexual health services representing diverse ethnic groups. Previous published qualitative studies have either recruited an underrepresented sample from ethnic minorities or only recruited minority groups as shown in chapter 6. In this study there was even distribution of White, Black, and Asian ethnic groups recruited in the study and perceptions were captured from both the current (n=9) and potential clients (n=5) of the service which is unique to this study.

Previous studies ADDIN EN.CITE (34, 167, 171, 174, 176) have highlighted the significance of confidentiality (while visiting a sexual health clinic) from a patient's perspective reporting their concerns. The fear of breach of confidentiality causes a lot of distress among patients and is also considered an important barrier in accessing the service. ADDIN EN.CITE (34, 168, 169, 223) Similar findings were reported from this study. Various strategies were discussed by patients and potential clients in this study to address the issues of confidentiality. These suggestions included further staff training to better address concerns of patients, discretion at reception desk, reassurance about confidentiality, offering and signing a confidentiality agreement form and overall reassuring behaviour of the healthcare staff. Similarly, a strong stigma and embarrassment associated with visiting a sexual health clinic was reported in the study which was emphasized more by some participants (mainly from ethnic minorities). These findings are similar to those found in previously published literature. ADDIN EN.CITE (295, 296) Interestingly in this study the difference in stigma among patients from ethnic minorities was acknowledged by White participants (who are representative of the majority of the general population in the UK) who were either current or potential clients of the services.

In the study various components of the service were discussed by the participants highlighting the ones considered most important by them. Different aspects of the service delivery were discussed such as; staff attitudes and behaviours, importance of clear and comprehensive information, sympathetic and comprehensive clinical assessment, and clean and calm environment. These reported expectations are similar to the findings of the previous studies. ADDIN EN.CITE (43, 168, 169, 173) In the study perceived efficiency of the service was associated with lesser waiting times for consultation and STI testing. Waiting time is a well-established indicator for quality of care from patients' perspective. ADDIN EN.CITE (168, 169, 171, 176) Hence, waiting time is an important indicator for judging the efficiency and the quality of service from a patients' perspective and should be taken into consideration while evaluating the service.

In contrast to other studies these perspectives were discussed in a logical sequence providing a detailed account of every component. Moreover, suggestions were also provided to improve each component of service delivery as previously discussed in results section. In previous studies generalized statements were reported pertaining to the various components of the service without specific focus on each individual component due to the heterogeneity in the objectives of the different studies (findings of qualitative synthesis and meta-ethnography presented in Chapter 6). For example, in this study an important sub-theme of comprehensive and sympathetic clinical assessment emerged along with other related sub-themes such as clear communication and staff attitudes and behaviours (Table 7.2). Additionally, the current and potential clients desire to be involved in the decision-making process including active involvement in selecting the different treatment options & STI testing was explicitly highlighted in the study. Such aspects have been somewhat

covered in previous studies but not in a focused or detailed manner due to the different objectives of each study (chapter 6).

Furthermore, the significance of the physical environment of the sexual health clinic and its impact on the comfort & satisfaction levels of patients has been reported in previous studies. ADDIN EN.CITE (43, 168, 176) Similarly, in this study, a clean and calm environment of the sexual health clinic was associated with relieving the anxiety of patients. This finding suggests that it is Important to take into consideration the physical clinical environment while evaluating and designing or redesigning the service to ensure its conducive to a relaxed atmosphere for the patients while they wait for their clinical consultation.

The accessibility to sexual health services has been negatively impacted by the Covid-19 pandemic and there was minimal or zero accessibility to the services during the lockdown period.(44, 45) The majority of participants particularly those from Asian ethnic background reported a preference for a face to face to consultation in comparison to online consultation in context of the current Covid-19 pandemic. In contrast, more recent literature ADDIN EN.CITE (44, 45, 297) suggests online consultation (for example, Telemedicine etc.) as a safer and more feasible route to access services. However, it can be argued that such inferences may not be truly representative of the general population and inclusive of views of ethnic minorities or marginalized groups who have the highest prevalence of disease and are most negatively affected by the condition. This particular finding of the study adds to the existing knowledge base pertaining to the preference of service delivery pathway during the pandemic from a patients and potential client's perspective.

7.4.3 Strengths and limitations of the study

The salient feature of the study is that it holistically captures the various components of the sexual health services considered most important by its clients as well as discusses suggestions to improve these aspects of service delivery from a patient or potential client perspective. Moreover, the study tool was informed by a qualitative synthesis and meta-ethnography to ensure all important components (pertaining to various patient experience dimensions of the service) were included. The study sample although drawn by convenience sampling was substantially diverse representing the various ethnic minority groups within UK settings which strengthen its external validity.

One of the main limitations of the study was that it only included young participants aged between 18-24 years. The perceptions and suggestions documented by them may not be representative of other patient groups. However, it is worthwhile to mention and as previously discussed in detail in chapter 2, that the prevalence of STIs is highest among the young groups within the UK and OECD settings. ADDIN EN.CITE (47, 263, 298) This fact was taken into consideration while designing the study methodology. In the study both current and potential users of the service were recruited by convenience non-probability sampling. Arguably, patients′ perceptions are more validated as they have real life experience of the service delivery as compared to potential users whose expectations maybe exaggerated or not based on real life experience or accessing the services. Nevertheless, the study had a significant percentage of participants who were currently utilising sexual health services. Another counter argument can be that the potential clients add a wider perspective and value in context to end users′ preferences of sexual health services. Moreover, it should be acknowledged that they are also an important stakeholder and beneficiary of the service and should not be excluded in evaluation of service. This is substantiated by the fact that

public and patient involvement in research is endorsed and is one of the key priorities of leading funding government research body such as National Institute of Health Research in the UK. ADDIN EN.CITE (299-301)

Although it was considered that data saturation was being approached, this may have reflected the sample of participants recruited, and the views of minority groups may not have been fully captured. As the study was undertaken during the pandemic, there were limitations around the sample that could be recruited and hence the data that could be collected and analysed.

Moreover, the epistemological view of the main researcher (MA) may have influenced the responses from participants (302). It is important to acknowledge this limitation because the researcher is a medical doctor and has experience of working in clinical settings and treating patients with sexually transmitted diseases. However, strict measures were followed to avoid asking any leading questions during data collection and analysis, through the application of well-designed topic guide and a rigid framework index.

Furthermore, since the interviews were conducted over the telephone, any facial cues that would have been evident via online video calls or in face to face interviews would have been missed, and these might have provided rich information about participants' feelings relating to various aspects of the service. However, there was also an advantage of conducting interviews through telephone as participants felt more comfortable and felt their anonymity was maintained while providing detailed responses.

7.4.4 Recommendations for future research and policy implications

The primary research has identified important components of the services considered important for current or potential users of sexual health services. The study explored individual components of service and gaps identified by previous reviews (chapter 5 & 6). Additionally, the study extracted suggestions from participants for improvement of overall quality of care of the service. The finding of the study has important policy implications particularly during evaluation of local services in Birmingham area & future designing or re-designing the service in the UK. The study also provides foundations for further exploratory research which can be conducted in other regions of the UK and OCED settings. This will help further determine whether the perceptions of patients or potential clients vary in context of sexual health services in other regions. Moreover, the important themes identified by the study help provide solid foundations and help determine important outcomes that can be utilized in the future development of a preference-based PROM specifically for economic evaluation in this area. This will be discussed further in chapter 8 (section 8.4) which will collate the findings of previous chapters.

7.5 Chapter summary

This chapter has presented the findings of the primary research (qualitative study) which was conducted among current or potential users of sexual health services. Important themes have been discussed pertaining to various components of the service considered most important by patients or potential clients. The next chapter will comprise of the

summary of the main findings of each chapter with comparison and discussion in context with the overall aim of the thesis.

CHAPTER 8: Discussion

8.1 Summary of the thesis

The research was conducted to highlight the various components and aspects of sexual health services which are considered to be the most important by potential clients or patients while accessing the service within OECD settings. Additionally, the aim of the study (thesis) was to highlight important themes that can help outcomes (items and domains) for a future preference-based patient reported outcome measure for economic evaluation in

this area. Thus, the thesis took the following steps to achieve this objective:

i) An analysis of the concepts pertaining to patient satisfaction, patient-centred care, patient reported outcomes in context to sexual health services to construct a 'logic model' signifying the need of a preference-based PROM

ii) An analysis of the existing theories and methodologies within health economics to determine the most appropriate theory and techniques for measurement and valuation of outcomes pertaining to sexual health services

iii) A systematic review was undertaken to assess the tools that have previously been utilized to capture patient reported outcomes and the perceptions of patients, relating to different components of sexual health services and to identify any existing gaps. The review considered OECD settings

iv) A Qualitative synthesis and mete-ethnography was carried out to highlight the important patient experience dimensions relating to the service

v) A primary research project using qualitative interviews with potential clients and patients to further establish important themes that can provide solid foundations for developing outcomes that can be utilized in the future development of a preference-based PROM specifically designed for sexual health services

In this final discussion chapter, the main findings of each chapter are summarized, compared, and discussed in context with the overall aim of the thesis. The strengths and limitations of the thesis are presented. Finally, potential policy implications and recommendations for future research are proposed.

8.1.2 Chapter 2: Background of important concepts included in the research

In Chapter 2 the theoretical foundations and issues pertaining to sexual health services are highlighted in the context of OECD settings. The economic theories (Welfarism and Extra-Welfarism) commonly utilized in health economics and their applied methodologies were also briefly introduced. Evidence was provided of the high prevalence of STIs in OECD countries particularly among young and marginalized groups of the population. The chapter reported that sexual health and contraceptive services have gone through considerable changes and new models of service delivery have been introduced in recent times with little or no patient involvement. The cost implications of untreated disease and other complications such as unwanted pregnancy were also mentioned. Moreover, the main challenges and barriers associated with accessing sexual health services were found to relate to issues such as the strong stigma and confidentiality. The chapter also alluded to the significant pressures associated with delivering the services due to the rise of prevalence of STIs, their associated adverse outcomes and reductions in funding over the years (particularly in the UK). The conclusion of the chapter stressed that it is essential to capture outcomes that are considered important for patients accessing sexual health services since these are different from other type of illnesses and associated health services. Such outcomes were reported to have a direct impact on patient satisfaction, accessibility to service, compliance to treatment and contribute towards complications of untreated STIs and unwanted pregnancy. It was emphasized that such outcomes can be utilized in economic evaluation of interventions to ensure the service is cost effective and patient centred.

8.1.3 Chapter 3: Significance of preference-based PROM for sexual health services

Chapter 3 aimed to cover in detail the theoretical foundations of patient satisfaction, patient centred care in modern healthcare systems, patient reported outcomes to provide evidence-based argument for the need and benefits of developing a preference-based PROM specifically for sexual health services. The chapter also differentiated between preference and non-preference-based measures and the rationale of utilising preference-based measures in economic evaluation (as they allow valuation of outcomes). The various steps of standard PROM development were outlined in the chapter. A Logic model was also constructed which demonstrated that patient satisfaction with sexual health services influences their compliance to treatment, increases engagement with service and contributes towards recommendation of service to friends and family members. It was also demonstrated by the end-point model that outcomes captured by a PROM specifically designed for sexual health services can be utilized in an economic evaluation to assess the cost effectiveness of interventions and ensure the service is patient-centred.

8.1.4 Chapter 4: Measurement and valuation of outcomes pertaining to sexual health services for use in economic evaluation

Chapter 4 analysed the two main theories of Welfarism (in which the evaluative space is focussed on individual utility only, and individual utilities are the function of commodities consumed by individuals such as good or services (66, 69)) and Extra-Welfarism (which encompasses 'extra' measures and indicators of wellbeing such as health or health gain, distribution of health or health gain, patient satisfaction, caregiver burden etc (69)) and its applied methodologies to suggest which is more feasible for measurement and valuation of

outcomes pertaining to sexual health services.

The analysis suggested that the Extra-welfarist approach is likely to be the best suited for the evaluation of sexual health services. It was discussed that although the Extra-Welfarist approach has been criticized for being narrowly focused on health alone, it potentially offers the most in the context of the economic evaluation of sexual health services. The main arguments provided to support the Extra-Welfarist approach included:

i) the QALY commonly utilized within Extra-Welfarist approach provides a 'common currency' for comparison across interventions and other disease conditions, and is endorsed by many decision makers within OECD settings

ii) the Extra-Welfarist framework allows a consideration of outcomes beyond individual utility which can include a wide range of indicators of well-being

iii) In recent times there have been attempts to expand the evaluative space within the Extra-Welfarist approach.(163) Such approaches allow consideration of a broader range of outcomes, and also allow the measures utilized to capture outcomes that are most important for patients and yet still be sensitive enough to detect meaningful changes.

iv) The fact that the provision to sexual health services within the OECD and particularly to UK settings is through publicly funded resource allocation. The objective of publicly funded healthcare is to improve population health.(58) Hence Extra-Welfarist framework is more feasible as it focuses on maximisation of health, and cost per QALY analysis is more directly received by policy makers. It is more pragmatic in such healthcare systems to include the different stakeholders in the valuation of outcomes of interest which is permissible within

the extra-welfarist framework which focuses on technical efficiency

However, it is important to acknowledge that the budgeting of sexual health services by local authorities is also being considered alongside other public health services that don't obviously 'fit' within a health context such as active travel, green spaces, interventions within schools, housing etc. Nonetheless, it can be argued that although such other public health services do have important effects on the overall health and wellbeing of individuals (e.g., green spaces lead to more physical activity, which can mitigate the adverse health implications of sedentary lifestyle). Moreover, STIs are highly infectious and have long term complications which can lead to chronic disease, mental health issues and are associated with high economic burden (in the long term if left unaddressed) as mentioned particularly in Chapter 2. Hence it is important to consider improving services and increasing patient engagement by capturing the outcomes considered most important by current or potential clients of the service.

It was further discussed in the chapter that generic preference-based measures used to calculate QALYs tend to focus on narrow health dimensions and are not relevant for a sexual health context. However, there are certain issues associated with utilising QALY as a measure of value. It is debated in literature whether QALY is a fair measure of value and truly captures what matters to patients.(303) For example, the drugs used among cancer patients cause tiredness, which is not picked up by a QALY. The QALY is also criticized for not picking other benefits such as carers' quality of life and issues extending the concept of wellbeing. Another ethical issue associated with QALY is valuing one individual's life over other. The statement a QALY is a QALY is a QALY, emphasizes the fact that all QALYs are equal irrespective of patient characteristics or situational factors.(303) the individual factors

have an impact but remain unaccounted in QALY calculations.

It was mentioned that there are a range of strategies which have been recently proposed in literature to expand the evaluative space (expanding the QALY beyond health) within Extra-Welfarism. These strategies were assessed considering their strengths and weaknesses. The chapter concluded by suggesting two approaches that seem appropriate in a sexual health setting which were namely: bolt-on and de-novo preference-based outcome measure specifically designed for sexual health services.

It was discussed that the bolt-on dimensions pertaining to sexual health services can be added to generic PROM such as EQ-5D to allow a broader range of dimensions to be included increasing the validity of the instrument in sexual health context. This would also allow us to observe the impact of these dimensions on the health state values. In contrast, a standalone, sexual health services specific preference-based measure would allow particular focus on the dimensions which are important to the service, with increased ability to detect meaningful changes in the status of patients. It was mentioned in the chapter that it was unclear to establish without further evidence (by gathering information by comprehensive literature review and conducting primary research) which of the two above mentioned techniques would be most appropriate for capturing outcomes pertaining to sexual health services. Moreover, evidence was provided in the chapter to suggest that providing services that are patient focussed is more likely to increase service uptake and engagement. This is important on economic grounds because of untreated disease and the lack of utilisation of services has health complications and incurs additional costs which directly affect the patients, their families and health services.(177) The chapter concluded that establishing and confirming important themes (domains and items) through further empirical research

would either aid in developing a bolt-on for sexual health or inform the development of a sexual health services specific preference-based measure for cost per QALY analysis. It was suggested that gathering evidence (through literature review and conducting interviews with service users) would allow further investigation of whether a bolt-on would adequately allow coverage of what is important to patients (alongside EQ5D) or whether a de-novo outc ome measurement tool is needed.

8.1.5 Chapter 5: Systematic review of existing literature to assess the various tools utilized to capture patient perceptions pertaining to sexual health services within OECD countries

Chapter 5 reports on a systematic review which was conducted to assess the various tools utilized to capture patients' perceptions pertaining to various aspects of sexual health services within OECD countries. The systematic review provided the first analysis of studies which had attempted to capture patient views on services, using questionnaires and other instruments. The key findings of the review related to methodological limitations (the tools were developed without following the standardized steps of PROM development process) in the tools utilized in the studies. For instance, out of the total 42 studies included in the review only 18 studies reported information on the development process of the tools utilised. Information about the tool development process is important to determine instrument validity and reliability of the findings of the study. The review also highlighted that there was minimal patient involvement in the development process of the tools in most of the studies. These tools were mostly developed by market research and based on

feedback from associated sexual healthcare staff. Most of the study tools were brief and the domains (of the aspects of care) and items included in the instruments were not clearly defined. The tools utilized in the studies were non-preference-based type of PROMs which cannot be utilized in an economic evaluation.

