

**Awareness, knowledge, and perceptions of
HIV pre-exposure prophylaxis (PrEP)
among women in England: A mixed
methods exploration through an equity
lens**

Melissa Ann Cabecinha

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Doctor of Philosophy

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Declaration of authorship

I, Melissa Ann Cabecinha, confirm the work presented in this thesis as my own.
Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed

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Abstract

Background

HIV Pre-exposure prophylaxis (PrEP) is a powerful biomedical tool for HIV prevention. In England, PrEP has routinely been available from sexual health services since October 2020. Despite accounting for ~20% of new HIV diagnoses in 2021, <2% of PrEP users were women. In this thesis, complementary methods are used to investigate awareness, knowledge, and perceptions of PrEP among women in England through an equity lens in order to inform policies and practice that may increase HIV prevention access and engagement in this population.

Methods

A systematic review of observational studies in high-income countries which explored definitions “PrEP awareness” and “PrEP interest” and whether factors known to influence health equity were considered when reporting outcome measures.

Eighteen semi-structured interviews with women resident in England to explore their awareness, knowledge, and perceptions of PrEP and PrEP implementation.

An online, self-completion, cross-sectional convenience survey of 974 women resident in England to investigate the sample’s level of awareness of and preferences for PrEP. Sample characteristics were compared to the most recent census data, and logistic regression was used to identify associations between PrEP interest and awareness and sociodemographic and other factors that influence health equity.

Results

Findings from the systematic review suggest that there is a lack of consistency in the definitions of PrEP awareness and PrEP interest in the published literature.

Qualitative evidence suggests that a lack of awareness, knowledge gaps, and assumptions around PrEP eligibility contribute to low PrEP coverage among women. Quantitative evidence suggests that awareness of PrEP is associated with previous

engagement in HIV prevention and that current PrEP provision services may not meet the preferences of women.

Conclusion

To improve equitable access to PrEP, education and awareness campaigns should include women-specific information and clear indications for PrEP candidacy.

Addressing HIV stigma, integrating HIV prevention in conversations around sexual health, and expanding PrEP provision outside of sexual health services may help increase the accessibility of PrEP and PrEP information for women.

Impact statement

This thesis presents research investigating awareness and knowledge of HIV Pre-exposure prophylaxis among women in England. Women have historically been absent from PrEP research in high-income countries, and in England specifically, and this thesis helps to address this gap.

The research presented in this thesis shows that among a sample of women in England, PrEP awareness and knowledge are closely linked to knowledge of, and engagement with, HIV prevention. This means that improving women's engagement with PrEP information and services should happen alongside improving engagement with HIV information and prevention services more generally. Furthermore, this thesis has highlighted the difference between PrEP awareness (e.g., knowing that PrEP, a medication that can prevent HIV, exists) and PrEP knowledge (e.g., knowing who can take PrEP, why they might want to take it, and how to access it). This difference means that it is not enough to simply raise awareness, but that knowledge of PrEP among women must also be improved, so that they can recognise themselves as PrEP candidates and make informed decisions about their sexual and reproductive health. This distinction will be important when designing health promotion campaigns or materials.

This thesis also offers suggestions to improve equity in PrEP awareness and knowledge for women in England. It has recognised the need to embed PrEP and HIV prevention information and services within the range of settings that women access for their sexual and reproductive healthcare. It also asserts that outreach or engagement campaigns to improve PrEP awareness among women need to take the priorities and concerns of target communities into consideration to prevent further stigmatisation of HIV and/or marginalisation of communities or people.

The recommendations in this thesis have been presented at national and international conferences, and they will be further disseminated to the wider scientific community through planned publications. Finally, lessons learned from issues that

were encountered during study recruitment will be included as a case study in an upcoming publication describing the challenges and solutions of recruiting online participants for qualitative research.

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Table of Contents

Declaration of authorship	1
Abstract	2
Impact statement.....	4
UCL Research Paper Declaration Form	6
Acknowledgements	12
Table of Contents	13
List of tables	21
List of figures.....	23
Appendices	24
List of abbreviations	25
Chapter 1 Introduction.....	27
1.1 Overview	27
1.2 Narrative of the thesis	28
1.3 Research focus	30
1.4 Thesis aim and research questions.....	30
1.5 Thesis structure.....	31
1.6 Role of the candidate	32
1.7 Research dissemination	33
1.7.1 Publications	33
1.7.2 Conference presentations.....	33
Chapter 2 Background	35
2.1 Chapter overview	35
2.2 The HIV Epidemic	35
2.2.1 Human Immunodeficiency Virus (HIV).....	35
2.2.2 HIV Globally.....	36

2.2.3	HIV in the United Kingdom and England	36
2.3	Targets for the elimination of HIV	37
2.3.1	UNAIDS Fast-Track strategy to end the AIDS epidemic by 2030	37
2.3.2	“Towards zero” and eliminating new HIV transmissions in England by 2030	38
2.3.3	Meeting global and national HIV elimination goals	39
2.4	Combination HIV prevention	39
2.4.1	Primary prevention	40
2.4.2	Secondary prevention	43
2.4.3	Tertiary prevention	44
2.4.4	A “serostatus neutral” approach to HIV prevention	46
2.4.5	Effective implementation of combination HIV prevention strategies	46
2.5	Combination HIV prevention in England	46
2.5.1	Commissioning responsibilities for sexual health services and HIV prevention	47
2.6	HIV Pre-Exposure Prophylaxis	48
2.6.1	A brief history of PrEP	48
2.6.2	PrEP regimens, formulations, and modalities	49
2.6.3	PrEP Implementation	50
2.7	Health Inequalities and Health Equity	53
2.8	Health equity and HIV	54
2.8.1	Health equity and HIV in the UK and England	54
2.9	Health equity and PrEP	55
2.9.1	Health equity and PrEP in England	55
2.9.2	Research gaps in PrEP equity in England	58
2.10	Conclusion	58
Chapter 3	Women, HIV, and PrEP	60
3.1	Introduction	60

3.2	Women, HIV, and PrEP	60
3.2.1	Women and HIV Globally	60
3.2.2	Women, HIV, and HIV prevention in England	61
3.2.3	Inequities in HIV and HIV prevention among women in England.....	62
3.3	Women and PrEP	64
3.3.1	Evidence for PrEP efficacy in cisgender women	64
3.3.2	Evidence for PrEP effectiveness in transgender women	64
3.3.3	Women and PrEP use	65
3.3.4	Women and PrEP in England	65
3.4	Inequities for women and PrEP	67
3.4.1	Women are not well represented in PrEP research	67
3.4.2	Biological barriers	68
3.4.3	Awareness and willingness to use PrEP.....	68
3.4.4	Social and interpersonal barriers to PrEP.....	69
3.4.5	Structural barriers to PrEP use	70
3.5	Study rationale	71
3.6	Overall aim	72
3.7	Conclusion	72
Chapter 4	Methodological approach.....	73
4.1	Chapter overview	73
4.2	Aim, research questions, and objectives	73
4.3	Thesis methodology	74
4.4	Mixed methods as an approach to research	75
4.4.1	Rationale for taking a mixed methods approach.....	77
4.4.2	Choice of a convergent mixed method design.....	78
4.5	Applying an “equity lens” to the research	79
4.5.1	Health equity frameworks	79

4.5.2	Health equity in the study designs	82
4.5.3	Health equity in the study analyses, findings, and interpretation	82
4.6	A brief note on intersectionality and syndemics	82
4.7	Patient and public involvement.....	84
4.7.1	The importance of Patient and Public involvement advisors.....	84
4.8	Conclusion	85
Chapter 5	Systematic review.....	86
5.1	Chapter overview	86
5.2	Background.....	86
5.3	Systematic review aims and objectives.....	90
5.3.1	Adaptation of the original systematic review.....	91
5.4	Method	92
5.4.1	Search strategy, including databases searched	92
5.4.2	Study inclusion and exclusion criteria.....	92
5.4.3	Study selection	95
5.4.4	Data extraction	95
5.4.5	Risk of bias assessment.....	97
5.4.6	Data synthesis.....	97
5.4.7	Patient and public involvement.....	98
5.5	Results.....	99
5.5.1	Characteristics of included studies	99
5.5.2	Assessment of PrEP awareness and interest.....	103
5.5.3	Consideration of PROGRESS-Plus categories.....	105
5.6	Discussion.....	108
5.6.1	Summary of findings.....	108
5.6.2	Paper characteristics	108
5.6.3	PrEP awareness and interest	110

5.6.4	Recommendations for reporting PrEP awareness, knowledge, interest, and intention	111
5.6.5	PROGRESS-Plus equity characteristics.....	111
5.6.6	Strengths and limitations	112
5.7	Conclusions.....	113
5.8	Implications for the rest of the thesis	113
Chapter 6	Qualitative exploration of women’s awareness and knowledge of PrEP	115
6.1	Chapter overview	115
6.2	Background	115
6.3	Research aims and objectives	116
6.4	Method	117
6.4.1	Study design.....	117
6.4.2	Patient and public involvement	120
6.4.3	Ethical considerations and research governance	120
6.4.4	Participants.....	122
6.4.5	Recruitment	125
6.4.6	Data collection	126
6.4.7	Analysis	127
6.4.8	Reflexivity	130
6.5	Results	133
6.5.1	Sample Description	133
6.5.2	Demographics	134
6.5.3	Themes.....	136
6.6	Discussion.....	168
6.6.1	Summary of findings	169
6.6.2	Discussion of the findings in the context of health literacy	170
6.6.3	Discussion of the findings in the context of the current literature	177

6.6.4	Strengths and limitations	183
6.7	Conclusions.....	184
6.8	Implications for the rest of the thesis	184
Chapter 7	Exploration of women’s PrEP awareness and interest: a cross sectional survey	185
7.1	Chapter overview	185
7.2	Background.....	185
7.3	Research aims and objectives	187
7.4	Method	187
7.4.1	Ethics approval and data governance	187
7.4.2	Sampling method.....	188
7.4.3	Participants.....	188
7.4.4	Recruitment	189
7.4.5	Survey development.....	190
7.4.6	Survey hosting and data collection	200
7.4.7	Survey piloting	200
7.4.8	Patient and public involvement	200
7.4.9	Data management.....	201
7.4.10	Analysis	202
7.5	Results	205
7.5.1	Survey recruitment and final sample	205
7.5.2	Recruitment drive	207
7.5.3	Final survey sample.....	207
7.5.4	Item response.....	208
7.5.5	Participant characteristics.....	210
7.5.6	Plus category characteristics	216
7.5.7	SHS attendance, STI testing and risk perception	216

7.5.8	HIV status, testing, and risk perception	218
7.5.9	Sexual Behaviour	219
7.5.10	PrEP items.....	220
7.5.11	Logistic regression analyses.....	222
7.6	Discussion.....	236
7.6.1	Summary of findings	236
7.6.2	Discussion of findings in the context of the published literature.....	237
7.6.3	Strengths and limitations	245
7.7	Conclusions.....	247
Chapter 8	Discussion	248
8.1	Chapter overview	248
8.2	Summary of the rationale and aims of the thesis	248
8.3	Main findings	251
8.3.1	Main findings from Chapter 5.....	251
8.3.2	Main findings from Chapter 6.....	252
8.3.3	Main findings from Chapter 7.....	252
8.4	Integrated discussion of awareness, knowledge, and preferences for PrEP among women in England	253
8.4.1	Improve engagement with combination HIV prevention to improve PrEP awareness and knowledge among women.....	253
8.4.2	The importance of choice and meeting people where they are	255
8.4.3	Improving equity in PrEP awareness and knowledge for women	256
8.5	Strengths and limitations of the thesis.....	258
8.5.1	Strengths of the thesis	258
8.5.2	Limitations of the thesis	259
8.6	Implications of the thesis findings.....	261
8.6.1	Implications for HIV prevention outreach and health promotion	261
8.6.2	Implications for policy and practice	263