Other key conclusions drawn from the systematic review included suggestions that there should be continuous monitoring to ensure quality improvement and facilitate evaluation of existing sexual health services by active involvement of patients and healthcare staff and that utilising current users of service are a useful tool for SHS evaluation. It also suggested that there is potential for suitability, acceptability, and feasibility of newly planned care pathways by patients if the service is carefully designed by incorporating their suggestions and views. Additionally, delivery of service by GPs and nurses was reported to be generally acceptable to patients (although varied by patient sex and ethnicity). These findings are similar to a latest review which was conducted to highlight the expectations of young people with STI testing in high income countries.(153)

One of the key methodological recommendations suggested from the review was that the study tool selected for any research assessing sexual health services and capturing patient reported outcomes should have both a strong theoretical basis and ideally should be constructed in accordance with the standard criteria for PROM development process. It became apparent that there is a lack of preference-based PROM (the type which allows valuation of outcomes as described in detail in chapter 3 and 4) that can be specifically utilized for economic evaluation in this area of research. Additionally, the data management, collection and analysis plan should be carefully designed applying robust techniques following strict protocols. This will strengthen the external validity and reliability

of the findings. Furthermore, the researchers involved in formulating the study design, data collection, data analysis and drafting of the research manuscript should be sufficiently trained in basic principles of conducting scientific research and ideally not be directly related to the service. This is to exclude any reporter bias which may result in preconceived influence in interpretation of findings projecting more of a healthcare provider perspective. The review concluded that despite the diverse objectives and methodological variance in the reviewed studies, these data were consistent with the notion that service delivery mechanisms, and the quality of care can be considerably improved by comprehensively incorporating patient derived experiences. This promotion of patient-centred care which has been increasing recognized as an essential component of service planning, implementation, and evaluation ADDIN EN.CITE (33, 176, 216, 217).

8.1.6 Chapter 6: Qualitative synthesis and meta-ethnography to capture patient experience dimensions pertaining to sexual health services

Chapter 6 presents a qualitative synthesis and meta-ethnography which was conducted to explore the important patient experience dimensions while accessing sexual health services. The review highlighted several aspects of the service delivery process which were considered important for patients while accessing sexual health services and allowed the development of six overarching concepts namely: (i) issues of confidentiality, (ii) quality indicators important for patients, (iii) perceived barriers to accessing the service, (iv) preferences for STI testing, (v) support mechanisms and (vi) gaps in service. These concepts identify specific areas of the service which can be improved from a patient's perspective. There was some overlap between these concepts, for example, the synthesis showed that

issues of confidentiality were closely associated with staff behaviour and healthcare provider interactions when a relationship of trust and respect was not established between patients and healthcare provider on point of contact. The results of the synthesis demonstrated that there are individual and societal factors such as stigma, anxiety and fear associated with STIs among patients. One of the important gaps identified by the synthesis was the lack of understanding and recognition of needs of patients with different sexual orientations among healthcare providers of the sexual health services. These findings are similar to a latest systematic review (focusing on young patients expectations of STI testing services in high income countries) which also reported the importance of acknowledging and differentiating the specific needs of various patient groups (ethnic and sexual minorities in particular) while they visit the services.(153) The chapter reported that patient experience of the service is strongly dependent on the quality of interaction with the sexual healthcare staff and the level of understanding of their needs by service providers. These findings highlight the importance of designing the service that makes patients feel safe, non-judged, welcomed and understood while accessing the service in different settings with due consideration of patient characteristics particularly their ethnicity and sexual orientation.(153)

The chapter concluded that there are potential gaps that exist in level of understanding of patient needs particularly among sexual minorities by healthcare staff which need to be addressed. The issues of confidentiality among patients are complex and vary according to settings and their sexual orientation suggesting social constructs and other factors which need to be explored further by adopting a relevant theoretical framework for conducting high quality qualitative research in this area. It was emphasized that there is need for

further exploration through empirical work to capture patient experiences with sexual health disease or those seeking sexual health care to better understand the various indicators relating to service delivery which are considered most important by them.

8.1.7 Chapter 7: Capturing outcomes considered most important by current or potential users of sexual health services within UK settings: a qualitative study

The chapter outlined the methodology and reported the results and discussion of the primary research which was conducted as suggested in the conclusion of chapter 6. Nine main themes were identified by the thematic analysis: involvement in decision-making; clear and comprehensive diagnosis and treatment; being seen and getting results quickly; having a choice of appointment type; feeling respected and put at ease; non-judgemental and friendly staff; feeling reassured about confidentiality; having support with partner notification and being able to find & get to services. There was also an underlying theme relating to the stigma associated with accessing sexual health services.

Previous studies, which were analysed in chapter 6, had highlighted the significance of confidentiality (while visiting a sexual health clinic) from a patient's perspective. The fear of breach of confidentiality causes a lot of distress among patients and is also considered an important barrier in accessing the service. ADDIN EN.CITE (34, 168, 169, 223) Similar findings were reported from the primary research. Additional to previous studies (chapter 4), various strategies were discussed by patients and potential clients in this study to address the issues of confidentiality. Similarly, the stigma and embarrassment associated with visiting a sexual health clinic was reported in the chapter which was emphasized more by participants from the ethnic minorities. ADDIN EN.CITE (295, 296) These findings are similar

to previous published literature as outlined in chapter 4. Interestingly in this primary research the difference in stigma among patients from ethnic minorities was acknowledged by White participants (who are representative of much of the general population in the UK) who were either current or potential clients of the services.

In the chapter, various components of the service were reported as discussed by the participants highlighting the ones considered most important by them. Different aspects of the service delivery were documented such as; staff attitudes and behaviours, importance of clear and comprehensive information, sympathetic and comprehensive clinical assessment, and clean and calm environment. These reported expectations are similar to the findings of the previous studies ADDIN EN.CITE (43, 168, 169, 173) as highlighted in chapter 6 and a latest systematic review (reporting young patients expectations from STI testing services).(153) In contrast to other studies reported in chapter 6 & latest review(153) , these perspectives were discussed in a logical sequence providing a detailed account of every component in this chapter. Moreover, suggestions from participants were also reported to improve each component of service delivery. In previous studies (highlighted in chapter 5& 6) generalized statements were reported pertaining to the various components of the service without specific focus on each individual component due to the heterogeneity in the objectives of the different studies. For example, in the primary research, an important sub-theme of comprehensive and sympathetic clinical assessment emerged along with other related sub-themes such as clear communication and staff attitudes and behaviours. Furthermore, the current and potential clients desire to be involved in the decision-making process including active involvement in selecting the different treatment options & STI testing was explicitly highlighted by the primary research. Such aspects have been

somewhat covered in previous studies(153) but not in a focused or detailed manner due to the different objectives of each study as discussed in chapter 5.

Additionally, the chapter highlighted some important themes which encompass the various components of the service which are considered most important by patients and potential clients of service which can be utilized to develop outcomes for a preference-based PROM. This will be discussed further in section 8.4 (meaning of the study).

8.2 Strengths and Limitations of the study

The strengths and limitations of the overall thesis are discussed below.

One of the key strengths of the thesis is that the important themes (pertaining to attributes of service considered most important by patients or potential clients) were established based on two reviews (systematic review and qualitative synthesis and meta-ethnography) and from conducting primary research (qualitative interviews with potential clients and patients). The standard procedures of PROM development process were also discussed to provide an outline of how the information gathered through reviews and interviews can be utilized to develop items and domains of the instrument. Moreover, the thesis also analysed the theories and applied techniques for economic evaluation as used in resource allocation, inform the latest published literature, to suggest the most appropriate theory and applied techniques to capture outcomes pertaining to sexual health services for economic evaluation. Hence, the thesis provides solid foundations and a strong evidence-based argument for the need of development of a preference-based PROM for sexual health services.

In context to the reviews that were conducted, the main strength of the systematic review was that it was comprehensive and followed an explicit defined process for collating economic evidence. The search process was managed electronically at every stage ensuring the review is clear, thorough, reproducible, and transparent. A considerable amount of time was spent devising a comprehensive search strategy, formulating an inclusion/exclusion criteria and discussion and agreement on extracted data between MA, TR, LJ, JS and NT. The piloting of search strategy, supplementation of the electronic search with hand searching and searching of reference list of included studies strengthens the assumption that all relevant papers was included in the review and the inferences drawn from this review are reflective of all relevant evidence.

Similarly, the main strength of the qualitative synthesis was that it was comprehensive and followed a robust method including the systematic identification of papers and critical appraisal and discussion of individual papers among three different reviewers. Each paper was read and re read for second order constructs by MA. The second and third order constructs were discussed in detail among MA, LJ, TR and JS and revised several times as a part of iterative process. No study was removed based on quality in the critical appraisal process, but the process enabled to test the contributions of the studies to the synthesis based on their quality.

The salient feature of the primary research conducted is that it holistically captures the various components of the sexual health services considered most important by its clients as well as discusses suggestions to improve these aspects of service delivery from a patient's or potential client's perspective. Moreover, the study tool was informed by the two reviews as mentioned above (chapters 3 & 4) to ensure all important domains (pertaining to various

patient experience dimensions of the service) were included with particular focus on components excluded or unexplored by other studies or suggested specifically in these studies for future research. The study sample although drawn by convenience sampling was substantially diverse representing the various ethnic minority groups within UK settings which strengthen its external validity.

The limitations of thesis can be outlined in context to the reviews and primary research. One of the limitations of the systematic review was that it only included studies from OECD settings. However, it can be argued that studies from OECD countries were only included because the demographic characteristics and mode of service delivery may differ in other regions with variant socio-cultural characteristics, which would be different from the chosen settings and the dynamics of service delivery of sexual health and contraception services. Only published original research articles were included in the review excluding conference abstracts reports and theses to avoid inclusion of data collected without following validated research criteria. This may be a limitation of the review. However, a significant number of studies were identified encompassing a range of settings and addressing various components of the service. It is unlikely that excluding unpublished literature affected answering the research question of the review. The rich pool of the various study components or themes extracted from the reviewed studies provide a benchmark of the various aspects of the service with relation to the specific aim of the studies, which were questioned to capture associated patients' perceptions in diverse settings.

The limitations of the qualitative synthesis and meta-ethnography mainly include the heterogeneity in patient characteristics, study settings and the variance in the models of care of which patient experiences were explored. Patients accessing different types of

sexual health services in varied settings may report preferences which can be difficult to generalise. It may the case that the views may contradict or overlap, and the domains of patient experiences may have been overrepresented in certain second order constructs. Only published papers were included and relevant work reported in book chapters, or 'grey literature' was not included. It is also acknowledged that the process of synthesising translations is basically an interpretative process therefore a different research team may have formulated a different conceptual framework.

One of the main limitations of the primary was that it only included young participants aged between 18-24 years. The perceptions and suggestions documented by them may not be representative of the patient groups who fall in the middle age or elderly. However, it is worthwhile to mention and as previously discussed in detail in chapter 2, that the prevalence of STIs is highest among the young and ethnic minority groups within the UK and OECD settings. ADDIN EN.CITE (47, 263, 298) This fact was taken into consideration while designing the study methodology. In the study both current and potential users of the service were recruited by convenience non-probability sampling. Arguably, patients' perceptions are more validated as they have real life experience of the service delivery as compared to potential users whose expectations maybe exaggerated or not based on real life experience of the disease condition or accessing the services. Nevertheless, the study had a significant percentage of participants who were currently utilising sexual health services. Another counter argument can be that the potential clients add a wider perspective and value in context to end users' preferences of sexual health services. Moreover, it should be acknowledged that they are also an important stakeholder and beneficiary of the service and should not be excluded in evaluation of service. This is

substantiated by the fact that public and patient involvement in research is endorsed and is one of the key priorities of leading funding government research body such as National Institute of Health Research in the UK. ADDIN EN.CITE (299-301)

8.3 Meaning of the study

The findings of primary research and the two reviews (chapter 5& 6) highlight that there are various important themes (derived from patient experience dimensions and preferences of sexual health services within clinical settings) pertaining to various aspects of the service delivery process. These broader themes and associated sub-themes can be translated into desirable outcomes from a user's (patients or potential client) perspective that is specific to sexual health services. These outcomes are particularly different from other illnesses and healthcare services due to the characteristics of sexually transmitted infections including the complex non-health issues such as confidentiality and the strong stigma associated with its accessibility as discussed in detail in the thesis. As previously discussed in the thesis these preferences and associated outcomes (both health and non-health) have a direct impact on the satisfaction levels, compliance to treatment and continued accessibility to the services of the patients or potential clients accessing sexual health services.

Moreover, the outcomes (items and domains) included in a PROM should be systematically generated by conducting a comprehensive literature review, incorporating feedback from experts in the field and conducting interviews with the beneficiaries of the service as described in detail in chapter 3 and 4 of the thesis. The findings of the primary research were informed by a comprehensive systematic review, qualitative synthesis and meta-

ethnography & feedback from experts in sexual health (JS, NT, TR & LJ) in the UK. This was further substantiated by comprehensive analysis of existing theories and methodological techniques within health economics to provide solid foundations to generate possible outcomes (items and domains) which can be utilized in the development of a preference-based PROM for economic evaluation in this area.

An example of generating outcomes from the findings of the study is shown in table 8.1. It is important to reiterate that the thesis assessed existing tools, highlighted gaps in service and outlined important patient experience dimensions (factors and aspects of the services considered most important by patients or potential clients of the service) and analysed existing economic theories and methodologies existing in health economics which could inform determining outcomes pertaining to sexual health services to be utilized in economic evaluation in this area. Validation and valuation of these outcomes which are the next stages in the development of a preference-based PROM (as outlined in detail in chapter 4) which can be used to calculate QALYs is beyond the scope of this PhD.

Based on the evidence generated from the primary research combined findings of the two reviews (chapter 5 and 6) development of a de-novo sexual health services specific preference-based measure can ensure that the specific descriptions would be more sensitive to the implications of the outcomes considered most important by the patients and would allow greater precision and ability to differentiate between outcomes and changes over time. This would be achieved because such a measure would focus on important dimensions pertaining to this area which would be missed by a generic measure. Moreover, as discussed in detail in chapter 4, the addition of bolt on dimensions interferes with the value of other dimensions, where the addition of a dimension can reduce the

coefficient of another dimension. In our study nine important themes have been identified which can be translated into dimensions. The bolt-ons may be useful within healthcare in situations where one or two dimensions are missing but there is also little conceptual similarity between the different generic measures (ED5D, ASCOT, ICECAP, WEMWBS etc.).(75) Moreover there is a limitation of dimensions that can be included in a descriptive system to pragmatically apply to valuation tasks such as time trade-off and discrete choice experiments (chapter 4). Furthermore there is also risk of double counting as dimensions in one measure may be captured to some extent in dimensions in other measure.(58) However, as discussed in chapter 4, there would be a trade-off between using a sexual health specific preference-based measure which is more relevant to sexual health services and its interventions, against the comparability allowed by using generic measures.