8.6.3 Implications for future research	263
8.7 Conclusions.....	265
References.....	266
Appendices	320

List of tables

Table 1: Public health prevention levels for HIV prevention, adapted from Cabecinha and Saunders	40
Table 2: Systematic review inclusion and exclusion criteria	93
Table 3: PROGRESS-Plus categories for data extraction	96
Table 4: Proposed definitions for outcome measures in the early stages of PrEP engagement	111
Table 5: Demographics characteristics of study participants (N=18).....	135
Table 6: PROGRESS-Plus data collected in the survey.....	191
Table 7: The adapted Oslo Social Support Scale (OSSS-3) instrument.....	193
Table 8: Comparison of respondent's ethnicities in postcode item response and non-response groups	209
Table 9: Demographic characteristics of respondents (N=974) compared to Census 2021 estimates.....	211
Table 10: Additional respondent demographics (N=974)	215
Table 11: Respondent "Plus" characteristics (N=974).....	216
Table 12: STI testing and risk perception among respondents (N=974)	217
Table 13: HIV testing and risk perception (N=974).....	218
Table 14: Sexual behaviour in the previous six months (N=732)	219
Table 15: PrEP awareness, interest, and preferences (N=974)	221
Table 16: Associations with PrEP awareness among the general survey sample (unadjusted and adjusted odds ratios) (N=686)	224
Table 17: Associations with PrEP awareness among sexually active sample (unadjusted and adjusted odds ratios) (N=486)	228
Table 18: Associations with PrEP interest among the sexually active sample (unadjusted and adjusted odds ratios) (N=454)	232
Table 20: Summary of studies included in the systematic review	332

Table 21: Themes and subthemes with illustrative quotes	413

List of figures

Figure 1: The PROGRESS-Plus framework.....	81
Figure 2: The PrEP Cascade from the WHO Implementation tool for PrEP	87
Figure 3: United Kingdom Health Security Agency's PrEP monitoring and evaluation framework overview	89
Figure 4: Prisma Flow diagram for the systematic review	100
Figure 5: Thematic Map of women's awareness and perceptions of PrEP and PrEP provision.....	137
Figure 6: The domains of the Developing HIV Literacy Framework	173
Figure 7: The categories of the Developing HIV Literacy Framework	174
Figure 8: Domains of the Developing HIV Literature Framework mapped to the themes and subthemes	176
Figure 10: Ages of participants in the postcode item response and non-response groups	209
Figure 11: Five HIV Facts poster from the National AIDS Trust	390
Figure 12: Information leaflet used in the qualitative interviews	391
Figure 13: PROGRESS-Plus diagram used in qualitative interviews	392
Figure 14: Twitter (now X) qualitative study advertisement.....	406
Figure 16: Concept map used in the early stages of theme generation	412
Figure 17: Twitter (now X) quantitative study advertisement.....	421
Figure 18: Example Meta platform quantitative study advertisements	422

Appendices

Appendix 1. Patient and Public Involvement Planning and Assessment Form.....	320
Appendix 2. Original systematic review protocol	323
Appendix 3: Example search strategy for systematic review.....	329
Appendix 4. Studies included in the systematic review	332
Appendix 5: Topic guide for HIV negative participants	376
Appendix 6. Topic guide for participants living with HIV	384
Appendix 7. Five HIV Facts Poster.....	390
Appendix 8. PrEP information leaflet.....	391
Appendix 9: PROGRESS-Plus Diagram	392
Appendix 10: Distress Protocol	393
Appendix 11: Participant Information Leaflet for qualitative interviews.....	396
Appendix 12: Demographic Questionnaire.....	404
Appendix 13: Example qualitative study advertisement	406
Appendix 14: Consent form for qualitative interviews.....	407
Appendix 15: Qualitative concept map	412
Appendix 16: Tables of themes and supporting quotes	413
Appendix 17: Example social media advertisements for the quantitative study	421
Appendix 18. Quantitative survey.....	423

List of abbreviations

Term	Definition
AIDS	acquired immunodeficiency syndrome
ART	antiretroviral therapy
ARV	antiretrovirals
AURAH	Attitudes and Understanding Risk of Acquisition of HIV study
BHIVA	British HIV Association
CAB	cabotegravir
CAB-LA	long-acting injectable cabotegravir for PrEP
CDC	The Centers for Disease Control and Prevention
CI	confidence interval
DPV	dapirivine
DPV-VR	dapirivine vaginal ring
DSH	UCL Data Safe Haven
EDI	equality, diversity, and inclusion
EMA	European Medicines Agency
FDA	United States Food and Drug Administration
FTC	emtricitabine
FTC/TAF	tenofovir alafenamide and emtricitabine
GAHT	gender-affirming hormone therapy
GBMSM	gay, bisexual, and other men who have sex with men
GP	general practice
HCP	healthcare providers
HIV	human immunodeficiency virus
HPV	human papillomavirus
HSCA	The Health and Social Care Act 2012
ICS	integrated care systems
IDU	injection drug use
IMD	Index of Multiple Deprivation
IPV	intimate partner violence
LA	local authorities
LAI	long-acting injectable
Natsal	British National Survey of Sexual Attitudes and Lifestyles
NHS	National Health Service
NHSE	NHS England
NICE	National Institute for Health and Care Excellence
ONS	Office for National Statistics
OR/AOR	odds ratio/adjusted odds ratio
OSSS-3	Oslo 3 Social Support Scale

Term	Definition
PCC	PrEP care continuum
PEP	post-exposure prophylaxis
PEP(SE)	post-exposure prophylaxis following sexual exposure
PIL	participant information leaflet
PPI	patient and public involvement
PrEP	HIV pre-exposure prophylaxis
RCT	randomised controlled trial
REDCap	Research Electronic Data Capture research data collection service
RiiSH-COVID	Reducing inequalities in Sexual Health (RiiSH)-COVID surveys
RSE	relationships and sex education
SDOH	social determinants of health
SEM	Social Ecological model
SHC	sexual health clinic
SHS	sexual health service(s)
STI	sexually transmitted infections
TasP	treatment as prevention
TDF	tenofovir disoproxil fumarate
TDF/FTC	tenofovir disoproxil fumarate and emtricitabine
TGW	transgender women
U=U	Undetectable = Untransmittable
UK	United Kingdom
UKHSA	United Kingdom Health Security Agency
UNAIDS	The Joint United Nations Programme on HIV/AIDS
USA	United States of America
VMMC	voluntary male medical circumcision
WHIVPR	Women and HIV prevention research projects
WHO	World Health Organization

Chapter 1 Introduction

1.1 Overview

Human Immunodeficiency virus (HIV) infection is a global public health issue. In 2022, an estimated 39 million people were living with HIV, and 1.3 million people acquired HIV¹. Combination HIV prevention strategies, such as health promotion and treatment as prevention, are a vital factor in reducing HIV acquisition². Oral HIV Pre-exposure prophylaxis (PrEP) is a highly effective biomedical intervention whereby HIV-negative individuals take antiretroviral medication to prevent the acquisition of HIV. Clinical trials have demonstrated PrEP's efficacy in different populations, including gay and bisexual men who have sex with men (GBMSM)³ and heterosexual cisgender men and women⁴ and is recommended by the World Health Organization (WHO) as part of a comprehensive approach to HIV prevention.⁵ In recent years, PrEP provision has been increasing globally⁶; however, questions remain as to whether existing implementation strategies are equitable, e.g., whether PrEP is available and accessible to everyone for whom it is both clinically relevant and wants to use it^{7,8}. In high-income countries, PrEP demonstration projects, recommendations, clinical guidelines, and research has primarily focused on cisgender GBMSM. There is less evidence about PrEP awareness, knowledge, preferences, and use in other groups, such as heterosexual men, cisgender women, and trans and gender diverse people.

In 2019, the Department of Health and Social Care set a goal to end new HIV transmissions in England by 2030⁹. If this ambitious target is to be reached, combination HIV prevention strategies, including PrEP provision, must be strengthened to meet the HIV prevention needs of multiple populations at increased risk. In England, PrEP has been available from the National Health Service (NHS) at sexual health clinics (SHC) free of charge since October 2020. PrEP can be used by anyone considered at risk of HIV, but use among groups other than GBMSM has been low¹⁰. By gender and sexual orientation, the group with the lowest PrEP coverage (i.e., initiation or continuation of PrEP among those with a PrEP need) is women. Despite accounting for over two-fifths of new HIV diagnoses in 2021¹⁰, only 2% of PrEP users were women, and PrEP coverage (i.e.,

uptake of PrEP among people with a PrEP need identified at SHC) among women was 31%, compared to 72% for GBMSM¹¹. Although PrEP coverage among women rose to 41.9% in 2022¹¹, new HIV diagnoses among women also increased from 894 in 2021 to 1,391 in 2022¹², suggesting that women's HIV prevention needs are not being met.

A lack of PrEP awareness and knowledge, stigma related to both HIV and sex, restricted access to PrEP, and a lack of focus on women in PrEP research have contributed to low levels of PrEP use for women^{13–15}. However, most evidence comes from studies in the United States of America (USA), and research on PrEP awareness, knowledge, and use among women in England is scarce¹⁶. There is often no disaggregation by age, ethnicity, or other demographic factors in the published research. A better understanding of the PrEP needs and preferences of women and how PrEP fits into their existing HIV prevention needs is necessary to reach the goal of zero transmissions by 2030.

It is, therefore, essential to develop a better understanding of PrEP awareness and knowledge among women in England so that interventions and campaigns can be designed to improve PrEP coverage among women and so that health services can provide comprehensive HIV prevention services. In this thesis, I aim to improve our understanding of women's awareness, knowledge, and preferences for PrEP. To do this, I have taken a mixed methods approach to gain a more comprehensive understanding of the barriers and facilitators to PrEP use among women. I have conducted and analysed this research using an “equity-lens” in an attempt to identify populations with low PrEP awareness and knowledge within the broad category of women, taking into account characteristics that can impact health equity to explore and understand the existing structures and conditions that create inequities in PrEP and HIV prevention more generally.

1.2 Narrative of the thesis

When I initially embarked on this thesis, I developed a research proposal entitled “Equity considerations in the HIV Pre-exposure Prophylaxis (PrEP) care-continuum”. This proposal aimed to develop and evaluate a framework for measuring health inequities in PrEP implementation. This thesis would consist of

three studies designed to 1) explore how equity had been considered in each stage of the PrEP care-continuum, 2) develop a framework for considering equity across the stages of the PrEP care-continuum in high-income countries, and 3) explore the feasibility and useability of the framework for identifying inequities in PrEP provision in England.

The first study was a PRISMA-E systematic review of existing definitions of outcome measures of the PrEP Care Continuum¹⁷ (PCC) in high-income countries. In undertaking the review, I found that most research conducted between 2012 – 2020 focused on GBMSM and that most studies looking at PrEP implementation in high-income countries, outside of clinical trials, were from the USA. Additionally, while work on the systematic review was underway, the first results from England's PrEP Impact trial (hereafter referred to as the Impact trial), the pragmatic health technology trial investigating the PCC in England, became available. These results indicated that PrEP use was very low among women and other groups (i.e., people who were not GBMSM). The initial results from my systematic review and the Impact trial results highlighted existing inequities in PrEP research and PrEP provision. In response to this, I decided to change the direction of my thesis to focus on a population where an inequity in PrEP provision had been identified, i.e., women resident in England. Although low PrEP use among women in England had been identified by the Impact trial, the reasons behind this had not been explored in depth. As described above, studies from the USA reported low levels of PrEP awareness and knowledge among women^{14,15} but to my knowledge, few studies had investigated levels of awareness or interest among women in England. Furthermore, I was not aware of any studies that looked at women's perceptions of and preferences for PrEP provision in England. Therefore, the focus of this thesis changed to investigating awareness and knowledge of PrEP among women and exploring their perceptions of and preferences for PrEP provision. My supervisors were supportive and agreed to the change in direction, as did the patient and public involvement (PPI) advisors recruited to advise on my initial thesis project. A new research proposal to investigate PrEP awareness, interest, and preferences among women in England was subsequently developed and presented at my upgrade examination in May 2021. My upgrade examination also presented the searches, data extraction, and preliminary analysis from the systematic review. However, given

the shift in research direction, a truncated version of the review is presented in this thesis. This is discussed in more detail in Chapter 5.

1.3 Research focus

This thesis focuses on women resident in England. In this thesis, “women” refers to any adult who lives as and identifies as female. This definition includes cisgender women (i.e., women whose gender identity corresponds with the sex they were assigned at birth), trans women (i.e., women whose gender identity does not correspond with the sex they were assigned at birth sex), and gender diverse womenⁱ. I use the term “women” with the understanding that each woman will have multiple intersecting identities, and this includes gender identity. Wherever possible, I have endeavoured to allow participants in this research to self-define their ethnic, sexual, and gender identities, rather than being prescriptive. When referring to research or results that apply to a single or specific gender identity, I will clarify which population I am referring to. Although there are likely to be similarities in the HIV prevention needs, levels of PrEP awareness, and equity issues impacting women across the United Kingdom (UK), this thesis focuses on women residing in England, exclusively. There are two main reasons for this decision. Firstly, healthcare provision, HIV epidemiology, and delivery of combination HIV prevention varies across the devolved nations, meaning women’s experiences may not be directly comparable between countries. Secondly, although PrEP is currently available throughout the UK, initial implementation and access varied by country.

1.4 Thesis aim and research questions

The overall aim of this thesis was to investigate awareness, knowledge, and perceptions of PrEP among women in England through an equity lens. This was achieved by addressing the following research questions:

1. What are the current levels of PrEP awareness and knowledge among women in England?

ⁱ “Gender diverse” is an umbrella term that is used to describe gender identities that demonstrate a diversity of expression beyond the binary framework

2. How can gaps in women's PrEP awareness and knowledge be addressed?
3. What are women's perceptions of PrEP provision in England?
4. How can PrEP provision be made more acceptable and accessible to women?

A mixed methods study has been employed to address the thesis aim and research questions, and three distinct methods are employed: a systematic review, qualitative interviews, and a quantitative survey. An equity lens was applied in the design and analysis of findings for each method to identify and explore disparities in PrEP engagement and HIV prevention among women. Finally, the implications of the study findings for public health policy and practice are considered in an integrated discussion of the results.

1.5 Thesis structure

This thesis consists of eight chapters.

Chapter 2: I provide the background for this research. I first introduce the topic of HIV and provide a brief overview of HIV epidemiology globally, and in the UK. I then provide a general discussion of combination HIV strategies, followed by a description of their provision in England. I then provide a brief history of PrEP before discussing PrEP implementation in England. Finally, I introduce the concept of health equity, discuss known inequities in HIV and PrEP and explain why women are the chosen population for this research.

Chapter 3: I provide further context for this research. After discussing the HIV pandemic among women, I discuss PrEP use among women globally and then in England. I then discuss known barriers for PrEP use among women and identify gaps in the current literature around women and PrEP in England.

Chapter 4: I describe the methodology used to address the research aim and research questions, by first introducing the mixed methods approach to research, and then discussing how the health equity lens is applied in the thesis.

Chapter 5: I present the findings of my systematic review of literature, describing how the outcome measures "awareness" and "interest" have been defined, and how

factors influencing health equity have been considered when reporting these outcome measures in studies published between 2012 and 2020.

Chapter 6: I explore women's awareness, knowledge, and perceptions of PrEP, and how they relate to HIV literacy, using qualitative data from one-to-one semi-structured interviews that I conducted with 18 women who were resident in England.

Chapter 7: I present the findings from a cross-sectional, self-completed convenience survey of women resident in England. Descriptive statistics are used to present the demographics and level of PrEP awareness and interest of the sample. I then use logistic regression to identify associations between factors influencing health equity and PrEP awareness and interest, with and without adjustment for confounders.

Chapter 8: I summarise and integrate the findings from this thesis and summarise the strengths and limitations of this research. I also discuss the implications of this research for PrEP implementation in England, health promotion, and HIV prevention policy and practice, and implications for future research.

1.6 Role of the candidate

I developed and wrote the thesis research proposal with guidance and input from my supervisors and PPI advisors.

For the systematic review, presented in Chapter 5, I wrote the review protocol, submitted it to PROSPEROⁱⁱ, and submitted it for publication¹⁸. I devised the search strategy, carried out the searches, screened all results, and performed all data extraction and synthesis. Another PhD candidate carried out secondary screening (title, abstract, and full text) of 20% of the search results. My supervisors provided advice and feedback at all stages of the review.

For the qualitative interviews, presented in Chapter 6, I wrote the study protocol and submitted the ethics application. I drafted all study materials (including the topic guide, advertising materials, and patient information leaflet), and updated them considering comments from my supervisors and two PPI representatives. I carried

ⁱⁱ CRD: 42020169779

out all the recruitment activities and conducted all the interviews. Interviews were transcribed by a secure, confidential third-party transcription service. I completed all the analysis of interview data and interpreted the findings with feedback from my supervisors.

For the quantitative survey, presented in Chapter 7, I devised the study protocol and submitted the ethics application. The recruitment strategy was adapted from a study by McCarthy et al.¹⁹, at the suggestions of Professor Cath Mercer, a member of my thesis committee. I led the development of the survey design and updated it considering feedback from my supervisory panel and PPI representatives. I programmed the survey and undertook all the fieldwork, data cleaning and management, and statistical programming, analysis, and interpretation. My supervisors provided advice and guidance on all aspects of the analysis and interpretation.

1.7 Research dissemination

The research presented in this thesis has been presented in a number of publications and at conferences and meetings. Below is a summary of the research dissemination.

1.7.1 Publications

Cabecinha M, Solomon D, Rait G, *et al.* Equity considerations in outcome measures of the HIV pre-exposure prophylaxis care continuum in high-income countries: a systematic review protocol. *BMJ Open* 2021;11:e040701. doi: 10.1136/bmjopen-2020-040701

Cabecinha, MA; Saunders, J; (2022) HIV prevention strategies. *Medicine* , 50 (4) pp. 228-233. 10.1016/j.mpmed.2022.01.007

1.7.2 Conference presentations

Panellist for live talk show entitled “Optimal PrEP access” at STI & HIV World Congress. 14-17 Jul 2021; virtual.

Cabecinha M, Solomon D, Rait G, et al. P182 Identifying the PrEP Gap: A systematic review exploring equity in the HIV-PrEP care continuum in high income countries. Poster presentation at: STI & HIV World Congress.14-17 Jul 2021; virtual.

Cabecinha M, Rait G, Saunders J, et al. Current PrEP provision does not align with women's preferences: Early results from a cross-sectional survey investigating PrEP awareness, interest, and preferences among women in England. Poster at: BHIVA Spring Conference 2023. 24th – 26th April 2023. Gateshead, UK. **Awarded a BHIVA highly commended poster presentation.**

Cabecinha M, Rait G, Saunders J, et al. "If you don't know, how can you know?": A qualitative investigation of HIV Pre-exposure prophylaxis knowledge and perceptions among women in England. Oral presentation at: BHIVA Spring Conference 2023. 24th – 26th April 2023. Gateshead, UK. **Awarded the BHIVA Chloe Orkin Award for Best Presentation in the field of social sciences.**

Chapter 2 Background

2.1 Chapter overview

In this chapter, I provide a brief background on HIV Pre-exposure prophylaxis (PrEP) and its role in combination HIV prevention. To provide context, I first discuss the HIV epidemic globally, and in the UK, with a focus on England. I then introduce the concept of combination HIV prevention strategies, followed by a brief history of PrEP as a biomedical tool for preventing HIV, and the history of PrEP implementation in the UK. This is followed by an introduction to concepts around health equity, and a discussion of health inequity in HIV and HIV prevention more generally, and for PrEP specifically. Finally, I argue that PrEP implementation should be monitored and evaluated through an equity lens.

2.2 The HIV Epidemic

2.2.1 Human Immunodeficiency Virus (HIV)

Human immunodeficiency virus (HIV) infection is a global public health issue. Since the beginning of the HIV epidemic in the 1980s, an estimated 85.6 million people have acquired HIV worldwide, and as of 2022 approximately 40.4 million people have died from HIV-related causes¹.

HIV is a blood-borne retrovirus that can infect and replicate in a variety of immune cells, including CD4⁺ helper T-cells and macrophages²⁰. It can be transmitted through blood and other fluids, including semen and breast milk. Routes of transmission include sexual exposure (i.e., through vaginal or anal sex), sharing injecting equipment such as needles, and occupational exposure (e.g., needlestick injuries). It can also be transmitted through pregnancy, breastfeeding, or childbirth (vertical transmission). Historically, HIV had been transmitted through blood and plasma products, but this has virtually been eliminated through screening and equipment use practices and policies²¹.

Advances in treatment and prevention have led to a decrease in new HIV transmissions since the peak in 1995¹, and with effective care and treatment, HIV is

a chronic, manageable condition. However, without access to treatment, people living with HIV experience progressive damage to their immune system and can develop acquired immune deficiency syndrome (AIDS), which leaves them vulnerable to life-threatening infections and cancers.

2.2.2 HIV Globally

The Joint United Nations Programme on HIV/AIDS (UNAIDS) releases annual HIV statistics, including estimations on the number of people living with HIV, HIV and AIDS-related deaths, and transmissions. In the most recent available data from 2022, it was estimated that 39 million people were living with HIV, 1.3 million people had newly acquired HIV, and 650,000 people had died from HIV-related causes¹. The majority of cases are concentrated in the WHO African regionⁱⁱⁱ; where an estimated 25.6 million people are living with HIV, and 50% of global new HIV acquisitions occurred²². New HIV infections have been reduced by 59% since a global peak in 1995, and since 2010, there has been a 38% decline in new HIV infections. During the same period (2010- 2022) there has been a 58% decline in new HIV infections among children¹.

Globally, the median prevalence of HIV among adults aged 15 – 49 is 0.7%, but the median prevalence varies greatly between settings and key populations. For example, median prevalence is estimated at 7.7% among GBMSM, 2.5% among sex workers, and 10.3% among trans persons¹.