Table 8.1 Example of how outcomes (domains and items) can be generated from the broader themes and associated sub-themes identified from the primary research

Domains	**Items**

Clear communication	a) The healthcare staff clearly communicated about my disease and addressed my concerns b) The healthcare staff communicated some aspects clearly about my disease and somewhat addressed my concerns c) The healthcare staff did not communicate clearly and addressed my concerns
Accurate diagnosis	a) I am satisfied that the doctor has made a accurate diagnosis of my disease b) I am somewhat satisfied that the doctor has made a accurate diagnosis of my disease c) I am dissatisfied, and the doctor has not made a accurate diagnosis of my disease
Involvement in decision making	a) I was fully involved in decisions about my treatment by the doctor or nurse b) I was somewhat involved in decisions about my treatment by the doctor or nurse c) I was not involved in decisions about my treatment by the doctor or nurse
Staff attitudes and behaviours	a) the staff in clinic were friendly, respectful and helpful during my visit b) the staff in clinic were somewhat friendly, respectful and helpful during my visit c) the staff in clinic were not friendly, respectful and helpful during my visit
Environment of clinic	a) the clinic was clean and had a relaxing environment b) the clinic was somewhat clean and had a relaxing environment c) the clinic was unclean and had a tense environment
Confidentiality	a) my confidentiality was maintained b) my confidentiality was somewhat maintained c) my confidentiality was not maintained
Stigma & embarrassment	a) I did not feel stigmatized or embarrassed b) I felt somewhat stigmatized and embarrassed c) I felt extremely stigmatized and embarrassed
Waiting times	a) the waiting time to get the appointment and wait for my consultation was fully acceptable b) the waiting time to get the appointment and wait for my consultation was somewhat acceptable c) the waiting time to get the appointment and wait for my consultation was unacceptable

8.4 Policy considerations

The thesis has highlighted that there are multifaceted challenges pertaining to sexual health service provision within the UK (and potentially wider OECD settings) particularly in publicly funded healthcare systems. These challenges include the unique characteristic of the sexually transmitted diseases (asymptomatic patients and highly infectious nature of STDs), associated complications of untreated disease, socio-cultural barriers (strong stigma and confidentiality issues) to accessibility of service, high prevalence of the disease among specific populations (younger age groups, ethnic and sexual minorities and marginalized segments), cost implications and limited budgets allocated and lack of availability of preference-based PROM specifically for sexual health services for economic evaluation. The following policy considerations are drawn from the findings of the thesis:

i) Importance of developing preference-based PROM for economic evaluation of sexual health services

In the UK there have been considerable cuts in the funds provided to sexual health services since its commissioning was transferred to local authorities in 2013.(15) Since, 2015 there public health budgets have been 'ring fenced' and the within the 'ring fence' the proportion spent on sexual health services has been substantially reduced.(15) A unscheduled 6% (£200 million) cut was reported in 2015-2016 and a scheduled cut of 9.6% in 2020-21.(15) With the financial constraints and increased demand for the services (with some local authorities reporting 6% increase in visits per year) there is ongoing pressure to ensure that services are designed efficiently.(15) The NHS currently already faces the challenge of shortage of medical doctors(55) specially genitourinary medicine where there is scarcity of

specialist.(56) Alarmingly, it is reported that one third of sexual and reproductive health consultants are due for retirement in next 5 years.(56)

Additionally, as mentioned in chapter 2, there is high cost associated with sexually transmitted infections globally which is often met with limited healthcare resources.(15) In the US alone, in 2010, STIs associated costs were 12 billion dollars to the healthcare system.(27) Similarly in the UK, approximately, £572 million was spent on sexual health services across the UK in 2017/18 (11) and there were 3.3 million visits to sexual health clinics in England, an increase of 13% from 2013. Additionally, the high rate of unplanned pregnancies in England have significant cost implications on NHS as direct medical costs.(7) Moreover, in terms of contraceptive services and its uptake, according to an estimate by National Institute of Clinical Excellence (NICE) if women convert from contraceptive pill to long acting reversible contraceptive methods NHS can save £100 million.(25)

Hence, it is important to conduct economic evaluations (to assess the costs and benefits) of the interventions pertaining to sexual health services because of the scarcity of resources associated with contracting STDs and its complications as supported by the evidence provided in the thesis. The existing generic preference-based PROMs such as EQ-5D as mentioned in detail in the thesis cannot capture wider health outcomes which are truly representative and specifically associated with sexual health services. The findings of the thesis highlight the lack of preference-based PROM appropriate for capturing the relevant outcomes that can be utilized in an economic evaluation in this area. Therefore, it is important to acknowledge the significance of developing a preference-based PROM specifically for sexual health services based on the theoretical foundations of health economics and standard PROM development process. Such a PROM can be effectively

utilized in economic evaluation of interventions pertaining to sexual health services which can substantially facilitate the decision-making process for resource allocation and future service design or re-design.

ii) Addressing issues of high-risk groups

The findings of the thesis propose that it is important to prioritise the patient groups which have the highest prevalence of STDs and have unmet needs pertaining to the service. The barriers associated with accessibility to sexual health services among such population groups need to be addressed both by active implementation within the service delivery processes and health education and awareness campaign to engage them with the service. Moreover, engagement with the service and continued client feedback can be achieved by active participation by both public (potential clients) and patient involvement in all stages of the future research processes (designing the protocol to data collection to drafting the findings and dissemination of the research etc.). The engagement strategies may involve arranging seminars and symposiums (ensuring identification and participation of vulnerable and high-risk groups) pertaining to health education and awareness of sexual health diseases and benefits of availing the service at individual and community level. There are various strategies that have been discussed in recent literature(304, 305) pertaining to engaging public and patients (including ethnic minorities and vulnerable groups) in health based interventions. Such strategies need to be considered, analysed and implemented for engaging high risk population groups with sexual health services.

iii) Mitigating the key barriers to accessing services

One of the key barriers to accessing services that emerged from the findings of the thesis was confidentiality issues within the domains of clinical settings which were mostly associated with staff attitudes and behaviours and the discrepancies in the standard procedures to document sensitive information relating to patients' disease and the reason for their visit. Another overlapping concept with confidentiality that was reported in thesis is the strong stigma associated with contracting a STD and accessing a sexual health service. The findings of the thesis suggest that both these major barriers are intricately interlinked with patients and potential client's expectations of other components of the service as discussed in detail in thesis. The confidentiality issues can be addressed by continuous staff training particularly focusing on their communication skills (relating to reassuring patients while handling sensitive information at reception and during history taking). Furthermore, the Covid-19 pandemic has significantly impacted the accessibility to sexual health and contraceptive services particularly face to face consultations with the patients in clinical settings.(44) For instance at the start of the pandemic accessibility to services was dramatically reduced or completely cut in the United States.(45) It is now increasingly recognized that sexual health services should be a component of future pandemic and emergency preparedness planning.(45) There has been more emphasis on online services(Telemedicine) which has gained recognition as an important route of delivering sexual health and contraceptive services.(44) However, the findings of the primary research report that despite the current pandemic face to face consultation is the preferred route of care for sexual health services particularly among ethnic minority groups (patients and

potential clients) who have the highest prevalence and face greater health inequalities. Therefore, safety measures/protocols for patients should be actively implemented and monitored within clinical settings and the healthcare staff should be trained accordingly to effectively manage patients who might face double burden due to anxiety of contracting a STI and Covid-19.

iv) Incorporating feedback by patients and potential clients to further improve the service

Substantial evidence has been provided in the thesis emphasizing that patient satisfaction with the service is strongly associated with their engagement with service and compliance to treatment. There are various aspects of service considered most important by patients and potential clients accessing sexual health services which have been identified and outlined by conducting two reviews and primary research reported in the thesis.

It is important to acknowledge that some of the important themes identified in the thesis such as ‘confidentiality’ and ‘stigma associated with accessing care’ are also highly relevant to other public health services such as addiction, gambling and weight management. However, the highly infectious nature of STIs the fact that many patients are asymptomatic, and the wider long term implications associated with unplanned pregnancy etc. mean that sexual health services require especial consideration from decision makers when allocating resources.

The pool of these themes can be potentially utilized for evaluating quality of the existing services or considered for future re-design of service to ensure that the service is patient centred. A service which is patient-centred will lead to increased accessibility and achieve the desirable health outcomes which are expected from the service by health professionals and policy makers.

8.5 Recommendations for future research

The thesis outlines important themes and provides substantial information which can be utilized to develop outcomes for a preference-based PROM specifically designed for sexual health services to be utilized in an economic evaluation. An example of how these important themes can be converted to outcomes is demonstrated in Table 8.1. The thesis covers the initial steps of PROM development namely; i) gathering input (collecting and analysing information from published literature, incorporating expert feedback and conducting interviews with patients and potential clients) and ii) identifying important themes that can be used to develop items and domains for a preference-based PROM for sexual health services. Moreover, the thesis also provides the basic theoretical foundations within health economics and its methodological application in the development of a preference-based PROM for economic evaluation relevant to sexual health services. Furthermore, the thesis discusses the limitations of the existing generic preference-based PROMs of capturing outcomes relevant from sexual health services context. This is further substantiated with analysis of the techniques that have been proposed in recent published literature to expand

the evaluative space within the Extra-Welfarist approach to capture wider health outcomes to be included in an economic evaluation (with aim to determine the most appropriate method in sexual health services context).

The further steps in developing a preference-based PROM specifically for sexual health services are beyond the scope of this PhD. The steps proposed for future research in the PROM development could include:

i) Establishing dimensions

This step will involve establishing dimensions which are structurally independent. This can be achieved by a number of techniques which include; factor analysis, cluster analysis and rash analysis to determine whether items belong to a single dimension.(58)

ii) Selecting items

This stage is an iterative and meticulous process which can be aided by previous studies by combination of 'conventional psychometric testing analysing the validity and responsiveness of items and conducting qualitative interviews with patients to understand their content and face validity'.(58) This is the refinement process in which items are eliminated, the best item per dimension is selected and item level reduction is further explored. 'Rasch is a useful technique in the process of selecting items. 'It is a mathematical technique that coverts qualitative responses to continuous latent scale using a logit model'.(58)

iii) Validation

The items that will be included in the PROM need to be improved and validated through standardized techniques namely; a) literacy level review, b) cognitive interviews and c) translation review (each step is described in more detail in chapter 5). In brief, these elements would involve:

a) Literacy review:

The literacy review step will ensure that the items included in the PROM are presented in simple easy to read format. This is an important consideration as the tool should be applicable to participants with different literacy levels.

b) Cognitive interviews:

The cognitive interviews will help to determine the clarity and importance of each item for patients. This step will involve a patient answering the items included in the PROM and then interviewed pertaining to the interpretation and thought processes involved in selecting a response. This will be an important assessment process which will allow the researchers (developers) to determine whether the understanding of an item included in PROM is same as themselves and patients. This step would allow fixing any issues of jargon, culture specific constructs technical language etc.

c) Translation review:

This step will allow the developers to assess whether it is possible to translate the PROM in other languages and any issues relating to verb tenses, units of measure etc. can be corrected.

iv) The valuation of outcomes

Valuation of outcomes included in the PROM can be achieved by a range of cardinal techniques such as standard gamble, time-trade off and visual analogue scales as discussed comprehensively in section 6.3 of chapter 6. A range of different participants can be included for the valuation of outcomes (which are permissible within Extra-Welfarist approach) which may include potential clients, patients, care givers, medical professionals or members of the general population.

8.6 Conclusions

The challenges associated with provision of sexual health services are complex due to the various factors such as the unique nature of the STDs, demographic distribution of disease, socio-cultural barriers pertaining to engagement with services and the cost implications of untreated disease and associated complications. Evidence suggests that patient satisfaction with sexual health services is linked with increased engagement, compliance to treatment & increased recommendation to friends and family members which may lead to desired health outcomes expected from the service. Therefore, it is important to holistically capture the outcomes considered most important by patients to evaluate the service & ascertain it is patient centred.

This PhD makes significant contributions towards the existing knowledge base in this area of research. Firstly, a robust systematic review was carried out within OECD settings to assess the various tools (highlighting the methodological limitations in their construction and reported findings) that have been utilized to capture patients' perceptions pertaining to various components of the service. Secondarily, a qualitative synthesis and meta-

ethnography was conducted to highlight important patient experience dimensions pertaining to the various attributes of the service. The findings of the two reviews were utilized to carry out primary research among patients and potential clients to further explore individual components of service and attributes specifically suggested for further investigation by previous studies. Moreover, the thesis also analysed the existing theories (Welfarist and Extra-Welfarist approach) and its applied techniques in health economics in context of measuring and valuation of outcomes for sexual health services. The thesis suggested the Extra-Welfarist approach more suitable. Out of the various latest techniques as discussed in literature to expand the evaluative space within this approach for calculating QALY, the findings of the thesis recommend developing a future de-novo preference-based PROM in this area of research.

APPENDICES

Appendix 1 Example of Search strategy (Systematic review chapter 5)

1. sexual health.mp. or exp Sexual Health/

2. sexual health services.mp.

3. contraception.mp.

4. sexually transmitted disease$.mp.

5. sexually transmitted infection$.mp.

6. contraceptive service$.mp.

7. genitourinary medicine.mp.

8. genitourinary medicine service$.mp.

9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8

10. patient reported outcome measure$.mp. or exp Patient Reported Outcome Measures/

11. Patient Satisfaction/ or patient reported experience$.mp.

12. patient view$.mp.

13. patient attitude$.mp.

14. patient perception$.mp.

15. patient opinion$.mp.

16. survey$.m_titl.

17. questionnaire$.m_titl.

18. 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17

19. 9 and 18

Appendix 2: Example of search strategy (Qualitative synthesis & Meta-ethnography)

Example of search strategy

1. sexual health.mp. or exp Sexual Health/
2. sexual health services.mp.
3. contraception.mp.
4. sexually transmitted disease$.mp.
5. sexually transmitted infection$.mp.
6. contraceptive service$.mp.
7. genitourinary medicine.mp.
8. genitourinary medicine service$.mp.
9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8
10. Patient Satisfaction/ or patient reported experience$.mp.
11. patient view$.mp.
12. patient attitude$.mp.
13. patient perception$.mp.
14. patient opinion$.mp.
15. survey$.m_titl.
16. questionnaire$.m_titl.
17. 10 or 11 or 12 or 13 or 14 or 15 or 16
18. exp Qualitative Research/ or qualitative.mp.
19. 9 and 17 and 18

Appendix 3: Materials for ethics approval (that were submitted to receive central university ethics approval) (Chapter 7)

UNIVERSITY OF BIRMINGHAM

Application for Ethics Review Form

What is the purpose of this form?

This form should be completed to seek ethics review for research projects to be undertaken by University of Birmingham staff, PGR students or visiting/emeritus researchers who will be carrying out research which will be attributed to the University.

Who should complete it?

For a staff project – the lead researcher/Principal Investigator on the project.
For a PGR student project – the student's academic supervisor, in discussion with the student.

Students undertaking undergraduate projects and taught postgraduate (PGT) students should refer to their Department/School for advice

When should it be completed?

After you have completed the University's online ethics self-assessment form (SAF), **IF** the SAF indicates that ethics review is required. You should apply in good time to ensure that you receive a favourable ethics opinion prior to the commencement of the project and it is recommended that you allow at least 60 working days for the ethics process to be completed.

How should it be submitted?

An electronic version of the completed form should be submitted to the Research Ethics Officer, at the following email address: aer-ethics@contacts.bham.ac.uk.

What should be included with it?

Copies of any relevant supporting information and participant documentation, research tools (e.g. interview topic guides, questionnaires, etc) and where appropriate a health & safety risk assessment for the project (see section 10 of this form for further information about risk assessments).

What should applicants read before submitting this form?

Before submitting, you should ensure that you have read and understood the following information and guidance and that you have taken it into account when completing your application:

- The information and guidance provided on the University's ethics webpages (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-of-Research.aspx)

- The University's Code of Practice for Research (https://www.birmingham.ac.uk/Documents/university/legal/research.pdf)

- The guidance on Data Protection for researchers provided by the University's Legal Services team at https://intranet.birmingham.ac.uk/legal-services/What-we-do/Data-Protection/resources.aspx.

Basic project details

Project Title: Investigating the outcome measures considered important by potential users of sexual health services within UK settings

Is this project a:

University of Birmingham Staff Research project ☐
University of Birmingham Postgraduate Research (PGR) Student project ✓
Other (Please specify below) ☐
Click or tap here to enter text.

Details of the Principal Investigator or Lead Supervisor (for PGR student projects):

Title: Dr
First name: Louise
Last name: Jackson

Position held: Senior Lecturer
School/Department Health Economics Unit

Telephone: [redacted]
Email address: [redacted]

Details of any Co-Investigators or Co-Supervisors (for PGR student projects):

Title: Prof
First name: Tracy
Last name: Roberts

Position held: Professor and Head of Department
School/Department Health Economics Unit

Telephone:
Email address:

Details of the student for PGR student projects:

Title: Dr
First name: Muslim Abbas
Last name: Syed

Course of study: PhD
Email address:

Project start and end dates:

Estimated start date of project: 27/04/2021
Estimated end date of project: 22/06/2021

Funding:

Sources of funding: University Hospital Birmingham NHS Trust

Section 2: Summary of Project

Describe the purpose, background rationale for the proposed project, as well as the hypotheses/research questions to be examined and expected outcomes. This description should be in everyday language that is free from jargon - please explain any technical terms or discipline-specific phrases. Please do not provide extensive academic background material or references.

Background:
Approximately, £572 million was spent on sexual health services across the UK in 2017/18 and there were 3.3 million visits to sexual health clinics in England, which is an increase of 13% from 2013. Moreover, screening for Sexually transmitted infections (STIs), Chlamydia, Gonorrhoea, Syphilis and HIV, has also risen by 18% (1,513,288 in 2013 to 1,778,306 in 2017. Clearly, STIs remain a common cause of morbidity in the UK. The prevalence of Chlamydia trachomatis infections is approximately 4% in adults aged 20-24 and although teenage pregnancy rates have been falling over the past decade, 8% of all conceptions still result in termination, and this is as high as 14% for women aged under 20 (Office for National Statistics 2016). Increasing the access to sexual health services can be a potentially efficient strategy for achieving the aims of the services and for reducing infection rates and the additional costs associated with complications of STIs.