2.2.3 HIV in the United Kingdom and England

In 2022 in the UK, 4,040 people were newly diagnosed with HIV, and 94% (3,805) of those people were diagnosed in England. This is a 22% rise from 2021 (3,118 new diagnoses in England), but a 2% fall from the last pre-COVID-19 pandemic data from 2019 (3,864). Overall, rates of new HIV diagnoses have declined since a peak in 2014 (5,784 in England)^{12,23}.

Of the 3,805 new diagnoses made in England, 1,361 were previously made abroad. It is worth noting that these diagnoses would not have been preventable through

ⁱⁱⁱFor a list of countries in the WHO Africa region see: <https://www.afro.who.int/countries>

public health measures taken in the UK, as they are unlikely to have occurred there. This leaves a total of 2,444 new diagnoses first made in England in 2022. Among these, 30% (724) were made in men exposed through sex between men, 23% (564) in women exposed by heterosexual contact, and 17% (411) in men exposed by heterosexual contact. Vertical transmission in England accounted for 0.5% (13) of new diagnoses first made in England. Twenty-eight per cent of diagnoses (679) occurred through an unknown route of exposure²³.

Coverage of treatment and care provision for people living with HIV is high. A total of 94,397 people accessed HIV care in 2022, and of these, 98% are on treatment. Ninety-eight per cent of people with a viral load reported in England were virally suppressed²³ (i.e., they had an undetectable viral load).

2.3 Targets for the elimination of HIV

2.3.1 UNAIDS Fast-Track strategy to end the AIDS epidemic by 2030

In 2014, the UNAIDS introduced the “Fast-Track strategy” to end the AIDS epidemic by 2030²⁴. The strategy included ambitious targets for detecting and treating HIV, and reducing new HIV transmissions, with milestones set for 2020 and 2030.

For the detection and treatment of HIV, the fast-track targets for 2020 were set at 90-90-90; i.e., 90% of people living with HIV knowing their status, of which 90% were on treatment, of which 90% were virally suppressed, and fewer than 500,000 AIDS-related deaths. By 2030, these targets rise to 95-95-95. Regarding HIV transmissions, the strategy set a target of fewer than 500,000 new infections by 2020, dropping to 200,000 by 2030.

In 2016, these targets were accompanied by the “Fast-track” commitments²⁵, aimed to be achieved by 2020. These commitments included ensuring that at least 30% of all HIV-related service delivery is community led; eliminating HIV infections among children; and eliminating gender inequalities and forms of violence and discrimination against women and girls, people living with HIV and key populations who are disproportionately affected by HIV, such as sex workers. These commitments were drawn from the 2016 United Nations Political Declaration on Ending AIDS²⁶, which was adopted by the United Nations member states at the 2016 United Nations

General Assembly High-Level meeting on Ending AIDS and the UNAIDS 2016-2021 strategy²⁷.

Global efforts were not on track to meet the fast-track 2020 targets, and progress was further disrupted by the COVID-19 pandemic. In response to the far-reaching effects that the pandemic had on health systems and public services, UNAIDS released a World AIDS Day report²⁸ with updated targets. The report discussed the success and shortfalls of the Fast-Track strategy regarding the 2020 commitments and included updated goals for putting “people at the centre” of strategies to prevail against pandemics. Through a review of available evidence and consultation with partner organisations, a new set of targets was proposed for 2025. The report asserts that if the 2025 targets are met, the 2030 goals (originally set in 2014), would be within reach.

2.3.2 “Towards zero” and eliminating new HIV transmissions in England by 2030

In England, the government has adopted the UNAIDS target to reduce HIV transmission in England to zero by 2030. In January 2019, this goal was announced by then Health and Social Care Secretary, Matt Hancock, followed by the establishment of the HIV commission²⁹, tasked with developing evidence-based recommendations on how this goal could best be achieved. The commission was a multi-disciplinary team made up of commissioners, academics, representatives from local and national government, people living with HIV, and members from organisations that addressed the needs of the most at-risk communities. The commission’s final report³⁰ was launched on World AIDS Day 2020, outlining a plan for England to become the first country to end new cases.

In 2021, the Department of Health and Social Care released the “Towards zero: The HIV Action plan for England – 2022 to 2025”⁹ policy paper, which outlines how England will achieve the 2030 target, with an interim goal of an 80% reduction in new HIV diagnoses among people first diagnosed in England by 2025 (i.e., from 2,860 in 2019 to under 600 in 2025).

2.3.3 Meeting global and national HIV elimination goals

The commitments to end new HIV transmissions by 2030 globally and at the national level are ambitious goals, but both the UNAIDS Fast-Track strategy and the HIV action plan for England provide guidance on the concerted efforts that will be needed to reach their targets. Although both strategies target different geographic areas and different populations, they both emphasize the importance of working within the local context to address the HIV prevention needs of local communities, including both people living with HIV and people considered at risk of HIV acquisition. Meeting these targets will rely on the effective implementation of combination HIV prevention methods.

2.4 Combination HIV prevention

Combination HIV prevention programmes, as defined by the UNAIDS Prevention Reference Group, are ‘rights-based, evidence-informed, and community-owned programmes that use a mix of biomedical, behavioural, and structural interventions, prioritized to meet the current HIV prevention needs of particular individuals and communities, so as to have the greatest sustained impact on reducing new infections’³¹. Combination HIV prevention programmes must consider the HIV epidemiology and conditions and should address both populations at immediate risk and those experiencing underlying vulnerabilities that can impact a person’s risk of HIV acquisition. Prevention strategies should be comprehensive, and incorporate capacity building and flexibility to adapt to changing environments. Prevention activities should operate across all levels of the socio-ecological model³² (e.g., individual, interpersonal, community, societal, policy), and at each of the three levels of prevention in public health: primary, secondary, and tertiary (Table 1). This section has been adapted from a publication by Cabecinha and Saunders²¹.

Table 1: Public health prevention levels for HIV prevention, adapted from Cabecinha and Saunders²¹

Prevention level	Definition	Example
Primary	Preventing the acquisition of HIV	Education, awareness campaigns, health promotion, condoms, voluntary male medical circumcision, needle and syringe exchange programmes, opiate substitution therapy, pre-exposure prophylaxis, post-exposure prophylaxis, treatment as prevention
Secondary	Reducing the severity of HIV and decreasing opportunities for HIV transmission	HIV testing, early diagnosis and treatment, contact tracing, linkage to treatment services
Tertiary	Improving the quality of life for people living with HIV	Antiretroviral therapy, peer and community support, mental health support, referrals to wrap-around services, reducing HIV stigma

2.4.1 Primary prevention

The aim of primary prevention programmes is to reduce the incidence of new cases of a disease, i.e., reducing the acquisition and transmission of HIV. Primary prevention methods include education and awareness campaigns relating to HIV and sexual and reproductive health, promotion and use of safer sex practices that reduce the risk of transmission, and biomedical interventions. Vaccines to prevent HIV are in development, and recent developments in vaccine technology and development have shown initial promise³³, however, as no effective vaccine has yet been produced and licensed, they will not be discussed further in this section.

2.4.1.1 Education, awareness and health promotion

Both educational attainment and educational campaigns are important facets of primary prevention. In general, higher educational attainment is associated with a lower risk of HIV diagnosis³⁴, and this is particularly true for women and young girls in areas with high prevalence³⁵, such as Southern Africa. Comprehensive relationship and sexual education has been shown to delay the age of sexual debut and decrease risk-taking behaviour^{36,37}.

More specifically, campaigns and educational programmes designed to increase awareness and knowledge around HIV can increase engagement with HIV prevention methods (e.g., increase testing rates), and reduce HIV-related stigma³⁸.

Health promotion is a core facet of primary prevention. Defined by the WHO as ‘the process of enabling people to increase control over, and to improve, their health’³⁹, it can include both interventions to change behaviours and risk at the individual level, and strategies and interventions to change societal and environmental factors.

Health promotion campaigns can be run to develop and improve HIV prevention literacy for the general population, or they can be targeted to specific key population groups who are at higher risk of infection in a given location.

2.4.1.2 Male Condoms

Male condoms are an effective and inexpensive method of HIV prevention. In 2002, a Cochrane review of longitudinal cohort studies concerning sexually active HIV serodifferent heterosexual couples reported an 80% reduction in HIV seroconversion with consistent condom use for vaginal sex⁴⁰. For anal sex, consistent condom use reduces HIV incidence by an estimated 70-90%^{41,42}. Currently, condoms are the only method that also protects against unintended pregnancy as well as HIV and other STIs.

2.4.1.3 Voluntary male medical circumcision (VMMC)

The efficacy of voluntary male medical circumcision (VMMC) for HIV prevention has been demonstrated in both clinical trials and observational cohort studies. For heterosexual acquisition of HIV in men, VMMC can reduce acquisition by approximately 60%^{43,44}.

The WHO and UNAIDS recommend VMMC as an additional HIV prevention strategy in areas where there is a generalised HIV epidemic (i.e., where HIV transmission is sustained by the sexual behaviour of the general population, rather than concentrated in clearly defined vulnerable groups). This generally refers to areas where the population prevalence is greater than 1%⁴⁵.

2.4.1.4 Support for people who inject drugs

Opioid substitution treatment, where illicit opioids are replaced with a prescribed opioid such as methadone or buprenorphine, may reduce drug dependency and injecting frequency and has been associated with a 54% reduction in the risk of HIV acquisition among people who inject drugs⁴⁶.

2.4.1.5 Antiretroviral medication for HIV prevention

Antiretrovirals (ARV) can be taken to suppress the replication of HIV in the body and are a powerful biomedical tool for HIV prevention. ARV can be taken in anticipation of a potential exposure of transmission event (PrEP), immediately following a potential exposure event (Postexposure prophylaxis, PEP) or by people who are living with HIV as treatment to suppress the virus and manage the condition (sustained ARV).

2.4.1.5.1 HIV Preexposure prophylaxis (PrEP)

HIV Preexposure prophylaxis, or PrEP, is ARV medication that can be taken by people who are HIV-negative before and after sex to prevent infection with HIV. PrEP is recommended by the WHO as an additional prevention choice for people who are at substantial risk of HIV², alongside other combination HIV prevention options. In general, PrEP may be appropriate for anyone at risk of HIV acquisition as indicated by sociodemographic or behavioural characteristics. PrEP, including formulations, modalities, and history will be discussed later in this chapter.

2.4.1.5.2 Postexposure prophylaxis

Postexposure prophylaxis, or PEP, is ARVs that are taken to prevent HIV after a known or potential exposure. PEP can be taken following occupational or non-occupational exposure in the community and following sexual exposure (also known as postexposure prophylaxis following sexual exposure, PEP(SE))⁴⁷. After an exposure, PEP should be taken as soon as possible; ideally within 24 hours, and no more than 72 hours after. Where appropriate, support for people taking PEP(SE) should include advice and counselling around safer sex strategies and other HIV prevention methods, and discussions around PrEP use.

2.4.1.6 Treatment as prevention

People living with HIV who are on treatment and have an undetectable viral load (<200 copies/ml) cannot transmit HIV to their sexual partners⁴⁸. This is known as Treatment as Prevention (TasP), and in some countries, such as the UK, it is known as Undetectable = Untransmittable (“U=U”)⁴⁹. Several studies have provided evidence to support this statement; The HPTN052 study⁵⁰ included 1,763 serodifferent, predominately heterosexual couples. Partners living with HIV were randomised to either early or delayed antiretroviral therapy (ART). When the viral load was undetectable in the partner living with HIV, there were no transmissions of HIV to the HIV-negative partner. The subsequent PARTNER⁴⁸ and PARTNER2⁵¹ studies also found that there were no HIV transmissions when the partner living with HIV had an undetectable viral load, and this was following more than 100,000 episodes of condomless sex among participants.

2.4.2 Secondary prevention

Secondary prevention methods aim to diagnose people living with HIV as early as possible, in order to reduce opportunities for transmission and offer treatment to prevent complications. Secondary prevention methods include access to HIV testing, community engagement and outreach services, contact tracing and management, and linkage and access to treatment services and support.

2.4.2.1 HIV testing

The first test for HIV was approved by the United States Food and Drug Administration (FDA) in 1985⁵², and since then testing modalities have expanded from laboratory tests to include self-testing (where the test is performed entirely by the user and the result is immediate or close to immediate), and self-sampling (where the sample is collected by the user and returned to the laboratory for testing).

HIV testing should be easily accessible, confidential, voluntary, non-discriminatory, and free. Testing guidelines vary between countries and may be influenced by differences in local epidemiology. This often means that testing is targeted at those deemed to be at the greatest risk of acquisition. However, a targeted approach should be balanced with a more generalised testing strategy to address and reduce

barriers to HIV testing. Barriers can occur at both the individual level (e.g., lack of awareness, fear of discrimination or stigma), and structural and organisational level (e.g., lack of access to services). Increasing opportunities and options for testing can help to overcome such barriers.

Integrating opt-out testing (wherein attendees are informed that they will be automatically tested unless they decline) into routine care has been successful in settings such as sexual health services (SHS) and ante-natal clinics. In 2020, the independent UK HIV commission called for opt-out testing wherever blood is taken⁵³, and recent successes of opt-out testing in emergency departments in the UK cities of Blackpool, Brighton, London, and Manchester led to calls for the expansion of opt-out testing to other areas⁵⁴. Based on these successes, in December 2023, the Department of Health and Social Care announced that the opt-out testing scheme is to be expanded to 46 additional emergency areas of high HIV prevalence^{iv} in England⁵⁵.

Providing access to community-based and community-led testing, self-testing, and self-sampling alongside testing in healthcare settings increases opportunities for HIV testing, promotes awareness of testing and HIV prevention, and normalises uptake of testing⁵⁶.

2.4.3 Tertiary prevention

Tertiary prevention methods aim to reduce the progression of diseases. In the case of people living with HIV, this means improving their quality of life through treatment and support.

2.4.3.1 Support for people living with HIV

ARVs were discussed earlier as a primary prevention method to protect the HIV-negative partners of people living with HIV through treatment as prevention/U = U. However, ARVs play a role in tertiary prevention, by preventing the progression of illness and co-morbidities that are associated with HIV.

^{iv}High prevalence areas are defined as areas with 2-5 cases per 1000.

HIV is a chronic condition, and people living with HIV must be supported over the course of their lives to take treatment effectively, and as prescribed. Competing priorities, such as financial problems, housing instability, or mental illness may act as barriers to adhering to treatment regimens^{57–59}. The standard treatment regimen consists of ARV medication that is taken daily, however, different formulations and delivery systems are in development. Recently the first long-acting injectable ARV regimen⁶⁰ was approved for use by the FDA⁶¹ in the USA and the National Institute for Health and Care Excellence (NICE)⁶² in England, however, daily ARV is still the most common regimen. Adherence to ARV may be supported through a combination of routine medical care and advice, and the provision of additional services, such as mental health and wellbeing support, and peer and community support⁶³. Referral and signposting to “wrap-around care”, i.e., services that provide support for issues such as finances, mental health, employment, transportation, and housing, can mitigate competing priorities, thereby supporting adherence to ARVs⁶⁴.

2.4.3.2 Reducing HIV related stigma and discrimination

The Centers for Disease Control and Prevention (CDC) defines HIV stigma as “negative attitudes and beliefs about people with HIV”⁶⁵. Stigma associated with HIV is a substantial barrier to HIV prevention and treatment programmes and can reinforce or compound stigma that exists around marginalized groups who are disproportionately affected by HIV, including GBMSM, sex workers, and people who inject drugs^{66,67}. The criminalisation of behaviours that carry an elevated risk of HIV, such as drug use or sex work, may also decrease willingness to engage with HIV prevention and treatments, for fear of criminal repercussions⁶⁸.

It is well recognised that reducing HIV related stigma is critical facet of combination HIV prevention strategies, however, HIV related stigma is both complex and linked with, and reinforces, other existing stigma and inequalities of ethnicity, gender, and sexuality. Therefore structural and programmatic approaches are required in dismantling HIV related stigma⁶⁶. In addition to changing public attitudes to end stigma²⁴, approaches can include universalist programmes that normalise HIV prevention, such as opt-out testing in emergency departments described above. An HIV prevention strategy that only targets interventions to particular sub-groups runs the risk of “othering” and labelling these groups with HIV-related stigma.

2.4.4 A "serostatus neutral" approach to HIV prevention

A "serostatus neutral" approach, asserts that every individual has an HIV status that guides how they engage with HIV prevention and care. The status neutral approach was first pioneered in New York City by Myers et al⁶⁹, for GBMSM, and has since been adapted, generalised²¹ and updated to include both individual and client/provider level issues⁷⁰.

The serostatus neutral approach starts with an HIV test (secondary prevention). Following a negative result, a person is linked to, or continues to engage with prevention. This may involve linkage to PrEP services, counselling for behavioural risk reduction, or reminders to test regularly where appropriate. Following a positive test, a person is linked to HIV care and treatment, and wraparound support services (tertiary prevention). The status neutral approach includes all levels of prevention and creates an entry point for engagement with HIV prevention and treatment.

2.4.5 Effective implementation of combination HIV prevention strategies

To be effective, combination HIV prevention strategies must be tailored to reflect the local HIV epidemic and the needs of local communities and populations, and this includes ensuring campaigns and messaging around HIV prevention are inclusive and culturally sensitive.

To prevent reinforcement of stigma, targeted and specific strategies and campaigns must be balanced carefully against more general campaigns to meet the needs of the local populations.

2.5 Combination HIV prevention in England

In England, a range of combination HIV prevention strategies have been employed. People diagnosed with HIV in England have access to free treatment and care, and ARVs for HIV prevention (i.e., PEP and PrEP) are available on the NHS for people who meet the guidelines for their use^{71,72}. HIV tests are also freely available on the NHS in a large range of settings, including SHS, charity and community testing sites, as part of antenatal screening, opt-out testing in emergency departments of high prevalence areas, and some general practice (GP) surgeries. Self-sampling and self-testing kits are also available; however, this may differ by location. Prevention efforts

are supported by community and third sector organisation which provide outreach, testing, peers support, and resources to combat stigma and increase awareness of HIV and HIV prevention services. Some of these organisations operate at the National level, such as the National AIDS Trust⁷³ and the Terrence Higgins Trust⁷⁴, while others cover smaller geographic areas, such as Positive East⁷⁵, which operates out of East London.

The provision of combination HIV prevention services in England is complex, and this is in part due to how services at the different level of prevention are commissioned and delivered. The Health and Social Care Act 2012⁷⁶ (HSCA) brought about significant changes in commissioning arrangements and responsibilities for sexual health, reproductive health, and HIV prevention and treatment provision. This means that at both the national and local level, HIV prevention and treatment provision is both diverse and fragmented.

2.5.1 Commissioning responsibilities for sexual health services and HIV prevention

As per the HSCA 2012, local authorities (LA) are responsible for commissioning comprehensive SHS services, including contraceptive services and prescription costs, sexually transmitted infection (STI) and HIV testing, and specialist services, including HIV prevention and sexual health promotion. HIV social care is also commissioned by local authorities⁷⁷. Integrated care systems (ICS), formerly clinical commissioning groups (CCGs), commission HIV testing where clinically indicated in ICS commissioned services (e.g., A&E and other hospital departments); CCGs were established as part of the HSCA 2012 but were replaced with Integrated Care Systems (ICSSs) through the Health and Care Act 2022⁷⁸. The NHS Commissioning Board, or NHS England (NHSE), the oversight body for the NHS in England, commissions HIV treatment and care, including the drug costs for PEPSE.

NHSE reimburses drug costs associated with PrEP, however, any service costs associated with PrEP fall to the LA, as they are responsible for commissioning HIV prevention services⁷⁹. The next section introduces a brief history of PrEP as a biomedical tool for HIV prevention, and the implementation of PrEP in the UK and England

2.6 HIV Pre-Exposure Prophylaxis

HIV Pre-Exposure Prophylaxis (PrEP) is a highly effective biomedical prevention method, whereby HIV negative individuals take antiretroviral drugs to prevent the acquisition of HIV. Clinical trials and real-world evaluations have demonstrated PrEP's efficacy in different populations, including GBMSM³, trans individuals⁸⁰, and heterosexual cisgender men and women⁴. The WHO recommends PrEP as an additional prevention choice for people who are at substantial risk of HIV, as part of a comprehensive approach to HIV prevention⁵.

2.6.1 A brief history of PrEP

Chemoprophylaxis (i.e., taking medication before a potential exposure to prevent disease or infection) of diseases such as malaria, typhus, and traveller's diarrhoea had been well established as a prevention method in non-infected individuals⁸¹. In the 1990s, post-exposure prophylaxis for HIV (PEP) became available for people who had an occupational exposure to HIV⁸², and in 2005 the United States Department of Health and Human Services published recommendations for non-occupational PEP for people who may have been exposed to HIV through sexual contact or injection-drug use⁸³. Research into chemoprophylaxis for HIV prevention was first suggested in 2003 as a way of bolstering prevention efforts while waiting for an effective vaccine to be produced⁸⁴.

Tenofovir disoproxil fumarate (TDF), an existing antiretroviral drug that was already widely used in the treatment of HIV, was identified as a potential PrEP candidate, due to its tolerability, safety, and limited side effects⁸⁵. Trials in non-human models showed that a combination of Emtricitabine (FTC) and TDF was more protective than TDF alone⁸⁶. Subsequently, clinical trials in humans demonstrated the efficacy of combination TDF/FTC in reducing the risk of HIV acquisition in GBMSM^{3,87,88}, heterosexual men and women⁸⁹ (including heterosexual men and women in serodifferent partnerships (i.e., relationships where partners have different HIV statuses))⁴, people who inject drugs⁹⁰, and transgender women⁹¹. In 2012, the FDA approved TDF/FTC (under its brand name Truvada) for use as PrEP⁹², and in 2016 it was authorised by the European Medicines Agency (EMA) to be used as PrEP⁹³.

2.6.2 PrEP regimens, formulations, and modalities

Initially, PrEP was only available to be taken as oral medication, however, since its approval by the FDA in 2012, additional PrEP formulations and modalities have become available.

2.6.2.1 Oral PrEP regimens

Current TDF/FTC PrEP regimens involve either taking a pill once daily (daily PrEP) or taking pills in advance of and following an anticipated sexual exposure (known as event-driven, on-demand, or event-based PrEP). In 2019, a second daily pill, containing a combination of tenofovir alafenamide and emtricitabine (FTC/TAF), brand name Descovy, was approved for use as PrEP in the USA⁹⁴ for men and transgender women.