Rationale of the project:
This research aims to explore and determine the outcomes and processes that are important for potential users (young individuals who are aged 18-24) of sexual health services. In England, the commissioning of sexual health services moved to local authorities in 2013with changes in responsibilities for service delivery also taking place. Alongside this, there have also been other changes to services such as increased use of postal based testing using self-taken samples, delivery of services via pharmacies and third sector providers, changes in clinic staff profiles with increased use of health care assistants and nursing staff to deliver care, and integration of contraception services with infection testing services. In addition, funding for sexual health services has reduced significantly over the last few years. The speed of change has been rapid and there has been little patient or public input into the redesign of services. This research aims to ensure that services are focussing on what truly matters to young people in terms of access to services.

Main research question
The principal research question is: what are the outcomes (components, processes and results of care) that are considered important by potential users accessing sexual health services.

The research will address the following objectives:
- *To explore the various factors and aspects of sexual health services those are considered important by young people when accessing sexual health services;*
- *To determine how these outcomes can be utilised for the development of a future tool for assessment of services, to be used within an economic evaluation to improve the*

overall quality of services for patients

Expected outcomes
Important outcomes will be identified which truly reflect what is considered important by young people in relation to access of sexual health services. These outcomes (health dimensions) will lead to development of questions (domains and items) which can be utilized to constructing a future measurement tool specifically for economic evaluation of interventions pertaining to sexual health services.

Section 3: Conduct and location of Project

Conduct of project

Please give a description of the research methodology that will be used. If more than one methodology or phase will be involved, please separate these out clearly and refer to them consistently throughout the rest of this form.

This research aims to identify what matters to young people when they access sexual health services, which will inform the design of a future tool to measure the quality of these services to be used within an economic evaluation. It is therefore necessary to conduct qualitative research to analyse what particular aspects of services and outcomes are considered most important for patients and potential patients while accessing the service. . A series of one-to-one interviews will be undertaken with young people. The interviews will be semi-structured and a topic guide has been developed following a systematic review of the literature and qualitative synthesis. It is anticipated that around 15 participants will take part in an in-depth interview, as this is likely to be the point at which saturation is approached, (when additional emerging data is not shedding additional useful light on the research question). The participants will be recruited by convenience sampling (first come first served). Evidence suggests that to design an effective questionnaire, qualitative work is initially undertaken to explore and understand the various factors that are considered important for the sample of interest in a research study. For this project a qualitative synthesis and meta-ethnography was conducted to analyse the constructs that are considered important for patients accessing sexual health services. Moreover, a comprehensive systematic review was also conducted to explore the various tools utilized in previous studies assessing sexual health services within OECD countries and identifying gaps in the service from a patients′ perspective. The systematic review and qualitative synthesis were used to develop a list of important topics and questions (domains and items) that are considered important for potential clients while accessing sexual health services. This resource was used to inform the development of a topic guide to be used in-depth interviews. The topic guide will be used to stimulate discussion about the characteristics of the sexual health services focusing on the clinical consultation process.

Geographic location of project

State the geographic locations where the project and all associated fieldwork will be carried out. If the project will involve travel to areas which may be considered unsafe, either in the UK or overseas, please ensure that the risks of this (or any other non-trivial health and safety risks associated with the research) are addressed by a documented health and safety risk assessment, as described in section 10 of this form.

The interviews will be conducted online or via telephone (not in person). The postgraduate research student will conduct in-depth interviews of 30-40 minutes duration via an online platform or by phone.

Section 4: Research Participants and Recruitment

Does the project involve human participants?

Note: 'Participation' includes both active participation (such as when participants take part in an interview) and cases where participants take part in the study without their knowledge and consent at the time (for example, in crowd behaviour research).

Yes ✓
No

If you have answered NO please go on to Section 8 of this form. If you have answered YES please complete the rest of this section and then continue on to section 5.

Who will the participants be?

Describe the number of participants and important characteristics (such as age, gender, location, affiliation, level of fitness, intellectual ability etc.). Specify any inclusion/exclusion criteria to be used.

The participants will be young people aged 18 -24. Participants will be recruited from the University of Birmingham and via Birmingham City Council Youth Service.
Inclusion criteria
- Participants who are able to provide informed consent
- Participants 18 -24

Exclusion criteria:
- Participants under 18 years of age or over 24.
- Participants who are unable to provide informed consent

How will the participants be recruited?

Please state clearly how the participants will be identified, approached and recruited. Include any relationship between the investigator(s) and participant(s) (e.g. instructor-student). Please ensure that you attach a copy of any poster(s), advertisement(s) or letter(s) to be used for recruitment.

The participants will be recruited in the study by the following steps:
Identification of participants:
Participants will be recruited from the University of Birmingham and via Birmingham City Council Youth Service.
Approaching the participants and recruitment in the study:
The participants will be approached through different electronic mediums including, social media, email communication and electronic newsletters. The strategy for approaching students through each medium is described briefly below.

d) Email communication: Youth workers from Birmingham City Council will use their contact list to send details of the research to young people aged 18-24. Young people who are interested in taking part will be asked to contact the main researcher via email (Muslim Syed). The researcher will then contact the participant to send further details about the study and arrange a convenient date and time for the interview. For University students, the communication leads of various departments/colleges in the university will be approached and requested to send group email with advertisement of the research so interested students might approach the researcher to be recruited in the study. The undergraduate admission tutors and programme leads will also be asked to circulate details of the study. The contact information of the administrative staff and programme leads will be accessed through the University website for making the initial request to circulate details of the research to students.
e) Social media: Different social media forums such as Twitter and Facebook will be utilized to tag various colleges of University of Birmingham to advertise the research and request for recruitment in the study. Interested participants will email the researcher to find out more information about the study.
f) Snow ball technique: Participants who will participate in interviews will be requested to identify potential participants who might be interested in the research. They will be requested to pass on the details of the researcher to these new potential participants.

Section 5: Consent

What process will be used to obtain consent?

Describe the process that the investigator(s) will be using to obtain valid consent. If consent is not to be obtained explain why. If the participants are under the age of 16 it would usually be necessary to obtain parental consent and the process for this should be described in full, including whether parental consent will be opt-in or opt-out.

The study will only include participants who are aged 18-24. Verbal consent will be obtained by the researcher prior to the start of the interview and will be recorded on the digital audio recorder with the participants' permission.

Please be aware that if the project involves over 16s who lack capacity to consent, separate approval will be required from the Health Research Authority (HRA) in line with the Mental Capacity Act.

Please attach a copy of the Participant Information Sheet (if applicable), the Consent Form (if applicable), the content of any telephone script (if applicable) and any other material that will be used in the consent process.

Note: Guidance from Legal Services on wording relating to the Data Protection Act 2018 can be accessed at https://intranet.birmingham.ac.uk/legal-services/What-we-do/Data-Protection/resources.aspx.

Use of deception?

Will the participants be deceived in any way about the purpose of the study?

Yes ☐
No ✓

If yes, please describe the nature and extent of the deception involved. Include how and when the deception will be revealed, and the nature of any explanation/debrief will be provided to the participants after the study has taken place.

Click or tap here to enter text.

Section 6: Participant compensation, withdrawal and feedback to participants

What, if any, feedback will be provided to participants?

Explain any feedback/ information that will be provided to the participants after participation in the research (e.g. a more complete description of the purpose of the research, or access to the results of the research).

It will not be possible to inform participants individually about the results as we will not retain any personal details about them after the interviews have taken place. Email

addresses and contact telephone numbers will be destroyed immediately after the interviews have taken place. However, all those who take part in the study will be given the details of the project website and informed that the study findings will be available on this website, after the study has been completed. The participants will be informed prior to the interview while taking verbal consent that the information provided by them will be anonymized to maintain their confidentiality.

What arrangements will be in place for participant withdrawal?

Describe how the participants will be informed of their right to withdraw from the project, explain any consequences for the participant of withdrawing from the study and indicate what will be done with the participant's data if they withdraw.

Before the start of the interview, participants will be reminded that at any point of the interview if they feel uncomfortable they can terminate the interview. The participant will not face any consequences by withdrawing from the study. The data will be immediately destroyed if the participate withdraws from the study.

Please confirm the specific date/timescale to be used as the deadline for participant withdrawal and ensure that this is consistently stated across all participant documentation. This is considered preferable to allowing participants to 'withdraw at any time' as presumably there will be a point beyond which it will not be possible to remove their data from the study (e.g. because analysis has started, the findings have been published, etc).

The participants will be ensured that they have the right their data from the study up till 2 weeks after participating in the interview as after that time period the data analysis process would be started and it will be not be possible to remove their data from the study.

What arrangements will be in place for participant compensation?

Will participants receive compensation for participation?

Yes ✓
No □

If yes, please provide further information about the nature and value of any compensation and clarify whether it will be financial or non-financial.

The participants will be given a £10 gift voucher as a compensation for participating in a 30-40 minutes interview.

If participants choose to withdraw, how will you deal with compensation?

The participants will receive the £10 gift voucher once completed the interview. If they wish to withdraw their data latter they will not be expected to return the compensation amount.

Section 7: Confidentiality/anonymity

Will the identity of the participants be known to the researcher?

Will participants be truly anonymous (i.e. their identity will not be known to the researcher)?

Yes ✓
No

In what format will data be stored?

Will participants' data be stored in identifiable format, or will it be anonymised or pseudo-anonymised (i.e. an assigned ID code or number will be used instead of the participant's name and a key will kept allowing the researcher to identify a participant's data)?

Personal data about the participants will not be collected by the researchers during interviews. The details collected to contact participants will be immediately destroyed once the interviews have taken place. Audio recordings will be retained only until transcription has been undertaken and then they will be securely deleted. The only data collected and retained will be the anonymised transcripts. These will be stored for 10 years in line with the University's Code of Practice.
Direct quotations from participants in the interviews will be utilised, but all quotations will be anonymised so that no information that makes an individual personally identifiable is included in the quotation. Quotations will only be attributed via study numbers or via the use of false names. Furthermore, Audio recordings will be transferred onto University computers at the earliest opportunity and deleted from the portable recording device. Verbatim transcripts and digital recordings will be stored in a separate password protected file or on a password protected section of the UoB server. Transcripts and recordings will be indexed solely with the study ID number so that participants are not identifiable. Only members of the research team will have access to the study data. After completion of the study, data will be stored for 10 years (in line with University of Birmingham recommendations), after which electronic files will be deleted and hard copies will be shredded.

Will participants' data be treated as confidential?

Will participants' data be treated as confidential (i.e. they will not be identified in any outputs from the study and their identity will not be disclosed to any third party)?

Yes ✓
No

If you have answered no to the question above, meaning that participants' data will not be treated as confidential (i.e. their data and/or identities may be revealed in the research outputs or otherwise to third parties), please provide further information and justification for

*this:*Click or tap here to enter text.

Section 8: Storage, access and disposal of data

How and where will the data (both paper and electronic) be stored, what arrangements will be in place to keep it secure and who will have access to it?

Please note that for long-term storage, data should usually be held on a secure University of Birmingham IT system, for example BEAR (see https://intranet.birmingham.ac.uk/it/teams/infrastructure/research/bear/index.aspx).

Audio recordings will be transferred onto University computers at the earliest opportunity and deleted from the portable recording device. Verbatim transcripts and digital recordings will be stored in a separate password protected file or on a password protected section of the UoB server. Transcripts and recordings will be indexed solely with the study ID number so that participants are not identifiable. Only members of the research team will have access to the study data. After completion of the study, data will be stored for 10 years (in line with University of Birmingham recommendations), after which electronic files will be deleted and hard copies will be shredded.

Data retention and disposal

The University usually requires data to be held for a minimum of 10 years to allow for verification. Will you retain your data for at least 10 years?

Yes ✓
No □

If data will be held for less than 10 years, please provide further justification:

Click or tap here to enter text.

What arrangements will be in place for the secure disposal of data?

Personal data about the participants will not be collected by the researchers during interviews. The details collected to contact participants will be immediately destroyed once the interviews have taken place. The only data collected and retained will be the original anonymized audio recordings. The digital recordings will be securely deleted after transcription..

Section 9: Other approvals required

Are you aware of any other national or local approvals required to carry out this research?

E.g. clearance from the Disclosure and Barring Service (DBS), Local Authority approval for work involving Social Care, local ethics/governance approvals if the work will be carried out overseas, or approval from NOMS or HMPPS for work involving police or prisons? If so, please provide further details:

There is no other approval required.

For projects involving NHS staff, is approval from the Health Research Authority (HRA) needed in addition to University ethics approval?

If your project will involve NHS staff, please go to the HRA decision tool at http://www.hra-decisiontools.org.uk/research/ to establish whether the NHS would consider your project to be research, thus requiring HRA approval in addition to University ethics approval. Is HRA approval required?

Yes
No ✓

Please include a print out of the HRA decision tool outcome with your application.

Section 10: Risks and benefits/significance

Benefits/significance of the research

Outline the potential significance and/or benefits of the research

The participants will get an opportunity to express their opinions about the various attributes of the service and can identify various components that they consider can be improved. As patients are direct beneficiary of the service it is extremely important to incorporate their views to improve the quality of the service.

Risks of the research

Outline any potential risks (including risks to research staff, research participants, other individuals not involved in the research, the environment and/or society and the measures that will be taken to minimise any risks and the procedures to be adopted in the event of mishap.) ***Please ensure that you include any risks relating to overseas travel and working in overseas locations as part of the study, particularly if the work will involve travel to/working in areas considered unsafe and/or subject to travel warnings from the Foreign and Commonwealth Office (see*** https://www.gov.uk/foreign-travel-advice)***. Please also be aware that the University insurer, UMAL, offers access to RiskMonitor Traveller, a service which provides 24/7/365 security advice for all travellers and you are advised to make use of this service (see https://umal.co.uk/travel/pre-travel-advice/).***

The outlining of the risks in this section does not circumvent the need to carry out and document a detailed Health and Safety risk assessment where appropriate – see below.

The young people may be particularly concerned about confidentiality issues. In all of the information that is given to participants, we will explain that participation is voluntary and that we will keep all information confidential. We will also make it clear that we will not publish any information which could allow individuals to be identified. We will also explain that the researchers will not have access to personal details about participants and we will explain that their confidentiality will be protected. We will make it clear that participants can withhold any information that they feel is too sensitive and can withdraw from the study until the end of the interview. All data collected in the study will be stored securely and in accordance with the University of Birmingham's Code of Practice for Research. The main researcher has completed good clinical practice training and has a strong academic background and has previous research experience in conducting qualitative research.

University Health & Safety (H&S) risk assessment

For projects of more than minimal H&S risk it is essential that a H&S risk assessment is carried out and signed off in accordance with the process in place within your School/College and you must provide a copy of this with your application. The risk may be non-trivial because of travel to, or working in, a potentially unsafe location, or because of the nature of

research that will carried out there. It could also involve (irrespective of location) H&S risks to research participants, or other individuals not involved directly in the research. Further information about the risk assessment process for research can be found at https://intranet.birmingham.ac.uk/hr/wellbeing/worksafe/policy/Research-Risk-Assessment-and-Mitigation-Plans-RAMPs.aspx.

Please note that travel to (or through) 'FCO Red zones' requires approval by the University's Research Travel Approval Panel, and will only be approved in exceptional circumstances where sufficient mitigation of risk can be demonstrated.

Section 11: Any other issues

Does the research raise any ethical issues not dealt with elsewhere in this form?

If yes, please provide further information:

Click or tap here to enter text.

Do you wish to provide any other information about this research not already provided, or to seek the opinion of the Ethics Committee on any particular issue?

If yes, please provide further information:

Click or tap here to enter text.

Section 12: Peer review

Has your project received scientific peer review?

Yes ✓
No □

If yes, please provide further details about the source of the review (e.g. independent peer review as part of the funding process or peer review from supervisors for PGR student projects):

The project has been peer reviewed from supervisors of the PhD project.

Section 13: Nominate an expert reviewer

For certain types of project, including those of an interventional nature or those involving significant risks, it may be helpful (and you may be asked) to nominate an expert reviewer for your project. If you anticipate that this may apply to your work and you would like to nominate an expert reviewer at this stage, please provide details below.

Title: Click or tap here to enter text.
First name: Click or tap here to enter text.
Last name: Click or tap here to enter text.
Email address: Click or tap here to enter text.
Phone number: Click or tap here to enter text.

Brief explanation of reasons for nominating and/or nominee's suitability:

Click or tap here to enter text.

Section 14: Document checklist

Please check that the following documents, where applicable, are attached to your application:

Recruitment advertisement ✓
Participant information sheet ✓
Consent form ✓
Questionnaire ✓
Interview/focus group topic guide ✓

Please proof-read study documentation and ensure that it is appropriate for the intended audience before submission.