2.6.2.2 The dapirivine vaginal ring (DPV-VR)

The dapirivine vaginal ring (DPV-VR), also known as the PrEP vaginal ring, was the first topical HIV prevention method to be submitted for regulatory approval. Intended for use by cisgender women, the DPV-VR ring consists of a silicone ring that is inserted into the vagina and slowly releases the medication dapirivine (DPV) over the course of 28-days, after which time it can be removed and replaced with a new ring. In clinical trials, the DPV-VR showed decreases in HIV transmission between 27 – 50%⁹⁵. In 2020, the EMA's human medicines committee adopted a positive opinion for the DPV-VR⁹⁶, and in 2021 it was recommended as an additional choice for HIV prevention in the WHO's 2021 updated recommendations on HIV prevention⁹⁷. It has received regulatory approval in a number of low- and middle-income countries, including Kenya, Uganda, and Zimbabwe, however, it is not yet licensed in any high-income countries. The DPV-VR was accepted for review by the FDA⁹⁸, but in December 2021, the FDA advised the DPV-VR developers that, given the available data and current landscape of HIV prevention for women in the USA it was unlikely to receive approval, and the application was withdrawn⁹⁹.

2.6.2.3 Long-acting Injectable cabotegravir for PrEP

Cabotegravir (CAB) is an antiretroviral medication used in the treatment of HIV and is now available for use as long-acting injectable (LAI) PrEP. Long-acting injectable cabotegravir for PrEP (CAB-LA) is administered by injection once every two months and is the first injectable treatment to be approved as a pre-exposure prophylaxis for HIV. Following clinical trials demonstrating its efficacy as a pre-exposure prophylaxis for HIV in cisgender MSM and transgender women¹⁰⁰, and in cisgender women¹⁰¹, the FDA approved CAB-LA in December, 2021¹⁰². In 2022, the WHO published guidelines on CAB-LA, which included the recommendation that CAB-LA be offered as an additional HIV prevention option for people at substantial risk of HIV infection¹⁰³. At the time of writing, CAB-LA had been approved for use by seven countries and had been submitted to the EMA for use as PrEP in Europe¹⁰⁴.

2.6.2.4 Additional formulations and modalities

Additional formulations and modalities for PrEP are currently being researched and developed for injectable PrEP, vaginal rings, and oral tablets¹⁰⁵. Long-acting, subdermal implants¹⁰⁶, and multipurpose prevention technologies¹⁰⁷ (e.g., delivery systems that provide both contraception and protection against HIV) are also in development. Expanding the availability of PrEP formulations and modalities will allow individuals to choose prevention methods that suit their own unique needs and circumstances, and more choices may increase engagement with, and equitable access to, PrEP. However, unless stated, hereafter the term “PrEP” is used to refer to the TDF/FTC formulation of oral PrEP.

2.6.3 PrEP Implementation

Since its approval by the FDA, the availability of PrEP has increased globally. Between 2016 – May 2023, there were over four million initiations of PrEP (including available formulations of oral PrEP, DPV-VR and CAB-LA) worldwide¹⁰⁸. Service model delivery varies greatly between countries and settings, ranging from centralised PrEP services in clinics or hospitals to community and home-based models¹⁰⁹.

Currently PrEP is available for free on the NHS from sexual health clinics in all four nations of the UK, although initially implementation varied by country.

2.6.3.1 PrEP implementation in England (2012 – present (2024))

Initially in England, PrEP was provided to participants of the PROUD study⁸⁸; an open-label, randomised trial to assess the efficacy of PrEP^v. The study, which began recruitment in November 2012, was conducted at 13 sexual health clinics in England, and enrolled 544 GBMSM age 18 years or older who had anal intercourse without a condom in the previous 90 days. Initially, participants were randomly assigned to one of two study arms- the “immediate group” received PrEP at the enrolment visit, while the “deferred group” received PrEP after a period of one year. After early results showed evidence of the effectiveness of PrEP in a “real-world” setting (i.e., outside of a placebo-based clinical trial), the deferred arm was closed, and all participants were offered a prescription for PrEP. The PROUD study reported that PrEP reduced the risk of acquisition by 86% in GBMSM, demonstrating PrEP’s efficacy in a real-world setting.

Fragmentation of HIV prevention services in England meant that routine funding of PrEP services would not be straightforward- even were NHSE to reimburse the drug costs associated with PrEP, the associated provision costs (e.g., training and guidance for health care providers, increased demand on services and staff) would fall to LA. However, SHS were already facing intense financial pressure and reduced funding due to Government cuts to LA’s public health budgets¹¹¹ meaning that routine PrEP implementation could put services under further pressure.

Shortly after the results of the PROUD trial were published, NHSE released a statement that indicated NHSE did not have the power to commission PrEP services, reiterated the responsibilities of LA to commission HIV prevention services, and posited the risk of legal challenges if NHSE were to commission it¹¹². This position was challenged by the National AIDS Trust, a UK HIV rights charity, and taken to judicial review by the High Court in 2016. The High Court concluded that both NHSE

^vEfficacy on the PROUD study was defined as the net effect of efficacy, adherence, and any risk compensation behaviour as a result of PrEP¹¹⁰.

and LA had the power to commission PrEP in both an initial ruling¹¹³ and an appeal hearing¹¹⁴.

Following the court ruling, PrEP became available as part of the Impact trial. The Impact trial was a “pragmatic health technology assessment of PrEP and implementation” that ran from 2017 – 2020^{115,116}. The Impact trial aimed to address three key questions: 1) How many people attending sexual health clinics had a need for PrEP; 2) How many of these people would start PrEP; and 3) How long would they need PrEP? The Impact trial collected data on PrEP eligibility, uptake, and duration of use on a large scale to inform service commissioners about the scale, cost, and support needed to provide PrEP.

Initially, the Impact trial had space for 10,000 participants, but this was increased to 13,000 in July 2018, and to 26,000 in February 2019, as both PrEP need and uptake were greater than originally estimated¹¹⁶. Unlike in the PROUD study, groups other than GBMSM, including heterosexual cisgender men and women and transgender and gender diverse people, were able to access PrEP through the Impact trial. Initially, 2,000 places on the Impact trial were allocated to these populations, however, this was reduced to 1,000 in response to the rapid uptake of places by GBMSM and low uptake among other groups¹¹⁶.

In the spring of 2020, prior to the end of the Impact trial, the Department of Health and Social Care announced that PrEP was to be made routinely available on the NHS¹¹⁷, and that LAs would receive additional funding to deliver PrEP.

Currently, TDF/FTC PrEP is available on the NHS from specialist SHS^{vi} in England. A recent policy update from NHSE recommends the use of TAF/FTC PrEP in people who are intolerant to TDF, or in whom TDF is contraindicated⁷⁹. NHSE routinely reimburses the drug costs associated with PrEP (both TDF/FTC and TAF/FTC) for

^{vi}Specialist sexual health services are also known as level 3 genitourinary medicine (GUM) services. They provide STI management and services provided by level 1 and level 2 sexual health services. Additional services provided by specialist SHS include (but are not limited to): Testing and treatment of symptomatic STIs, testing and treatment of STIs at extragenital sites, provision of PrEP and PEP, specialist HIV treatment and care, and management of syphilis and blood-borne viruses¹¹⁸.

the prevention of HIV, however, other associated costs for PrEP provision (e.g., staffing, running SHS, etc.) are the responsibility of LA, as per the HSCA 2012.

The current guidelines recommend PrEP^{vii} for HIV-negative GBMSM and transgender women who report condomless anal sex in the previous six months and ongoing condomless anal sex, and HIV-negative individuals having condomless sex with partners who are HIV-positive and have not been on ART for at least six months. The guidelines also recommend PrEP on a case-by-case basis for individuals considered at an increased risk of HIV acquisition due to a combination of factors, some of which include: sexual behaviours (such as engaging in group sex or chem sex), drug use (such as sharing injecting equipment), and factors that may affect sexual health autonomy (such as precarious housing or homelessness)⁷¹.

When a prevention tool such as PrEP is introduced, its implementation must be monitored to ensure that it is effective in real-world settings (i.e., outside of randomised controlled trials (RCT), and does not exacerbate existing health disparities, inequalities, and inequities in HIV prevention.

2.7 Health Inequalities and Health Equity

The WHO defines health inequalities as “differences in health status or in the distribution of health determinants between different population groups¹²⁰”. Health inequalities can be caused by biological, structural and environmental factors, however, when an inequality in health or healthcare is considered “unnecessary, avoidable, unfair and unjust”, this is referred to as a health inequity¹²¹. For example, health inequities can be due to the unequal distribution of goods and services, such as challenges with access to healthcare services due to geographical or financial barriers. Inequities in health can occur due to variations in access to health services, which in turn can be impacted by a variety of factors, including structural and environmental considerations (e.g., the quality of services on offer, whether services

^{vii}New PrEP guidelines that address some of the inequities that were identified during the first years of provision were announced at the 2023 Conference of the British Association for Sexual Health & HIV¹¹⁹. However, they have yet to be implemented at the time of submission.

are physically within reach, or whether opening hours limit a service's accessibility), individual circumstances, and structural or society level.

The inverse care law, originally suggested by Hart in 1971¹²², describes the situation whereby those who are most in need of medical care are the least likely to receive it. This means that people experiencing health disparities are also often experiencing inequities in healthcare access. In order for health technologies, interventions, and programmes to be effective in tackling the inverse care law, they must be accessible, acceptable, and effective in both the general population and populations experiencing health inequity¹²³. When monitoring and evaluating the implementation of an intervention or programme, an “equity-lens” should be employed to identify and address sources of inequity that drive health disparities, thus improving the provision of equitable care and services. The application of an equity lens will be discussed further in Chapter 4.

2.8 Health equity and HIV

Health equity is an important consideration in HIV prevention, as HIV disproportionately affects marginalised populations. Gender and sexual minorities^{124–126}, ethnic minorities^{124,127}, vulnerable populations such as people who inject drugs¹²⁸, people experiencing housing instability¹²⁹ and other social disadvantages¹³⁰ are at a greater risk of HIV acquisition compared to the general population¹. These categories are not mutually exclusive; an individual may identify with multiple categories concurrently¹³¹ and the experience of belonging to multiple marginalised groups may contribute to an increased risk of acquiring HIV¹³².

2.8.1 Health equity and HIV in the UK and England

2.8.1.1 Populations that are disproportionately affected by HIV

In 2020, the independent HIV Commission published its final report³⁰, which highlighted inequities in HIV transmission and outcomes in England. In England, GBMSM have been disproportionately impacted by HIV; despite only making up an estimated 2.6% of the population in the UK, the community accounts for 47.8% of all people living with HIV in the UK, and GBMSM are more likely to be living with HIV if they are black or minority ethnic, younger, or migrants³⁰. People from ethnic minority

communities are overall more likely to be living with HIV, and black African communities, in particular black African women, are disproportionately affected¹³³.

Communities that have been identified as key populations at risk of HIV acquisition, can also face multiple barriers to access appropriate services. For example, people who inject drugs experience higher HIV prevalence compared to the general public, but also experience a lack of access to appropriate or informed services that cater for their sexual health and wellbeing¹³⁴.

Trends and inequities in new HIV diagnoses and HIV prevention in England will be discussed further in Chapter 3.