Section 15: Applicant declaration

Please read the statements below and tick the boxes to indicate your agreement:

I submit this application on the basis that the information it contains is confidential and will be used by the University of Birmingham for the purposes of ethical review and monitoring of the research project described herein, and to satisfy reporting requirements to regulatory bodies. The information will not be used for any other purpose without my prior consent. ✓

The information in this form together with any accompanying information is complete and correct to the best of my knowledge and belief and I take full responsibility for it. ✓

I undertake to abide by University Code of Practice for Research (https://www.birmingham.ac.uk/Documents/university/legal/research.pdf) alongside any other relevant professional bodies' codes of conduct and/or ethical guidelines. ✓

I will report any changes affecting the ethical aspects of the project to the University of Birmingham Research Ethics Officer. ✓

I will report any adverse or unforeseen events which occur to the relevant Ethics Committee via the University of Birmingham Research Ethics Officer. ✓

Please now save your completed form and email a copy to the Research Ethics Officer, at aer-ethics@contacts.bham.ac.uk. As noted above, please do not submit a paper cop

Remember these are not patients..

Study tool for Primary research: Topic guide for one-to-one interviews

1. Introduction

- Brief introduction to the researcher and the project
- Study topic and funder
- Explanation of the aims and objectives of the study
- Remind about confidentiality and anonymity
- Go through consent issues explaining what they may withdraw at any time from interview as whole, and do not have to answer any questions they would prefer not to; participants will be reminded that they will be asked for their general views about services and should not share details relating to their own sexual health.
- Check whether they have any questions
- Check that they are happy to continue

2. Background

Aims: to get participant talking and find out information about views on sexual health services. Ask general questions about:

- What do you think matters to young people about sexual health services?
- Are the things that matter to them about sexual health services similar or different to other kinds of services e.g. GP appointment for a cold.

3. Expectations of the service

Aims: to understand the expectations of young people visiting the sexual health clinic pertaining to the external environment and the healthcare staff.

- What would your expectations be for a good environment while visiting a sexual health clinic (discuss the desirable attributes, reception area, waiting area, waiting times etc.)
- What are would your expectations be for how you would want to be treated by healthcare staff (focus on staff at reception or any chaperones that maybe available, how treated by doctors and nurses)
- What do you think would be a good outcome from a clinical consultation with a doctor or nurse at the sexual health clinic (discuss the role of the doctor, desirable attributes of the consultation that young people would expect)?
- What would be considered most important by you during the visit (probe both the environment, the attributes of the healthcare staff, the outcomes of the consultation)

4. Concerns about confidentiality

Aims: to understand in detail any concerns and fears about confidentiality during a visit to sexual health clinic.

- In your opinion what is the significance of confidentiality while visiting a sexual health clinic
- What are the factors/issues (mental health etc.) associated with confidentiality and how can they be addressed?
- Are there any differences for particular groups of young people?
- How might staff attitudes and behaviours reassure young people about confidentiality (probe on views on different issues faced)

5. Pathways of care

Aims: to understand the various attributes of pathway of care which may affect young people's satisfaction and engagement with the service?

- What are your expectations of the acceptable waiting times at a sexual health clinic to get an appointment, to wait to be seen, to wait for results (inquire about acceptable waiting in their opinion)
- Was it easy or difficult finding the service initially and identifying how to engage with it for advice or an appointment?

- Would you be happy to book on a web site and take samples yourself while in the clinic?
- Have would you prefer to receive the results of a STI test (phone, email, text etc.) and for partner notification?
- What might influence young people's choices about whether to go to a sexual health clinic, order an online testing kit or not? How would they decide which clinic to attend?
- If necessary prompt: Would things like waiting times, privacy, waiting areas, the types of screening on offer, support, speed of results, etc. matter? Why?

6. Quality of medical care

Aim: To understand young people's perceptions pertaining to the quality of tests and treatment provided at the clinic

- How would you judge the quality of care provided by clinical staff?
- What would make you feel you had received good care?
- Would you have any views about having particular tests? Are there particular STIs people would want to be tested for or for everything?
- Would you want to be involved in discussions about the best treatment? What would you want to know about treatment?
- (Probe if participants have any concerns about this or do they assume that they will receive the right tests and treatment).

7. Direct and indirect costs associated with attending the service

Aims: to understand the direct and indirect costs associated with visiting a sexual health clinic and its influence on continued engagement with service and better compliance of young people.

- If you needed to, how would you commute to access the nearest sexual health clinic and would be the cost associated with travel (public transport), car parking etc.?
- What other costs would be associated with making a visit (missing a shift at work etc.)
- Would this be important to you?

- Would there be any issues around social or family support around making a visit and might be the challenges associated with it?

8. Suggestions to improve service

Aims: to encourage young people to give suggestions to improve service.

- What are your suggestions to improve services (probe interviewees to discuss the external and internal attributes of the service including healthcare provider roles) and to engage young people with the service?

9. Outcomes

So, if you had to sum up, what would be the most important things for you, that you would think about to decide whether you had had a 'successful' visit to a sexual health clinic?

(If they say several things – which of these would be the most important)

10. Any other issues

Are there any other things that would be important about visiting a sexual health clinic that we have not discussed?

11. In conclusion

Thank the participant for their time. Reiterate that the interview will remain confidential.

Tell them that they are welcome to contact members of the study team to ask questions at a later date if they wish.

Give information about local sexual health services in case they have any concerns.

APPENDIX 4: Initial analysis of qualitative data (Broader themes and direct quotations utilised to synthesize main themes and sub-themes for primary research, ref. Chapter 7)

Broader theme	Associated sub-themes	Direct quotations
	Clear communication & accurate diagnosis	'For me it would be getting the information and treatment for the problem that you went in for, I mean in some cases you go in with a problem to a clinic and come out even more confused, hahaha. So you get what you wanted for when you get in' **(Participant no 2, Female age 23, African Black, Current user)** 'Well, it'd be going there and then feeling like they've helped my issue. So feeling like I've got the right answer that I need or that feeling like I've been heard or feeling that, okay, I've got these results and they've told me the proper ways to care for myself' **(Participant no 13, Male**

age 21, Asian British, Current user)

'I think a good outcome will be that the young person is able to tell all the symptoms and what is bothering them, and they get the diagnosis and treatment, what they would need' **(Participant no 5, Male age 18, White, Current user)**

'I think it's about being thorough. So sometimes when you have a problem you'll explain what your problem is, but in science terms when a GP or a doctor tries to explain it back to you it's not something that we might understand. So like for example when you go to the dentist I've noticed that this particular dentist that my cousin goes to, he draws out a diagram and he kind of annotates the diagram and explains it to her in a way that she'll understand. She's just a child. So instead of using all these big and fancy words, sometimes just by saying, 'Look this is the

problem and this is how it's happened, but don't worry this is what you can do.' Sometimes the GP, they don't really pay much attention. They just scribble notes down and then they say, 'Okay, go to the pharmacy, this is what you need.' Sometimes they don't take enough time to actually explain what the route cause or what the problem is, do you know what I mean? Just the general conversation. So yeah, that's probably the most important thing I would say' **(Participant no 14, Female age 20, British Black, Current user)**

'They don't ask you too many questions. They're just there to listen and answer your questions and then if they need to, they ask the right questions that are topical to what you're talking about, not about them trying to pry into any other details maybe that aren't relevant' **(Participant no 6, Female age 22, White, Current user)**

Being involved in decision making	‘I just what to be in control, if I go to a sexual health clinic I want to be in control of my own decisions’ **(Participant no 4, Female age 21, White, Current user)**
	‘I would say feeling, the understanding what is going on, so as adult you feel that you are involved in the care and the decisions are not being made for you, they are made with you, I would probably say that is most important for me’ **(Participant no 2 Female age 23, African Black, Current user)**
	‘First of all I’d want to know if there were any side effects for··· no actually I’d want to know what exactly the treatment does, for example if it’s a viral infection, how exactly it helps to destroy or helps to subdue the virus, I’d also like to know any form of side effects because I feel that’s very important to me, a lot of these treatments actually have a lot of side effects [sure] so things like this need to be properly checked so yeah that’s it, also I’d like to know the method of treatment as well because I think that some people may be a bit ok with oral treatment of drugs whereas some people would not like them to be injected with a syringe so the actual method of treatment is very important as well’

(Participant no 15, Male age 21, White, Current user)

'Respectfulness···a·····not receiving advice but information, I would also think that they are willing to do what I am suggesting' **(Participant no 10, Female age 20, British Asian, Current user)**

'British culture, the British culture shapes sexual health services, people from other cultures would probably feel the decision of their culture, would be suggestive in any way. For me it would feel that someone else has made my decision. If I thought my thoughts were accepted and my culture was and I made my own decisions I would feel I had a successful visit to the sexual health clinic' **(Participant no 1, Male age 21, White, Potential user)**

'Usually it's the treatment that the doctor gives you and you just eat it.

It's really good to discuss the different treatment options, some are

better than others. Yea I would like to be involved' **(Participant no 3,**

Male age 23, African Black, Potential user)

Preferences of service delivery components	**Staff attitudes and behaviours**	‘There are times where, sometimes I understand that you know people, like everybody’s human but there's times where doctors actually just reach a quick conclusion without actually listening to everything you have to say. So, I think that sometimes also can affect the service. So, even though they're doctors, I think they still need to be patient in terms of listening to the actual patient, the person who’s in front of them’ **(Participant no 6, Female age 23, White, Current user)** ‘I would say the friendliness and professionalism, I mean if I receive the care I was expecting I would say, if I came out of the appointment happy I would say if I got the treatment I would judge it as good quality of care’**(Participant no 12, Female age 19, White, Potential user)** ‘And I would say a friendly personality and someone you can relate to can be really helpful. As the people that walk in are stressed and

worried and a friendly face or a warm personality can really help and go a long way…′**(Participant no 13, Male age 22, Asian British, Current user)**

′I think that would be the most important thing and definitely like I said, the approach of the staff to patients, I think that′s very important, the atmosphere that they create, I think that′s also very important′ **(Participant no 8, Female age 24, Asian British, Potential user)**

′I want them to just be really friendly, really approachable. You know, people′s body language can really put you off so if they are looking quite grumpy and sort of slouched, that is going to put me off, I mean open body language… if I′m saying to them, you know, I feel really embarrassed about this they could say to me things like ok we can have a talk privately in the next room, but just you know always being really,

really approachable and friendly, I think that's just, that's so paramount to this kind of service' **(Participant no 2, Female age 23, African Black, Current user)**

'I would say probably just to have excellent customer service because if you have excellent customer service there's nothing else that could go wrong, whereas some people don't have that sort of nature about them and therefore they may come across rude or may come as making someone who's already uncomfortable even more uncomfortable' **(Participant no 8, Female age 24, British Asian, Potential user)**

'Being acknowledged when I enter the clinic, being asked whether I know where to go, being asked if I need any help, just general customer service questions I would guess. Again, just to be acknowledged and to know that if I do have questions there is always someone that can help' **(Participant no 15, Male age 21, White, Current user)**

'Well, somewhere that's friendly, kind. The staff aren't too··· How do you say? They don't ask you too many questions. They're just there to listen and answer your questions and then if they need to, they ask the right questions that are topical to what you're talking about, not about them trying to pry into any other details maybe that aren't relevant'

(Participant no 5, Male age 19, White, Current user)

'They need to sort of address it in more of a less professional manner in the fact that the person needs to be approachable because these things are quite sensitive so the person definitely needs to be approachable'

(Participant no 3, Male age 23, African Black, Potential user)

'It would be that it's private and it's safe between you and the doctor or nurse, like everything's protected and you just feel like you can chat to this person more like a figure like to express everything as it's more

	Maintaining privacy & confidentiality	personal and private, nobody else will know about it so it's like a way that you just feel safe and open and you talk about it so that would be my most important thing' **(Participant no 14, Female age 20, British Black, Current user)** 'For me its privacy, that's always the most important thing. Even when I've been to like a normal consultation with the GP the privacy has been the most important thing because that has made me feel comfortable and safe as well' **(Participant no 2, Female age 23, African Black, Current user)** 'Being able to talk without judgement, without having to give too many details about yourself with just being able to be there and it's all about the problem, nothing else. Just the anonymity about it, the

	anonymousness of it' **(Participant no 5, Male age 18, White, Current user)**
Comprehensive & sympathetic clinical assessment	'If all my points are taken into account, and you know a collective solution is reached, medication is given, all the tests are done, instead of simply brushing something of like, oh it's not that serious but if it persists, come back, you know, dealing with it at that, you know at that minute. So, I think that's something that would you know, yes' **(Participant no 10, Female age 20, British Asian, Current user)**
	'I think firstly the main objective should be to find out the treatment or cures to whatever is happening, if I need either the relevant tests, should be carried out or planned. That should be the main aspect'

'If the doctor is able to advise me give me the right antibiotics, giving me the right advise you see, a···. for example if I need a antibiotic for a disease I would want to be given the right medicine, and if I am provided with the treatment that I really need, I would expect it to be the right one, that will be, I guess..a···.a good outcome, you see' **(Participant no 2, Female age 23, African Black, Current user)**

'I think a good outcome will be that the young person is able to tell all the symptoms and what is bothering them, and they get the diagnosis and treatment, what they would need'**(Participant no 12, Female age 19, White, Potential user)**

'I would say that a good outcome would be being able to identify the root of the problem or whatever issues you may have and also being able to provide the right services and the ease of the patient as well

	Clean and calm environment	because a lot of patients come in and they may not really get on well with people so I would say that being able to understand the patient, being able to understand exactly what the problems are they are facing and trying to mitigate those problems according to you know the patient's emotions or any other underlying background' **(Participant no 15 Male age 21, White, Current user)**
		'A·····.clean, cleanliness, a lot of information in the environment, which people can read, I mean..a···.a calm environment, if someone comes in they can really anxious, so a calm environment can really make someone, I mean at ease. So a calm environment can really help' **(Participant no 5, Male age 18, White, Current user)**

	‘a..umm···like I have been, if there is something as simple as music in the waiting area like magazines to look at, if you are nervous and embarrassed about attending, you have got something whilst you are waiting for appointment., something that will keep you occupied. The main thing is I would say is welcoming, ummm···something private and safe place to go to’**(Participant no 12, Female age 19, White, Potential user)**
Feeling of being respected	‘a···.a good environment would be a friendly staff, you are already going there feeling anxious, there is someone that can put you at ease, and make you feel comfortable, maybe it is not that quiet, there is a tv or a magazine, books, maybe games to put your mind off while you wait for your appointment’ **(Participant no 6, Female age 23, White, Current user)**

‘I would say definitely for sexual health services I would always advise that the place is very sanitary, because that matters a lot, more than ever, whatever they are giving you, it may be medication, it might be maybe more physical things that relate to your blood, definitely I would say the quality and the hygiene of the environment would be very important and also ‘**(Participant no 13, Male age 22, Asian British, Current user)**

‘Probably respect. Coming out and feeling respected not as a person but my views and opinions and my sexual health is respected and me as a person as well’ **(Participant no 2, Female age 23, African Black, Current user)**

	‘One can really feel vulnerable while visiting a sexual health clinic··· self respect is important, I guess to everyone, and when you visit a sexual health clinic, one can feel that it can be compromised, I mean if they are made to feel that way while in the clinic. It is very important for the clinic staff to consider this and give the respect that a patient deserves, that is what I believe’ **(Participant no 10, Female age 20, Asian British, Current user)**
Waiting times	‘Being time efficient, so from the minute I’d booked the appointment, I know my appointment’s going to be at this time, I’m seen quite efficiently, the clinic was easily accessible, I didn’t have to waste a long time travelling to and from it, so just being time efficient in general would make me feel like it was successful’ **(Participant no 4, Female age 22, White, Current user)**

'Yes because somebody going to the service, they don't want to waste a lot of time there, they don't want to be seen there they are going to be embarrassed to be there so being very time efficient definitely' **(Participant no 13, Male age 22, British Asian, Current user)**

Comprehensive testing

'I would say it's good to be tested for everything, as there are so many STIs, there are diseases like gonorrhoea and chlamydia, so you want to be tested for everything that you don't have any of them' **(Participant no 9, Male 21 Years, Asian British, Current user)**

'I think they would want all kind of tests because they're already there and because it takes so long to get an appointment, when you get one, I think a young person would just want to do everything at once. And just get it done with. And just you know get the person done, because they think, for example, they think blood could be used to do several test. So that is something, you know they want to do everything, several various tests at once' **(Participant no 12, Female 19 years, White, Potential user)**

'I would say people first of all would have the immediate ones like HIV is the most common one that they would want to be tested for, if I was to think about any other ones they would probably be··· the ones that are usually the most common, like syphilis or maybe gonorrhoea, some people who are actually not sure what type of STI they have would want to take as many tests as possible just to be able to you know narrow it down but like I said earlier, HIV AIDS would be the most common test that people go for' **(Participant no 2, Female age 23 years, African Black, Current user)**

Notification of STI test results	'Definitely not the post, hahaha··· so what would be helpful it would be text message or email that will be really useful, sometimes people can miss a call, so yea a text message and email will be helpful' **(Participant no 14, Female age 20 years, British Black, Current user)** 'There are pros and cons for everything, with text messages they are good, but sometimes the text messages can pop up on someone screens, and people also borrow each other phones, it's a quicker way to send, and then with emails, like people can get a abundance of emails and it can get lost in that, junk, both text messages and emails are secure ways of getting test results' **(Participant no 9, Male age 21 years, Asian British, Current user)**

Partner notification

'I think probably through a phone call as it's such a sensitive issue. A text message will be really problematic because they get a very very very difficult situation without a explanation about it'**(Participant no 1, Male age 21 years, White, Potential user)**

'Umm··· I am not sure; I think I was also asked about partner notification when I visited. It would be the same I guess a text message and email will be better as well. A call can actually make them angry, imagine if they are no longer in a relationship, it can create a bit of drama, so I would say a text message or email would be better'**(Participant 11, Female 21 years, Black British, Current user)**

'I think a telephone call will be appropriate, I mean if they don't even know that their partner has a STI, and then they get a text message, it's a bit fishy, but on a phone call you can call and say hi, I am calling from

STI testing services	this place, your name is Mr or Miss, it's easier to introduce yourself' **(Participant no 14, Female 20 years, Black British, Current user)**
Acceptable waiting time to receive STI test result	'a···so I don't think I didn't get the results of my STI test when I last visited I need to check about that. If you get your results within a week that is really helpful and put someone waiting for the result at ease, as it is really stressful waiting for the results. It should not be more than 2 weeks I would say' **(Participant no 2, Female 23 years, African Black, Current user)**

'Well··· I think 1 week is enough, not more than that. As you know STD's are very infectious and other people can get infected. Especially those related to the person. It's very important, even in contraception or pregnancy. It has a big effect on the person state of mind. It's very stressful so it should not be more than 1 week' **(Participant no 7, Male 24 years, Asian British, Current user)**

Stigma associated with accessing service

'a···. it's just because the stigma is already there it's important that stigma is restricted it's a tough situation for people who are entering there. For example, different people have different opinions about abortion, about sex, about marriage and other things··· its different for different cultures and religious backgrounds···' **(Participant no 1, Male 21 years, White, Potential user)**

'Personally I wouldn't tell my family and I would just go there because of my ethnicity and I am really worried about telling them, I would keep that private' **(Participant no 10, Female age 20 years, Asian British, Current user)**

'It's very important. Yes, very important. For young people when they enter a clinic, it is a fear that they have that other people might find out and that can be problematic for them, so I guess it is important for

everyone who visit the clinic, I guess' **(Participant no 5, Male 18 years, White, Current user)**

'Yea··· I would say that perhaps···ummm···maybe more stigma when going to sexual health services rather than for example to other serives like going to a GP, ummm.. you would be like, like, like more embarrassed to go, to access sexual health support, ummm···yea..I would say it is different in that aspect, I would say , ummm..maybe its not that much talked about, if you feel unwell you might feel ok sharing about it with friends or family… that you have a appointment with the GP, umm··· if it is for example something to do about sexual health you can't be that open about it with people that I have a appointment with umbrella about sexual health as compared to other health problems' **(Participant no 14, Female age 20 years, British Black, Current user)**

Stigma and embarrassment associated with accessing the services	'I think it will be different because there's still like a stigma attached to like sexual health problems. So, people are not really confident when they go in for like sexual health related problems as opposed to like a GP, having a general illness. Sexual health is more specific and because people are not as open minded or like people still feel a bit shy, people would feel like, oh these people are judging me, I think it's very different, you know with the sexual health clinic and the GP' **(Participant no 3, Male age 23 years, African Black, Potential user)**
Fear of leakage of personal information	'That's the most important thing because I feel like most young people, especially myself, I wouldn't disclose that something was wrong necessarily so if I am disclosing it that would be a massive fear of mine that would come and if I felt for any reason that my information wasn't being kept confidential that would cause me a horrendous amount of emotional distress and probably really heighten the anxiety and depression that some people may have' **(Participant no 11, Female 21**

years, Black British, Current user)

'I think to begin and just in terms of patient level, if it should be confidential so many patients feel happy with approaching these sexual clinics regarding any issues. They don't want to be exposed so, that's very important, that the information isn't leaked. Especially living in a small town or city where it's very easy to get access to this information, spread across.' **(Participant no 14, Female 20 years, British Black, Current user)**

'It's probably the most important thing as well. Like you have that trust as soon as you step into that door. So knowing that your details would not be shared, because you could be attending a place that a lot of people that you know have attended and you're not going to be the only person in the same area that visits there. So even if you do bump into someone that's there that's also in the waiting room, you have that

confidence that whatever you've shared with the staff there, whether that be the receptionist or the person behind the desk, that's not going to be breached. And that's something that you don't ever – in this country anyway – we don't ever question it. So the significance is massive' **(Participant no 4, Female 22 years, White, Current user)**

'Very, very significant because it's somebody's livelihood because if somebody, like most people get something like that they want to keep it private to themselves and they wouldn't want anyone else to know because confidentiality is very important because they don't want anyone else to know because it's trauma like their experience and they don't want to share with other people so it should be very highly rated' **(Participant no 9, Male 21 years, Asian British, Current user)**

Privacy issues	‘I think when you’re initially going to speak to a receptionist they always ask you what the problem is and I feel like in that instance there’s no enough privacy. Like the people behind you that are waiting in a line to also speak with the receptionist can hear your whole conversation and I don’t think that’s very private. So there’s no privacy’ **(Participant no 5, Male 18 years, White, Current user)**
	‘I think when you’re initially going to speak to a receptionist they always ask you what the problem is and I feel like in that instance there’s no enough privacy. Like the people behind you that are waiting in a line to also speak with the receptionist can hear your whole conversation and I don’t think that’s very private. So there’s no privacy. That’s probably my only thing’ **(Participant no 2, Female 23 years, African Black, Current user)**

Social and family pressure

'Personally for me no, but for some young people, I would probably say it can be difficult to let your family know. For example some young people might not get the support from their family and I guess they would, probably make the visit without letting them know. There is this embarrassment that is there with sexual diseases and that can weaken the family and social support you see, as people are afraid to reach out..so..yea there can be those issues' **(Participant no 6, Female age 23 years, White, Current user)**

'Yeah I think stigmatisation is a problem these days as you know when people hear that someone has a sexually transmitted disease people tend to you know either make fun of them or mock them or you know just avoid them or stay away from them, I would say there are issues like that but that's also dependent on the type of background that you have, some people have very supportive backgrounds trying to help

them with whatever problems they have whereas other people may say that oh what if I get this thing from being around you, that kind of thing, so yes there are issues' **(Participant no 3, Male 23 years, African Black, Potential user)**

Being reassured of confidentiality	**Confidentiality issues among different patient groups**	'I have got a mixed group of friends, you see, we as Asians have more problem and are more concerned about the confidentiality aspect while visiting the clinic, whereas the white friends I have are more relaxed and discussed matters of sexual health with their family more openly I guess, something that we Asians can't do. So I guess, it does depend on the kind of ethnic background of the patients, I am not sure whether you have any statistics or figures about such issues among different ethnicities··· if there is some staff from Asian background would really help specially for me, a Asian face would help and would make me feel comfortable' **(Participant no 10, Female 20 Years, Asian British, Current user)** 'I think the levels of confidentiality would differ because some of them might be a part of the LGBT community, but it's not out yet, so they would not want everyone to know about their sexual preferences,

	like…a…..'**(Participant no 15, Male 21 years, White, Current user)**
	'Absolutely they will differ. They will be different from one person to another because as you because of race, because of gender, because of sex, just because every person's way of thinking. So yeah, absolutely everyone will experience this in a different way'**(Participant no 1, Male 21 years, White, Potential user)**
Addressing confidentiality issues	'I mean, a….not shouting out loud on phone your name, when they are ready to call you in, and if they are asking you personal questions, sensitive questions, it should be done in a private place, not like in a main waiting area' **(Participant no 4, Female 22 years, White, Current user)**
	'The staff should be trained and should be capable, and I mean they should be spot on when it comes to giving instructions and reassuring the patients that everything that they share will be confidential. There

can be a form; I think···a agreement that can be signed. That will make the patients feel protected. If it's possible' **(Participant no 12, Female age 19 years, White, Potential user)**

'a···..the behaviour of the staff, if they can reassure that it is a confidential service, if the young people can be convinced, a···. it's the kind of trust that is build up which is very important, so I would say the initial conversation at the reception is important, and I guess, I would probably say that if they are reminded about the protection of their personal information that they will share, ···I guess it will really help them and put them at ease. This is what they can do in terms of putting the people at ease' **(Participant no 13, Male 22 year, Asian British, Current user)**

'I mean, a···.not shouting out loud on phone your name, when they are ready to call you in, and if they are asking you personal questions, sensitive questions, it should be done in a private place, not like in a main waiting area' **(Participant no 6, Female age 23 years, White, Current user)**

Factors associated with accessibility to service	**Finding service initially**	‘Yeah I would say that I think in this modern generation it has been a bit easier to find services, there’s a lot of awareness and also information and easy ways to··· like for example links that take you to the website and probably maybe before it was··· you actually had to look for the institution itself···’ (**Participant no 12, Female 19 years, White, Potential user)** ‘Well now I don’t think it’s been that difficult, I mean depending on the people attending, I mean for example young people would find it very easy as they could easily log into··· it could be an app or a website and trying to book an appointment because now appointments could be booked online but I don’t know, maybe back in the day or with the older generation they actually had to go to the place so I would say that it’s slightly easier, it’s not as difficult as it used to be’ **(Participant no 5, Male 18 years, White, Current user)**

	'I don't think it's that easy. Better signposting at GP, maybe pharmacies, maybe some adverts at the TV, so people know that there is special care available for sexual health rather than going to a GP' **(Participant no 8, Female 24 years, Asian British, Potential user)**
	'I think it would be easy…as a lot of young people are being taught at schools and community centres about the service. You can go online and search a GP to seek help for sexual health' (**Participant no 11, Female 21 years, Black British, Current user)**
Location	'I think accessibility can be a big thing, if a clinic is down the road, or the opening and closing time of the clinic matches with theirs, as if they hear from their friends and there are some recommendations'

(Participant no 3, Male 23 years, African Black, Potential user)

'Umm···.for me it would the one which is more easier to get to within my local area, which one is easier to get to, quicker to get to, and yes the opening times as well, if someone has to go in evenings, and also the location of the clinic if it is in a area that is obvious, like why are you there and why are you walking into,umm, also the kind of services they are offering as it may be different for different clinics' **(Participant no 10, Female 20 years, Asian British, Current user)**

Mode of transportation

'I'd have to use public transport and I think most young people would also be using that because it's really expensive to start driving and to get a car and most of the people coming into the service are going to be 18+ so they most likely wouldn't have access to a car so I would hope

that this sexual clinic should be easily accessible by public transport because there will be a large proportion of people who don't have access to a car' **(Participant no 12, Female 19 years, White, Potential user)**

'I would commute by bus and will get a day saver. A lot of people don't use the car and use public transport' **(Participant no 5, Male 18 years, White, Current user)**

'Umm··· I would say I would take the bus. I wouldn't pay as my partner works in travel' **(Participant no 11, Female 21 years, Black British, Current user)**

'I'd likely probably do it by bus. If I had my own car, I'd drive there. I wouldn't necessarily go by taxi and that's because if I can go by bus, I can get the bus to the nearest place in the main town centre where it'd likely be and then I can just walk there, so it's more anonymous' **(Participant no 1, Male 21 years, White, Potential user)**

'I'd likely probably do it by bus. If I had my own car, I'd drive there. I wouldn't necessarily go by taxi and that's because if I can go by bus, I can get the bus to the nearest place in the main town centre where it'd likely be and then I can just walk there, so it's more anonymous. By bus, it'd be about just under £5 for a day saver, yeah, to get there, and if I drove by myself, in my own car if I had a licence, it would be the price of gas basically, if I have to refill or not, and that can vary. So I reckon probably about 10 or maybe 15' **(Participant no 1, Male 21**

	years, White, Potential user)
Costs associated with making a visit	'I guess they are not that important. I mean···for any person there health is of extreme importance. You can't put a price on that, and money is secondary to your health. I mean..if people are broke then maybe' **(Participant no 6, Female 23 years, White, Current user)**
	'I don't think the cost implications are unreasonable. I think there's reasonable things you would do like, you know taking the transport or you know, except for example, if you miss a day at work, that can account for something, but I don't think the cost implications are unreasonable giving that health is at stake. I think the costs are expended; they should be reasonable' **(Participant no 13, Male 22 years, Asian British, Current user)**

Increasing awareness and acceptability about sexual health services

'So improvements to the system, mostly the confidentiality and it's actually broadcasted that it's something not to be embarrassed of, that's the thing, in society, that it's open to anyone and everyone and it should be actually promoted more than it is nowadays because at the moment you don't see any adverts or anything regarding sexual health clinics so it should be more open' **(Participant no 15, Male 21 years, White, Current user)**

'I'm already thinking make it more widely known, ok if you've got this problem, this is how you get in touch, this is how you access the service, this is your local clinic, type in your post-code and this is where your local clinic is, so that is really easy and simple to understand and I think that would be the biggest thing to get more people into the service' **(Participant no 5, Male 18 years, White, Current user)**

'The society as a whole, I think plays a major role in the general perception of sexual health related diseases, and for this reason, promoting the service, there should be a component of also increasing awareness among the general public, that it is ok to visit a sexual health clinic without feeling judged by the society' **(Participant no 10, Female 20 years, Asian British, Current user)**

Utilising social media to engage young people with service

'To engage young people you can use social media like instagram or snapchat, where young people can join, a live stream for general information can really help, you know what I mean. Make youngsters aware through such social media groups, it can be discreet, no one will get to know and they can get all the information and that will really help as we are always on the phone' **(Participant no 14, Female 20 years, British Black, Current user)**

Having a choice about appointment type	**Online vs. face to face consultation**	'Umm.. a···.i would probably say face to face, as there are a lot of questions, that I guess are more easy to ask face to face, I would probably say, that there is more human contact which can make the patient comfortable, so if I have a option a face to face is much better than online, I would probably say, yea, and there might be issues which need to be solved there and then, for example a examination is always better face to face, if a physical examination is needed, or there is such a problem' **(Participant no 2, Female 23 years, African Black, Current user)** 'Umm.. for me I would say face to face consultation as I go for contraception. I have to go once a year, I have to get my weight taken and blood pressure measure so for that I need to have a face to face consultation' **(Participant no 11, Female 21 years, Black British, Current user)**

	‘I would rather have a face to face consultation so that if there were any testing they needed to do immediately, it could be done immediately instead of having a phone consultation and then still having to go back into the clinic for some tests. So, I think I would pick a face to face consultation’ **(Participant no 6, Female 24 years, White, Current user)** ‘I think because it’s more personal, I’d rather it be face to face, when it’s online I wouldn’t feel comfortable because once you put something online it’s out there, you can’t be sure who is receiving that message, whereas if it’s face to face you know exactly what’s being said and who it’s being said to’ **(Participant no 9, Male, 21 years, Asian British, Current user)**

Appendix 5: qualitative research checklists (chapter 7)

i) Consolidated criteria for reporting qualitative studies (COREQ)

No. Item	Guide questions/description	Reported
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	MA (PhD researcher)
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	MBBS, Dip.OHSE, MPH, MCPS HPE, MSc, PhD (I)
3. Occupation	What was their occupation at the time of the study?	Stated (PhD student)
4. Gender	Was the researcher male or female?	male
5. Experience and training	What experience or training did the researcher have?	Previous experience of conducting qualitative research and academic training in Qualitative modules in Master degrees
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Prior relationship established by a introduction (background of researcher)
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Academic background, role and purpose
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Stated in discussion component
Domain 2: study design		
Theoretical framework		

9. Methodological orientation and theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Thematic framework analysis
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Convenience
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Email and social media (Facebook, twitter etc.)
12. Sample size	How many participants were in the study?	15
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Nil
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	workplace
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	No
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Demographics presented in Table 1
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Topic guide provided in Appendix 2
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio-recording
20. Field notes	Were field notes made during and/or after the interview or focus group?	No
21. Duration	What was the duration of the interviews or focus group?	30-45 minutes
22. Data saturation	Was data saturation discussed?	Yes, in methods and results sections
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	2
25. Description of the coding tree	Did authors provide a description of the coding tree?	Yes