2.9 Health equity and PrEP

Despite being an effective HIV prevention method, concerns have been raised that PrEP is not reaching its potential as a prevention method¹³⁵ and globally disparities in PrEP awareness, access and use have been identified across different ethnicities¹³⁶, age groups¹³⁷, geographic regions¹³⁸, genders^{139–141}, and sexual identities^{139,142}. Structural and environmental factors that contribute to discrepancies in HIV rates have been shown to affect HIV treatment uptake and adherence^{79,80}, uptake of HIV prevention strategies in general⁸⁰, and for PrEP specifically. For example, lower levels of education, anticipated stigma, and higher PrEP costs have been associated with lower willingness to take PrEP¹⁴³. Low adherence to PrEP has been associated with competing survival needs (e.g., financial instability, housing)⁸² and substance use⁸³. In order to reach the potential of PrEP as a prevention method, it must be equitably accessible¹⁴⁴.

2.9.1 Health equity and PrEP in England

2.9.1.1 PrEP in England, pre-commissioning era

Concerns about PrEP accessibility and availability in England arose when NHSE made the initial statement regarding its ability to commission PrEP services. When SHS became the commissioning responsibility of LA, there were concerns that services were more prone to budgetary cuts¹⁴⁵ and growing pressure on services meant that PrEP provision and access may not be prioritised. This meant access to

PrEP could become a “post-code lottery”, e.g., access would be dependent on where people lived, with service provision dependent on each individual LA’s decisions on whether and how to fund and provide PrEP. It should be noted that SHS in England are “open-access” in nature, i.e., although a specific LA may commission SHS differently, people within a given LA are able to access SHS within any other LA in England. However, this means an individual must have the means to access these services, and there may be other barriers (e.g., geographical or environmental barriers, personal circumstances) that hinder their ability to do so.

As information on its effectiveness spread, demand for PrEP increased particularly among GBMSM communities. Charity, advocacy, and grassroots organisations played a large role in campaigning NHSE to fund PrEP, and to this day they continue to advocate for implementation strategies and policies that are inclusive and cater to a wide range of populations and needs.

The announcement to provide PrEP as part of the Impact trial after the results of the PROUD study were published gave rise to backlash. Activists and community groups argued that the trial was unnecessary for a number of reasons, e.g., the efficacy of PrEP had been established in RCTs, there was evidence to suggest its efficacy in real-world settings^{87,88}, Scotland’s decision to fully commission PrEP^{viii}, and the PrEPARED trial in Wales (which had no caps on recruitment). Concerns were also raised regarding the total number of places available on the trial and on the recruitment caps set for individual clinics participating in the trial. Both of these factors meant that some people seeking PrEP were unable to access it via the Impact trial¹³⁹, and there were instances of people acquiring HIV while waiting to access PrEP¹⁴⁶. In 2019, an online, non-probability, cross-sectional survey was run to assess PrEP access in the UK and capture the experiences of people using or who were unable to access PrEP. One in five of the survey respondents (533/2,389) reported being unable to obtain PrEP since 2017, 72% (n=382) of whom had tried to source PrEP from the Impact trial.

^{viii}This was in part possible because of the differences in HIV epidemiology in England and Scotland, and the differences in commissioning of SHS and HIV prevention services between the two nations

Before PrEP was routinely available on the NHS in England, many people (predominately GBMSM) were purchasing PrEP from online pharmacies^{39,40}. Two grassroots initiatives, PrEPster¹⁴⁷ and iwantPrEPnow.co.uk¹⁴⁸, were set up specifically to facilitate purchasing PrEP online; raise PrEP awareness; provide information and educational materials on PrEP effectiveness, safety, and candidacy; and campaign for PrEP access on the NHS. Both organisations provided advice and signposting for how to buy generic PrEP from reliable online pharmacies that were selling genuine PrEP.

Results from the Impact trial indicated that the majority of PrEP use in England had been by cis-gender, white, GBMSM with less than 5% of places on the Impact trial taken up by women and other groups (including heterosexual men and trans-gender/gender diverse people)⁷². Among GBMSM, PrEP use was low in younger people, compared to their older counterparts.

2.9.1.2 Health Equity and PrEP in England in the era of routinely commissioned PrEP

Many of the initial concerns around PrEP accessibility remain, despite PrEP being routinely available on the NHS from SHS. A recent survey and subsequent “Not PrEPared” report from NAT outlined a number of challenges faced by people trying to access PrEP, including difficulties booking appointments to access PrEP for the first time, waiting lists of more than 12 weeks to access PrEP, and concerns from clinicians about missed opportunities for PrEP initiation¹⁴⁹. Although some of these issues, such as waiting times to be seen in clinic, may not be PrEP specific (e.g., they may reflect service issues more broadly), they still present barriers to PrEP access.

The United Kingdom Health Security Agency’s (UKHSA’s) annual official statistics data release on HIV has included national surveillance data on PrEP need and PrEP initiations since the 2022 data release (i.e., data on PrEP is currently available for 2021 and 2022). The UK HIV pre-exposure prophylaxis (PrEP): monitoring and evaluation framework¹⁵⁰ defines the population having a “PrEP need” as “HIV negative individuals accessing specialist SHS who are at substantial HIV risk, and

therefore could benefit from receiving PrEP^{ix}. In 2021, 7.4% of people who were HIV-negative and accessed SHS in England had a PrEP need identified. Overall, 79.1% of those with a PrEP need had that need identified during a consultation, however, this varied substantially by demographics. The proportion of people who had their PrEP need identified at a clinical consultation was 81% for GBMSM, 50% for heterosexual men, and 34% for heterosexual and bisexual women. In 2022, the proportions increased slightly for both heterosexual men and heterosexual and bisexual women (62.7% and 58.6%, respectively), but identification of PrEP need during a consultation remained highest for GBMSM (84%)¹¹. Trends in PrEP need and use will be discussed further in Chapter 3.

2.9.2 Research gaps in PrEP equity in England

Much of the information that we have on PrEP implementation in England focuses on people who are aware of and trying to access PrEP (e.g., the 2019 PrEP user survey and the National AIDS Trust Not PrEPared report), or are engaging with SHS (e.g., the UKHSA HIV Official Statistics data on PrEP). While these resources provide valuable insight into both PrEP use in England and some of the challenges in PrEP implementation, they provide limited information on or about why use may be low among certain groups. For example, women have been highlighted as an under-represented population in both PrEP use and PrEP research in England, but little is known about women's awareness, knowledge, perceptions, and preferences for PrEP, or how factors influencing health equity may or may not drive disparities in PrEP awareness or access. I have therefore chosen women as the population of interest for my thesis.

2.10 Conclusion

In this chapter, I introduced and outlined key areas and concepts that provide context for this thesis, including combination HIV prevention, PrEP, and health equity. I discussed disparities in both HIV and PrEP use in England and highlighted

^{ix} PrEP need is defined separately for GBMSM and heterosexual men and women. These definitions will be explained and discussed further in Chapter 3.

inequities that have been observed in PrEP provision for different groups, including women.

The next chapter will explore disparities in HIV and HIV prevention experienced by women in more depth, both globally and in England.

Chapter 3 Women, HIV, and PrEP

3.1 Introduction

The previous chapter discussed the general HIV epidemic globally, and in England, and introduced concepts around combination HIV prevention, PrEP, and health equity. In the previous chapter, I posited that women are under-represented in PrEP research in England, and little is known about their awareness, knowledge, and preferences for PrEP.

In this chapter, I begin by discussing the HIV epidemic in women in more detail, first globally and then in England. I then discuss the current literature around women and PrEP, starting with the global picture before focusing on women in England. I conclude the chapter by highlighting research gaps for women and PrEP in England.

3.2 Women, HIV, and PrEP

3.2.1 Women and HIV Globally

Globally, women and girls account for 53% of all people living with HIV. In 2022, 46% of all new HIV diagnoses were in women, and each week approximately 4,000 young women between the ages of 15 and 24 acquired HIV¹. Among women, the risk of acquiring HIV is 30 times higher for female sex workers and 14 times higher for trans women, compared to the general population of adult women¹⁵¹. In sub-Saharan Africa, girls and young women aged 15 – 24 are twice as likely to be living with HIV than young men in the same age group.¹

Sexual activity is the primary route of HIV acquisition among women worldwide, but there are a number of sociological, biological, and structural factors that can influence transmission risk for women, including (but not limited to) characteristics of sexual partners (e.g., partner's HIV or circumcision status, involvement in concurrent sexual partnerships), history of sexually transmitted infections, injection drug use (IDU), and participating in commercial sex work (sex work)¹⁵².

Gender-based violence and a history of sexual abuse are both significant risk factors for HIV acquisition among women^{153–155}. Gender-based and intimate partner

violence (IPV) can also limit a woman's ability to negotiate safer sex practices, such as condom use, and being in a coercive or controlling relationship can limit access to HIV prevention services and resources^{156,157}.

Women may experience multiple risk factors at any given time. For example, IDU can often occur concurrently with sex work, particularly when sex work is undertaken to fund IDU or involvement in sex work leads to IDU¹⁵². Transwomen are disproportionately impacted by HIV. The most recent UNAIDS Global HIV & AIDS statistics estimate that the median prevalence of HIV among transgender^x persons is 10.3%, compared to 0.7% among the overall adult population globally¹. A 2021 meta-analysis reported that transfeminine^{xi} individuals have 66 times higher odds of acquiring HIV compared with all other individuals over 15 years of age¹⁵⁸. Several factors are thought to contribute to the increased risk for transgender women, including social stigma and discrimination, barriers to healthcare access¹⁵⁹ and involvement in sex work¹⁶⁰.

HIV epidemiology varies widely from setting to setting, and the population of women considered "at substantial risk" of HIV will vary depending on the local geography, culture, and HIV epidemiology. For example, in sub-Saharan Africa, women and girls accounted for 63% of new HIV diagnoses in 2022, whereas men and boys accounted for 70% of new acquisitions in all other geographic regions. In Eastern Europe and Central Asia, approximately one-third of women with HIV acquired it from IDU, whereas in the Middle East and North Africa, the majority of women living with HIV acquired it sexually from their partners¹⁶¹.

3.2.2 Women, HIV, and HIV prevention in England

As discussed in Chapter 2, the annual statistics data release on HIV²³ from the UKHSA presents data on HIV testing, PrEP, new HIV diagnoses, and care outcomes for people accessing HIV services in the UK. The most recent report presents data up to 2022, however, it is important to note that the COVID-19 pandemic impacted

^x Note, this figure is not disaggregated by gender identity

^{xi} The term "transfeminine" refers to people who were assigned male at birth but identify with femininity, or with a feminine identity

HIV testing and access to sexual health and HIV services in 2020 and 2021, and trends may be difficult to interpret between 2019 and 2022.

One third of people living with HIV in the UK are women¹⁶². Although this group is diverse in terms of demographics such as age, ethnicity, and gender identity, HIV disproportionately affects women of black African ethnicity. Treatment coverage for people living with HIV is high, with the UK exceeding the 90-90-90 targets and among women seen for HIV care in England in 2021, 98% were receiving ART¹⁶³.

In England in 2022, there were 766 new HIV diagnoses among women first diagnosed in England^{12,xii}. Of these, there were 564 diagnoses where the probable route of exposure was through heterosexual contact, representing 23% of all diagnoses first made in England^{12,23}. Among people who were first diagnosed in England and exposed through sexual contact, diagnoses among women increased by 26% between 2021 and 2022 (from 447 to 564), whereas diagnoses in heterosexual men decreased by 3% (from 423 to 411) and diagnoses in GBMSM decreased by 8% (from 784 to 724) for GBMSM. Late diagnosis^{xiii} was made in 49% of new HIV diagnoses among women first diagnosed in England¹⁶⁴ in 2022, and this proportion has been relatively stable since 2020.