26. Derivation of themes	Were themes identified in advance or derived from the data?	Derived from data, the study tool was based on a qualitative synthesis and meta-ethnography
27. Software	What software, if applicable, was used to manage the data?	NVivo 12.0
28. Participant checking	Did participants provide feedback on the findings?	No
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Yes
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	Yes (Appendix 1)
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes (Appendix 1)

ii) Standards for Reporting Qualitative Research (SRQR) checklist

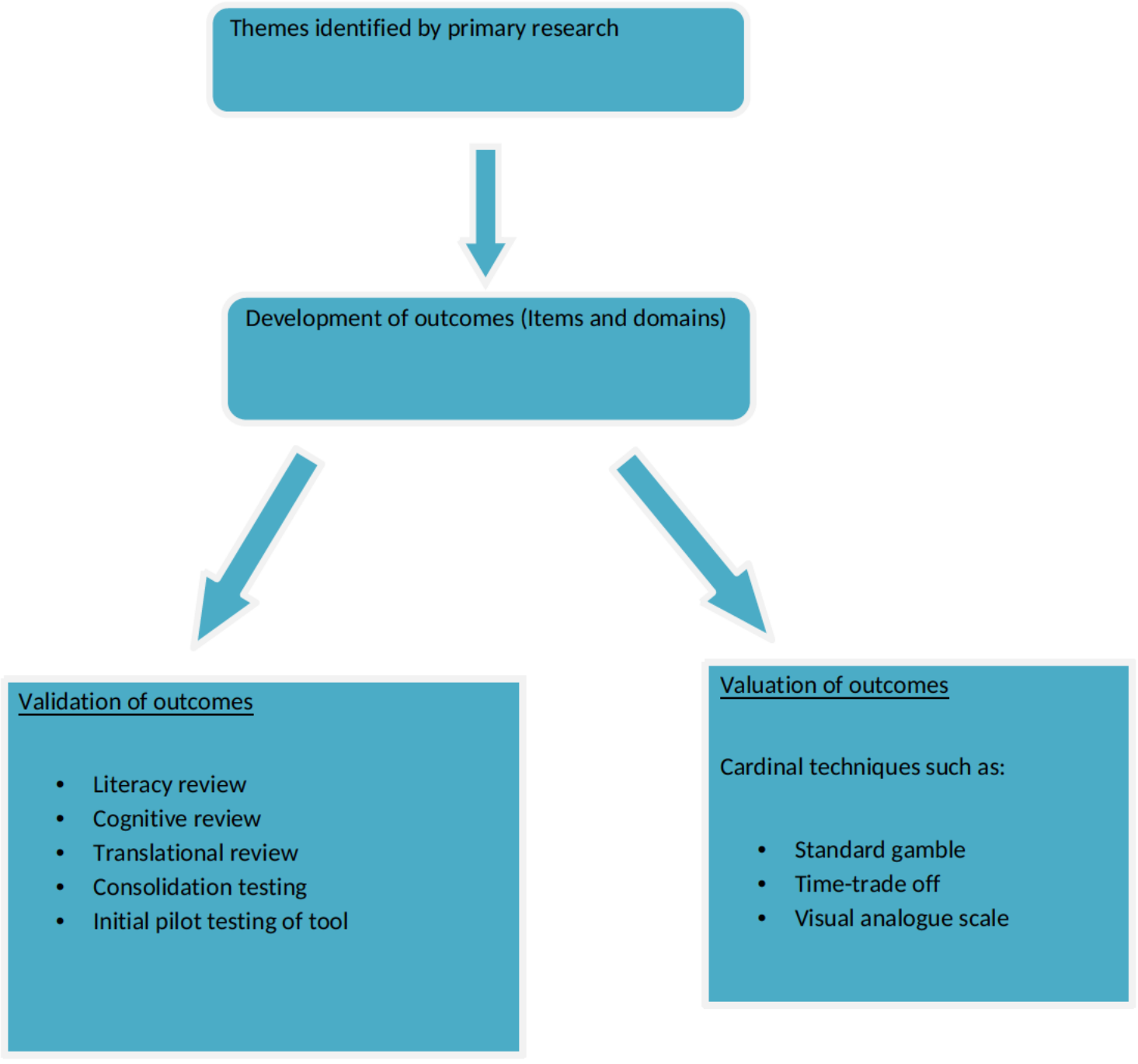
	Standards for Reporting Qualitative Research (SRQR)*	**Reported ?**
Title and abstract		
	Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	✓
	Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	NA
Introduction		
	Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	✓
	Purpose or research question - Purpose of the study and specific objectives or questions	✓
Methods		
	Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., post positivist, constructivist/ interpretivist) is	✓

	also recommended; rationale**	
	Researcher characteristics and reflexivity - Researchers′ characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers′ characteristics and the research questions, approach, methods, results, and/or transferability	✓
	Context - Setting/site and salient contextual factors; rationale**	✓
	Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	✓
	Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	✓
	Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	✓
	Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	✓
	Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	✓
	Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	✓
	Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	✓
	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	✓
Results/findings		
	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	✓
	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	✓
Discussion		

	Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	✓
	Limitations - Trustworthiness and limitations of findings	✓
Other		
	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	✓
	Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	NA

Appendix 6: Proposed steps for future development of a preference-based PROM for measuring and valuation of outcome pertaining to sexual health services

Figure: Flow diagram depicting the next steps in the development of preference-based PROM for sexual health services



Appendix 7 Sample transcription of interviews (2 randomly selected)

Participant 14 (male)

Interviewer: Hello, thank you for agreeing in the research. My name is Syed and I am the lead research for this project titled 'Investigating the outcome measures considered important by potential users of sexual health services within UK settings'. The study is part of an ongoing PhD and is funded by University Hospitals Birmingham NHS Trust. We have also received University ethics to carry out the interview from University of Birmingham. I will be conducting this interview with you to inquire about your general views about sexual health services and what matters to you regarding different aspects of the service. Your views and opinions will be utilized to assess the service to improve the quality of care provided. I want to assure you that all the information provided by you will remain anonymous and your identity will remain strictly confidential. At any point during the interview you feel uncomfortable you have the right to withdraw and are under no obligation to continue if you don't want to. If you are not comfortable in answering any question please do let me know during the interview and you don't have to talk about anything you are uncomfortable with.

If you have any questions before I start the interview please let me know, and if you give verbal consent then I can start the interview.

Participant 14:

Yea, you can start.

Interviewer:

Thank you. To start the interview, I would like to know your views about what matters the most to young people about sexual health services?

Participant 14:

I would say that it depends if it is accessible you see, ·····whether they can reach it easy, ·····.yes I guess for me that would matter the most, and yes confidentiality. If the service is

discreet.

Interviewer:

So what you think, would what matters to young people would be similar to other kinds of services, for example going to a GP for a common cold, or would it be different in sexual health services?

Participant 15:

Yes···ummm··· I think if you go to sexual health it's kind of more specialized area, a young person if is visiting a sexual health clinic might be worried that the information might get out through the GP to family and friends, it is these kind of concerns which makes this service, I guess..umm..different from other kind of services. that's all I think.

Interviewer:

Thank you that's helpful. What would your expectations of a good environment be while visiting a sexual health clinic?

There might be different aspects of the service which might be important for you, In terms of the overall environment of the clinic, things like reception area, healthcare staff or other things that you may have in mind?

Participant 14:

A·····.clean, cleanliness, a lot of information in the environment, which people can read, I mean..aa···.a calm environment, if someone comes in they can really anxious, so a calm environment can really make someone, I mean at ease. So a calm environment can really help. Interviewer:

Thank you. In your opinion what would be a good outcome from a clinical consultation with a doctor or nurse?

Participant 15:

I would want them to take care of me in a way that I feel comfortable, I mean, I would say..aa···.trustworthy, respectful and giving me the right information, to be treated well I

guess that is something that I would prefer and which will make me feel, you know, that I have received good care.

Interviewer:

Thank you. Building on what you said in your opinion what would be a good outcome from a clinical consultation with a doctor or nurse?

Participant 14:

If the doctor is able to advise me give me the right antibiotics, giving me the right advise you see, a···. for example if I need a antibiotic for a disease I would want to be given the right medicine, and if I am provided with the treatment that I really need, I would expect it to be the right one, that will be, I guess..a···.a good outcome, you see.

Interviewer:

Of all the aspects that you have mentioned what would you consider most important during a visit?

Participant 14:

a·····.the right treatment I guess···

Interviewer:

Thank you for the response. You did mention confidentiality at the start of the interview, what is the significance of confidentiality in your opinion for the young while making a visit to a sexual health clinic?

Participant 14:

Its very important. Yes, very important. For young people when they enter a clinic, it is a fear that they have that other people might find out and that can be problematic for them, so I guess it is important for everyone who visit the clinic, I guess.

Interviewer:

The factors and issues associated with confidentiality that you have discussed, how can they be addressed in a clinical setting in your opinion?

Participant 14:

a···..the behaviour of the staff, if they can reassure that it is a confidential service, if the young people can be convinced, a···. it's the kind of trust that is build up which is very important, so I would say the initial conversation at the reception is important, and I guess, I would probably say that if they are reminded about the protection of their personal information that they will share, ···I guess it will really help them and put them at ease. This is what they can do in terms of putting the people at ease.

Interviewer:

There people with different age groups, cultural and religious background who visit, would there be any differences in issues associated with confidentiality among these group of young people?

Participant 14:

It will be the same for everyone, yea. It will matter the same to everyone when it comes to confidentiality, I would say..

Interviewer:

I would now talk to talk about acceptable waiting times. What in your in your opinion is a acceptable waiting time to book a appointment to a sexual health clinic?

Participant 14:

I would probably say within a week, a···..i would not want to wait that long, so yea a week would be fine, I guess a acceptable waiting time, I would probably say, yea 1 week.
Interviewer:

What would be a acceptable waiting time for you once you are in clinic and waiting to be seen?

Participant 14:

Not more than 15 minutes, hahaha···I would not want to wait that long

Interviewer:

What would be a acceptable waiting time to receive the result of a STI test?

Participant 14:

a·····I would probably say not more than 2 weeks.

Interviewer:

So what do you think, is it easier or difficult finding the service initially to book an appointment ?

Participant 14:

I would say easy. Everything is available online these days···yea

Interviewer:

Once you are in a clinic would you like to book yourself using internet and would you be willing to take sample yourself?

Participant 14:

Yes···I will be ok with it

How would you want to be notified about a STI test result?

Participant 14:

aa·····tadaa····.i think a phone call, not a text msg or email, because other people can read it, so I would probably say phone call will be best, I would say..

Interviewer:

STIs are infectious and potential partners are also at risk. In your opinion how should partner notification be done?

Participant 14:

Same, I would say a phone call for the same reasons, as it will be a big news, you can't break bad news through a text msg, a…so I would say the best way will be by making a call, I would probably suggest this, yes through a phone call, you know.

Interviewer:

In your opinion what might influence young people's choices about visiting a sexual health clinic, booking an appointment or ordering a online testing kit? What factors might influence their choices about visiting a particular sexual health clinic? You can ask me for clarification if you don't fully understand a question

Participant 14:

I would probably say the distance would matter, the one which is near, the young people would like to visit that clinic, and then….dadada…I would say the behaviour of the staff, the one which is more friendlier, that will be important too I guess, and yes…the kind of services as some people want the contraceptive services too, so all these factors, I guess are important..yea..

Interviewer:

Having discussed the various aspects of the service, how would you judge the quality of care provided by the service?

Participant 14:

If I am treated from my STI, haha..that would be most important for me, I would judge it if I get my treatment and I am cured.

Interviewer:

What about the behaviour of the healthcare staff, would it influence your judgement of the quality of care?

Participant 14:

Yes, if they are professional, I would probably say, and give the right treatment and can also make me feel comfortable, that would, I mean be very good.

Interviewer:

There are different tests that are offered at the clinic for particular types of STIs. In your opinion would the young people visiting the clinic be interested in any particular type of test or would want to be tested for everything?

Participant 14:

I would say specific type of tests. Personally, I would want to be tested for everything if I go there, its good to know and be sure of your health, you see···

Interviewer:

What you like to be involved in discussion about the treatment and different treatment options?

Participant 14:

No···

Interviewer:

So you would trust the treatment provided by the doctor?

Participant 14:

Yea I would···.

Interviewer:

If you needed to, how would you commute to the nearest sexual health clinic and how much that cost?

Participant 14:

I would probably say, I will use my car. It will cost me £15

Interviewer:

Would there be other costs associated with making a visit?

Participant 14:

Ummmm…some people, I might, I guess…if I have to miss work or a shift that would add to the cost I would say. Yea other than it is the cost of visit if you use a bus or car, and yes, there is additional cost of parking too, I mean if you are using your car. So yea…

Interviewer:

Would there be any social and family support in while making a visit? What would be the challenges associated with it?

Participant 14:

Personally for me no, but for some young people, I would probably say it can be difficult to let your family know. For example some young people might not get the support from their family and I guess they would, probably make the visit without letting them know. There is this embarrassment that is there with sexual diseases and that can weaken the family and social support you see, as people are afraid to reach out..so..yea there can be those issues.

Interviewer:

If you had the option of a online consultation and having a face to face consultation considering the present situation with the pandemic, what would you prefer and why?

Participant 14:

Umm.. a….i would probably say face to face, as there are a lot of questions, that I guess are more easy to ask face to face, I would probably say, that there is more human contact which can make the patient comfortable, so if I have a option a face to face is much better than online, I would probably say, yea, and there might be issues which need to be solved there and then, for example a examination is always better face to face, if a physical examination is needed, or there is such a problem.

Interviewer:

You have discussed a lot of aspects of the service. I would know like to ask you that what are your suggestions to improve the service to engage young people with the service?

Participant 14:

Not that I can think of···.a···..

Interviewer:

It is just your opinions, how you would want the service to be, how can it better in terms of care at clinic, the healthcare staff so young people can be engaged?

Participant 14:

I would probably say, in terms of engaging young people, there can be a safe place, as everyone is using mobile these days, if there is a forum, where the participants, the young people or patients can remain anonymous and can interact with eachother and the healthcare professionals that can really help, like a app made for this purpose, a sexual health services app, that I think can really help, I would say···

Interviewer:

If you have to sum up, what would be the most important aspect about the service that would help you think or decide that you have had a successful visit to a sexual health clinic.

Participant 14:

Getting treated for the STI, getting the right treatment I would say..

Interviewer:

is there any point or aspect that you think we have not covered in this interview about what is important to young people visiting the service and how it can be improved that you would like to mention or talk about?

Participant 14:

No, we have, I don't think we missed anything, we did cover, I think all of it.

Interviewer:

Thank you. I would like to thank you again sincerely for participating in the interview. I want to reassure you again that all the information that you shared with us will remain anonymous and your identity will be kept confidential. If you would like to know more about the project or would like to meet rest of the team I will be more than happy to introduce or give their contact information. If you want to know more about the local sexual health service or have any concerns or further questions please let me know.

Participant 14:

Yea, sure, thanks.

I: Interviewer: Hello, thank you for agreeing in the research. My name is Syed and I am the lead research for this project titled 'Investigating the outcome measures considered important by potential users of sexual health services within UK settings'. The study is part of an ongoing PhD and is funded by University Hospitals Birmingham NHS Trust. We have also received University ethics to carry out the interview from University of Birmingham. I will be conducting this interview with you to inquire about your general views about sexual health services and what matters to you regarding different aspects of the service. Your views and opinions will be utilized to assess the service to improve the quality of care provided. I want to assure you that all the information provided by you will remain anonymous and your identity will remain strictly confidential. At any point during the interview you feel uncomfortable you have the right to withdraw and are under no obligation to continue if you don't want to. If you are not comfortable in answering any question please do let me know during the interview and you don't have to talk about anything you are uncomfortable with.

If you have any questions before I start the interview please let me know, and if you give verbal consent then I can start the interview.

IV: [I think every question will be fine] ok sure thing, so let's start this interview.

I: What do you think, in your opinion, matters to young people about sexual health services?

IV: I would say that health services would be very important to young people because a lot of people find themselves probably engaging in probably unprotected sexual activities and recently things have been happening in terms of sexual transmitted diseases and things like that so I think the general awareness is there with the sexual health services which help people to be able to understand how to be safe and how to avoid such occurrences [sure] I would also say in terms of things like unwanted pregnancy because a lot of these things I guess are very common with this generation so these are the things that are of concern to young people.

I: Sure and if I ask you that are the things that matter to them about sexual health services similar or different to other kinds of services, for example, if a person goes to a GP for an appointment for a cold, I mean so what things matter differently when it comes to sexual health services as compared to other kinds of services? For the people who are accessing them, this is what··· and you are more than welcome to ask any question if you are not clear about the question, I'm more than happy to elaborate, yeah.

IV: Yeah could you just elaborate that question please?

I: Yeah sure thing, it's that when people are accessing sexual health services, I mean would there be things that would matter more to them as compared to when availing other types of services, for example, if a person just goes to a GP for a common cold, so I mean would there be things that would matter then much more when it compares to sexual health services and if so what, in your opinion, would matter to them when they are actually accessing the sexual health services?

IV: I would say in that case it would definitely be the quality of the service because things like colds and things, many people don't really take them seriously, I feel like that sexual health, people are very particular to the type of service that they get, they look at things like the side effects they might get from taking any particular medication that they receive [sure] or yeah how it's going to affect them, maybe physically or, you know, mentally, with other health services people might try to do things a bit more confidential because I've noticed that obviously if you are just taking medication then that's very normal but a lot of people try to avoid the stigmatisation for things like taking medication for sexually transmitted diseases because some people feel maybe embarrassed, other people feel that you know there's this kind of stigma towards them so a lot of people would like confidentiality and you know making sure that things are private and personal when accessing the services.

I: Thank you, that's really helpful, so what would your expectations be for a good environment while visiting a sexual health clinic, in terms of you know the clinic environment, waiting areas, anything that you have in mind.

IV: I would say definitely for sexual health services I would always advise that the place is very sanitary, because that matters a lot, more than ever, whatever they are giving you, it may be medication, it might be maybe more physical things that relate to your blood, definitely I would say the quality and the hygiene of the environment would be very important and also I guess that in terms of privacy and confidentiality as well, that would be really important as you don't want your information about this kind of situation [sure] to be exposed in public or to any other person or unwanted audience.

I: So what would your expectations be in terms of being treated by healthcare staff, you know when a person comes in, the reception staff, I don't know if you would want any chaperones and then eventually the nurses and the doctors, so what are your expectations, how should people be treated by healthcare staff?

IV: Ok so for situations like that I would expect there to be one health professional, I would expect them to be friendly as well because there are situations where the doctors or the nurses who will be taking care of you, they may be a bit rude or a bit unfriendly [sure] so a friendly environment would be very necessary in situations like this and I'd also expect them to be able to know exactly what they are doing because, like I said, situations like this should be taken very carefully so you need to let them have someone who will give them the right medication or would give you the right help without any errors or any mistakes or mishaps [sure] that what I'd say.

I: Sure, so what do you think would be a good outcome from a clinical consultation with a doctor or a nurse at the sexual health clinic, in your opinion, what would be a good outcome from a clinical consultation, in terms of you know I'll elaborate on the question, in terms of different things, I mean obviously I want your opinion, so in terms of the role of the doctor, any desirable attributes during the consultation that young people would expect, so what would be a good outcome from a clinical consultation with the doctor or nurse at the sexual health clinic?

IV: I would say that a good outcome would be being able to identify the root of the problem or whatever issues you may have [sure] and also being able to provide the right services and the ease of the patient as well because a lot of patients come in and they may not really get on well with people so I would say that being able to understand the patient, being able to understand exactly what the problems are they are facing [sure] and trying to mitigate those problems according to you know the patient's emotions or any other underlying background. I would say yeah that a good outcome would be solving the problem as professionally as possible.

I: That's very helpful. So what would you consider the most important, you know, by you during the visit, so if you had to like think of it.

IV: Personally I am resource oriented so I would like to be able to just get the service without too much hassle because personally I am not a fan of bureaucracy, I don't really like having to go through too many processes to get something done that seems pretty straightforward [sure] so I would like if whoever I'm speaking to is well in-depth to understand the problem and to be able to refer me to the right

people just to get the job done as soon as possible.

I: Sure, sure, thank you, so in your opinion, what is the significance, although you did mention this thing, but in your opinion what is the significance of confidentiality while visiting a sexual health clinic?

IV: I would say the significance is well a lot of people don't like their condition to be obviously spread out to a number of parties and this helps a lot because if in that situation that actually happened it could lead to other things like blackmail, it could lead to stigmatisation in society [sure] even in modern days there's been a lot of bullying, especially like cyber bullying, it doesn't have to be a physical thing [sure] just getting any piece of information about somebody you could possible use it to ruin their future career or their opportunities and likewise so I would say that yeah confidentiality is very important [thank you] to ensure that.

I: Yes thank you for elaborating on that, I mean how can these issues be addressed then, according to your opinion?

IV: Well I would say personally in this situation it would make sense to have better security protocols, I would say in terms of if there was a computer database, just trying to make sure that the data is encrypted and even when the [0.10.44] takes place maybe you know you could be the room you are in, the room with the patient could be soundproofed so that people outside don't hear and also taking security measures to make sure that there are not recording devices or things lying around for people who could personally be trying to look around for this kind of information in services.

I: So would there be any differences for a particular group of young people in terms of the issues of confidentiality? Would there be many different groups? I mean what's your opinion? Or would there be any difference…

IV: I'm sorry, could you just repeat that question?

I: Yeah sure, I was talking about confidentiality, still talking about it, and I just wanted to know your opinion that would these issues vary among lots of groups of young people because different kinds of people access the service so do you think these issues vary amongst them, the different groups?

IV: Yes in a way they would because there are certain people who don't take these things as serious as others. I would say in terms of probably maybe very introverted or private personal people [sure] these kind of people you know try to make sure things about them stay hidden as much as possible. Sometimes the reason may not be very straightforward, it could just be something you know personal that the person asks for you but then there are also people who are not really as bothered because one, probably they are already known for having whatever problems, or two, they just don't have that emotional drive, that's what I'd say, there are different groups and it varies.

I: That's really helpful. So how might the staff attitudes and behaviours reassure young people about confidentiality?

IV: Well first of all definitely being friendly and trying to explain and understand because anybody who has information about you you have to… I would say that the

staff and the nurses, they have to be able to make the people trust them because obviously anybody holding information, they might think that if the staff or the nurse looks trustworthy for example there may even be things that the patient may not want to tell them but are really important, just because you know their behaviours are not professional, they don't see things, they don't talk with the actual etiquette for example, yeah that's what I would say.

I: That's very helpful, so what are your expectations of acceptable waiting times at a sexual health clinic, in terms of getting an appointment, waiting to be seen and waiting for results, let's take it step-wise so I mean what would your expectations be of acceptable waiting times in terms of like firstly let's talk about getting an appointment.

IV: I would say that for sexual health services appointments should generally be able to be given within a week, yeah [sure] depending on whatever situation they may be in. There may be spike in the number of applicants for appointments but I would generally advise that it stays within a week because sexually transmitted diseases and any other problems you know have symptoms and a lot of side effects and things like this need to be treated as soon as possible.

I: So once you··· sorry please go on, sorry you were saying···

IV: Yeah I just wanted to say that if we are talking about waiting times in an actual let's say clinic for example, people who are sitting there waiting for their appointment, I would obviously suggest that their appointments are scheduled on time because I know a lot of people, I may say, doctors who delay people's appointments even if

they are there so I would suggest that the people actually stick to the time frame.

I: So what kind of time frame, you actually··· I was about to ask this question and thank you so much for mentioning it, so what kind of acceptable waiting time would you think should be something that should be acceptable to people once they are there and waiting to be seen?

IV: Well once they are there and waiting to be seen, particularly I would say within an hour because I would just given an hour for any unfortunate circumstances but yeah you shouldn't keep people waiting too long because in these kind of situations it may be people who actually do need to be taking medication just to ensure that their bodies are still reacting properly so personally I would say if you arrive at a clinic and are waiting for an appointment, depending on when you arrive and when the appointment is, if you arrive a bit early then I would say that 30 minutes to an hour should be the max you should go until you are actually consulted.

I: Thank you and in terms of waiting for the result, you know, once you have, so how long do you think an acceptable waiting time for that would be?

IV: Yeah for that I would say that's a bit specific to the actual type of let's say test or things that take a while like the results may be coming through faster than others, depending on the type of technology that they use to analyse the data but for waiting for results, that's actually a very good question because I was thinking that the max results for any situation for that should be, in my opinion, two weeks [sure] that's the last resort [sure]. Some of the results, it might be that the results come back faster, I would not necessarily expect – I mean as a patient – I would

expect results like that to come out in say three days or a week max but if there's any problem at all I wouldn't want my results to come later than two weeks.

I: Sure, sure, thank you for answering that, so do you think it's easier or difficult finding the service initially and identifying how to engage with it for advice or an appointment?

IV: Sorry, please just repeat that question.

I: Yes of course, so do you think it is difficult in finding the service initially and identifying how to engage with it for advice or an appointment?

IV: Yeah I would say that I think in this modern generation it has been a bit easier to find services, there's a lot of awareness and also information and easy ways to··· like for example links that take you to the website and probably maybe before it was··· you actually had to look for the institution itself···

I: So how about engaging with it and seeking advice for an appointment, do you think that would be difficult or not?

IV: Well now I don't think it's been that difficult, I mean depending on the people attending, I mean for example young people would find it very easy as they could easily log into··· it could be an app or a website and trying to book an appointment because now appointments could be booked online but I don't know, maybe back in the day or with the older generation they actually had to go to the place [sure] so I would say that it's slightly easier, it's not as difficult as it used to be.

I: So it brings me to the next question, exactly adding on to what you are saying, would you be happy to book on a website and take samples yourself while you are in the clinic? Like would you be happy or comfortable in booking on a website and taking samples yourself while you are in the clinic?

IV: Yeah I think I would but it would depend on the actual thing, but yes I would accept something like that, being able to book online because a lot of people you know having time issues and things so yes I would.

I: Yes sure, sure, so how would you prefer receiving the results of an STI test, you know, through a phone, email, text, what kind of a medium do you think would be appropriate according to your opinion, to receive the result of an STI test?

IV: To receive the result of an STI I would prefer if I was able to actually go to the clinic to receive it or it was received by a letter [sure] because if receiving it by SMS or email or all these other things, it's very easy for data to be breached and for people to get information on line, [sure] certainly in this modern age, you know [that's very helpful] for people to access information and things whereas if it has been sent by letter, where it's just one copy or going to the clinic to receive it direct.

I: Sure so what about partner notification, you know that STI's are infectious so for partners, to notify them, what kind of a medium, in your opinion, would be appropriate to tell them?

IV: I would definitely suggest people to talk in person you know, because just like I say with the online things happening, we've seen a lot of information out there, you

sometimes···

I: Do you think the clinic should send information to partners and notify them and if so what medium would be appropriate?

IV: Well I would say it would depend on the person so maybe the consent of the person, so if they agree, personally I wouldn't want the clinic to tell my partner anything about it, I would sooner tell them myself after I had the results and if they were too then I'd sooner them send a letter to them as well rather than send it online.

I: Thank you. So what might influence a young people's choice about you know whether to go to a sexual health clinic, order an online kit··· how would they decide which clinic to attend, what would be those factors and you know, those influencing factors, in making these young people's choices about whether to go to a sexual health clinic, order an online testing kit or not and to decide which clinic to attend?

IV: I think personally one thing that would make people actually want to receive advice and receive help would probably be the consequences or urgency, maybe the symptoms are getting a bit out of hand and they probably cannot handle it or I would say that if it was a situation of going to a clinic, most people would want to go to the nearest one to them as young people you know may not be wanting to travel very far and I would say also the quality of the service used, because a lot of people check reviews these days on you know the way the actual type of quality of service that's given at the clinic and also the way the staff present themselves as

well, you know, their etiquette and things like that.

I: Sure, so how would you judge talking about quality of care you've mentioned that, how would you judge the quality of care provided by clinical staff for sexual health services?

IV: I would do that based on the actual procedures to generate results, that's in terms of you know the actual hygiene and type of technology that is used and also based on the staff as well, the general approach of staff towards patients and how they actually help them to medicate the problem.

I: So what would make you feel like you've received good care, the things that you mentioned, what would make you feel that you've received good care?

IV: Generally if I'm able to get there and I'm confident··· first of all if I'm able to trust the staff because I would say like everybody obviously has to give you a first impression, you as a patient looking at staff and things, the way they assess you is also the way you assess them so you have to look at everything, see how all of it turns out, look at how they assess you and look at the kind of questions they ask you, you know, depending on every day I feel like generally if you're quite comfortable with the service and they are able to help you without too much of a hassle, that would be to me good quality.

I: So what are your views about having particular tests, I mean are there particular tests, I mean particular STI tests, would you want to be tested or everything?

IV: I'm actually not sure about that question [yeah sure] yeah.

I: Sure no worries, thank you for asking for clarification, I just wanted to have your opinion about you know that once patients go to an STI clinic, they want to have tests, you know the different STI tests that are available, so first of all your views about having a particular test and you know if there was any particular STI for which they wanted to be tested or they would want to be tested for everything once they are there?

IV: I would say people first of all would have the immediate ones like HIV is the most common one that they would want to be tested for, if I was to think about any other ones they would probably be··· the ones that are usually the most common, like syphilis or maybe gonorrhoea, some people who are actually not sure what type of STI they have would want to take as many tests as possible just to be able to you know narrow it down but like I said earlier, HIV AIDS would be the most common test that people go for.

I: Thank you, so would you want to be involved in discussions about the best treatment? Would you want to know about the treatment if you want to be involved in that?

IV: Yeah sure, I'd love to be involved to be able to understand the way this thing is working.

I: So what would you want to know about treatment, if you were involved in a discussion about the best treatment?

IV: First of all I'd want to know if there were any side effects for··· no actually I'd want to know what exactly the treatment does, for example if it's a viral infection, how exactly it helps to destroy or helps to subdue the virus, I'd also like to know any form of side effects because I feel that's very important to me, a lot of these treatments actually have a lot of side effects [sure] so things like this need to be properly checked so yeah that's it, also I'd like to know the method of treatment as well because I think that some people may be a bit ok with oral treatment of drugs whereas some people would not like them to be injected with a syringe so the actual method of treatment is very important as well.

I: That's really helpful. So if you needed to, how would you commute to access the nearest sexual health clinic and what would be the cost associated with the travel?

IV: Depending on where the clinic is I think a suitable way to commute would be by train···

I: So I'm referring to you so how would you commute to access the nearest sexual health clinic, if you had to, if you needed to that is···

IV: If I needed to I would use a train if that was the best option because trains, you know, depending on where the station was···

I: So what would be the cost associated with this kind of travel?

IV: So I would say public transport generally would be, well actually can you elaborate on this question again?

I: Yes you've kindly mentioned the kind of transport that you would use, I just wanted to know roughly the cost associated with this kind of travel, you know, roughly how much would that cost?

IV: Ok if I was going, let's say, five miles that would probably be about £4 I guess, if it was something longer like 20 miles then…

I: Would there be any other cost associated with it in terms of missing a shift at work or anything else or any other kind of costs?

IV: Yes there would be other costs associated, the usual for example, maybe relaxation and also just like you mentioned, work as well, also family time and I would say other costs like you could be… there are so many things… appointments and things, but personally this would be important to me because for example, work, you know that's some of your income actually going away, the fact that you are not actually there [true] or if it's issues with family, you may miss an important ceremony or celebration or something that really means a lot to you, somebody very close. Also leisure time as well, I feel like commuting, depending on when your appointment is, let's say early in the morning for example, you would have to wake up very early, you may be tired, you may not have enough energy so yeah just all of those would be unwanted on any regular basis.

I: So are there any issues around any social or family support around making a visit and what might be the challenges associated with it? Issues around social or family support around making a visit?

IV: Yeah I think stigmatisation is a problem these days as you know when people hear that someone has a sexually transmitted disease people tend to you know either make fun of them or mock them [sure] or you know just avoid them or stay away from them, I would say there are issues like that but that's also dependent on the type of background that you have, some people have very supportive backgrounds trying to help them with whatever problems they have [sure] whereas other people may say that oh what if I get this thing from being around you, that kind of thing, so yes there are issues.

I: Sure, so what are your suggestions to improve the service, I mean what kind of suggestions would you give to improve the service?

IV: I'm not sure if there's any other thing besides what I've mentioned before, just general like the quality of the service, you know, the methods of testing, the actual responsibility of the staff as well and also awareness because a lot of people may not even know of the types of tests and the kind of help that you could receive.

I: So if I would ask you in terms of engaging young people with the service, are there any suggestions you can give?

IV: Well first of all just awareness on social media, that would definitely be good to actually engage young people to get involved with the service. I would say also incentives, because a lot of people may not be particularly interested in something unless there's something in it for them, you know, so I would say yeah probably incentives as well for young people would help them to engage with the service.

I: Thank you so I mean if we sum it up, what would be the most important thing for you, you know when if you think about deciding whether you've had a successful visit to a sexual health clinic, so what would be the most important thing in your mind to decide that you've had a successful visit with the sexual health clinic?

IV: Well the most important thing for me would be being able to resolve the problem I had in mind for them to resolve. If it was, in terms of medication or in terms of advice, I would say being able to get the answer I was hoping for would be first and foremost the most important thing, yeah, that's it.

I: Thank you, are there any other things that would be important about visiting a sexual health clinic that we've not discussed and that you know you want to comment on or highlight?

IV: No I can't really think of any other things, no.

I: Ok I would like to thank you sincerely for your participation and your valuable time. As I've mentioned in the start of the interview, all of the information that you've shared with us, it will be anonymous and we've not taken any personal details and your confidentiality will be maintained throughout and if you want to know more information you are more than welcome to contact our team and if you want information about local sexual health clinics I'm more than happy to provide you with information about that or if you have any concerns.

IV: Thank you very much for your time, I was very happy to participate in this discussion.

I: Thank you so much.

END OF INTERVIEW

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