In 2022, 575,486 women tested for HIV at all SHS in England¹⁶⁵. Since 2019 there has been a decrease in the number of people testing for HIV at SHS, related to COVID-19 service disruption, and testing levels for women in 2022 were only 81% of 2019 testing levels²³. More women are tested for HIV as part of antenatal care than in SHS; between 1 April 2020 to 31 March 2021 approximately 650,000 women entered the antenatal screening pathway, and coverage for antenatal HIV screening was 99.8%¹⁶⁶.

3.2.3 Inequities in HIV and HIV prevention among women in England

There is evidence to suggest that women's HIV prevention needs in England are not being met.

^{xiii} Late diagnosis is as having a CD4 count below 350 cells per cubic millimetre within 91 days of first HIV diagnosis in the UK and no evidence of recent seroconversion¹²

In England, the overall number of HIV diagnoses first made in England declined between 2015 – 2019, but trends in new diagnoses during this time varied among population groups. As discussed above, the most recent national surveillance data showed a 26% increase in new HIV diagnoses first made in England for women exposed through sexual contact with men between 2021 and 2022, and rates of testing are lower for women than both heterosexual men and GBMSM. Prior to the pandemic, women were both less likely to be offered and less likely to accept an HIV test when attending SHS than heterosexual men and GBMSM, and this trend continued in 2021 and 2022: among women attending specialist SHS in 2022 who were assumed to be eligible to be offered an HIV test, 40% were not offered a test, compared to 27% of heterosexual, and 23% of GBMSM. Among women who were offered a test, 22% declined the offer, compared to 12.0% of heterosexual men and 3% of GBMSM²³.

Women and HIV Invisible No Longer, a national study of women's experiences of HIV, published in 2019¹⁶², stated that women had been neglected in the UK's response to HIV. This included pitfalls in the response and services for women living with HIV, over representation of GBMSM in HIV related academic studies and clinical resources, and a lack of disaggregation by gender in resources focussing on black African communities. The report argues that women are also underrepresented in HIV prevention services and policies, and that insufficient efforts have been made to identify and define the characteristics of women who are at risk of acquiring HIV. For women, HIV risk is often defined along the basis of population characteristics (e.g., ethnicity), rather than an individual's sexual behaviour or circumstances. This means there is a need to re-examine how women at risk of HIV are described, and more efforts are needed to understand the sexual health needs of women who do not fall into the current definitions for "at risk" groups.

The independent HIV commission report³⁰ asserts that women's under-representation in the UK's response to HIV perpetuates HIV stigma and perceptions that women are not affected by HIV. This may not only impact how women perceive their HIV risk but may also prevent women from engaging with combination HIV prevention, including HIV testing and PrEP.

3.3 Women and PrEP

Many of the HIV prevention methods that are available to women are controlled by, or depend on the co-operation of, the male partner, e.g., VMMC, condoms, and anti-retroviral therapy (in serodifferent partnerships). Conversely, PrEP is a discreet prevention option that does not have to be negotiated with sexual partners¹⁶⁷. This has implications both for women who have autonomy issues or difficulty negotiating safer sex practices (e.g., due to IPV or other reasons), and women who want greater control over their own HIV prevention.

3.3.1 Evidence for PrEP efficacy in cisgender women

While the Partners PrEP trial showed that oral TDF/FTC PrEP was effective for cisgender women⁴, several other randomised, placebo-controlled trials to assess the efficacy of TDF/FTC PrEP in women showed low efficacy^{168,169}. Further investigation found that in trials where PrEP efficacy was low, adherence to drug regimens was also low. For example, in the VOICE trial, TDF/FTC was not found to reduce the rates of HIV acquisition among women, however, only 29% of a random sample of women had a detectable level of the medication in plasma samples, indicating low adherence¹⁶⁹. A subsequent qualitative study found that reasons for low adherence included worries about side effects or harm, negative comments from friends or family members regarding pill taking, peer influence, joining the study for the benefit of the health services provided by the clinic, a lack of support to take the medication, and HIV stigma¹⁷⁰. In 2016, a systematic review and meta-analysis of PrEP efficacy studies found that PrEP was protective across populations, with no difference in effectiveness by sex, but that effectiveness relies on adherence among people taking it¹⁷¹. Studies have also shown that PrEP is safe for women to use during pregnancy and breastfeeding¹⁷².

3.3.2 Evidence for PrEP effectiveness in transgender women

The iPrex trial was the first investigation of TDF/FTC PrEP effectiveness for transgender women¹⁷³. The trial was not designed to test the efficacy of PrEP for this population, however, ad-hoc analyses were performed for transgender women that were enrolled in the trial and open-label extension study⁸⁰. Concern that PrEP

interfered with the efficacy of gender-affirming hormone therapy (GAHT) was cited as a reason for underuse in transgender women, and providers were concerned that GAHT could interfere with the efficacy of PrEP. However, recent studies have shown that there are no “clinically meaningful bidirectional affects” between TDF/FTC PrEP and GAHT¹⁷⁴ (i.e., TDF/FTC does not interfere with the efficacy of GAHT and vice versa), and that GAHT does not affect the efficacy of either FTC/TDF or FTC/TAF PrEP¹⁷⁵.

3.3.3 Women and PrEP use

Shortly after the FDA’s approval of PrEP in 2012, availability was limited outside of high-income settings, where the majority of PrEP users were thought to be “well educated, affluent, white gay men”¹⁷⁶. In 2016, the UN general assembly Political Declaration on Ending AIDS by 2030 included a commitment to expand PrEP access to 3 million people at high risk of HIV²⁶. PrEP provision has scaled up in recent years in both high- and low- and middle-income countries, but access is mainly concentrated in high-income countries and five countries in sub-Saharan Africa: Kenya, Zambia, Uganda, South Africa and Nigeria¹⁷⁷. In 2019 it was estimated that 61.7% of oral PrEP users globally were cisgender women, primarily in the WHO African region¹⁷⁸.

In high-income countries, PrEP use among women is relatively low; from 2013 – 2022, women accounted for 7% of people prescribed oral PrEP in the USA¹⁷⁹, and in England, ~2% of PrEP users were women in 2021¹⁰.

3.3.4 Women and PrEP in England

PrEP first became available through the healthcare system to cisgender women through the Impact trial; transgender women were able to access PrEP on the PROUD trial, although only three transgender women were recruited among 554 participants¹⁸⁰. As discussed in Chapter 2, women and other groups accounted for less than 5% of the places on the Impact trial. At the time of writing, I was unable to find any information on the number of women buying PrEP privately before it was routinely commissioned.

The most recent PrEP use based on national surveillance data collected by UKHSA reports that 86,324 attendees at SHS initiated or continued taking PrEP in 2022, of which 1,676 were women, accounting for ~2% of all PrEP users (this figure includes cisgender and transgender women). This is an increase from 2021, where ~1% of all PrEP users were women (716/61,510)²³.

Low numbers of women using PrEP is not an issue per se, as the number of women estimated to be in PrEP need of PrEP is relatively lower. In 2021, 0.5% of women attending SHS were determined to have a PrEP need, compared with 1.4% of heterosexual men and 64.5% of GBMSM¹⁰, and in 2022 PrEP need rose slightly in all groups: 0.8% of women, 1.8% of heterosexual men, and 69% of GBMSM²³.

The cause for concern lies in the level of PrEP coverage for women. In order for women with a PrEP need to initiate PrEP, that need must be identified in a clinical consultation. As discussed in Chapter 2, there are variations in the proportion of people whose PrEP need is identified at consultation by gender and sexual identity. In 2021, 34% of women with a PrEP need had that need identified at a clinical consultation, compared to 50% of heterosexual men and 82% of GBMSM. In 2022, these proportions rose in all groups, with 59% of women 63% of heterosexual men^{xiv}, and 84% of GBMSM having their need identified²³. Although the increase for both women and heterosexual men is encouraging, identifying PrEP need at clinical consultation for these groups still lags behind GBMSM. For women who have their need identified, PrEP uptake is high (77% in 2021 and 67% in 2022¹¹), however, overall coverage for women is low; in 2022 42% of women with a PrEP need initiated or continued taking PrEP²³.

It is worth noting that PrEP need is defined differently for heterosexual men and women versus GBMSM. Heterosexual men and women are considered to have a PrEP need if any of the following are reported at an attendance to specialist SHS in the previous six months: a PrEP eligibility code (i.e., they were identified as being eligible for PrEP during the clinical consultation), a PrEP uptake code (i.e., they received a prescription for PrEP at the consultation), PrEP regimen codes, quantity

^{xiv} Although I acknowledge that there are similar issues in identifying PrEP need and PrEP coverage for heterosexual men, and that there may be overlap between factors impacting HIV prevention access for heterosexual men and women, it is beyond the scope of this thesis to explore this in detail.

of pills prescribed, or having received PEP for sexual exposure. For GBMSM, the definition includes all of the above, in addition to a diagnosis of a rectal bacterial STI, a diagnosis of syphilis, condomless anal sex, or sexualised drug use.

By this definition of PrEP need, women who have a PrEP need identified but who did not have a record of PrEP engagement (i.e., an eligibility code, uptake code, regimen code, or quantity of pills prescribed) will only account for women who were prescribed PEP for sexual exposure - i.e., there are no other markers or individual circumstances (such as participating in exchange sex, sexual health autonomy factors, and others outlined in the PrEP guidelines) that identify women as in need of PrEP from routinely collected surveillance data.

Surveillance data has previously been used to estimate the number of HIV-negative GBMSM who may be eligible for PrEP in England¹⁸¹, however, no such estimations have been made for other populations, including women. This may in part reflect the limitations of data captured by routine surveillance to predict HIV risk for women and other groups, but this does not discount the need to better identify women who are at risk of acquiring HIV. Furthermore, the national PrEP surveillance data only captures people attending specialist SHS, and little is known about the need for PrEP in women who attend other services for their sexual and reproductive health needs.

3.4 Inequities for women and PrEP

There are biological, social, behavioural, and structural barriers that may prevent women from accessing or using PrEP¹⁸². As with the risk of HIV acquisition, some of these barriers may be common across different settings, while others will depend on the local culture, social norms, and provision of PrEP services in each setting.

3.4.1 Women are not well represented in PrEP research

Both cisgender and transgender women are underrepresented in PrEP research and clinical trials. Although transgender women have been included in more clinical trials since their inclusion in the iPREX trial, they are still often under-enrolled and/or are aggregated with MSM¹⁸³.

The DISCOVER trial, which investigated the efficacy of and safety of TAF/FTC as PrEP, recruited GBMSM and transgender women who have sex with men. The trial

showed that daily TAF/FTC was non-inferior to daily TDF/FTC while being superior in bone mineral density and renal biomarker safety endpoints¹⁸⁴, and subsequently, TAF/FTC was approved for use as PrEP in GBSM and transgender women by the FDA in 2019¹⁸⁵. The company producing TAF/FTC had planned a comparative trial that would include cisgender women and adolescent girls¹⁸⁶, but that trial did not go ahead. However, there is a current clinical trial investigating the efficacy of injectable Lenacapavir as PrEP in cisgender adolescent girls and young women in South Africa and Uganda includes a direct comparison to both TDF/FTC and TAF/FTC¹⁸⁷.

3.4.2 Biological barriers

The Ipergay trial was the first to investigate on-demand dosing, or event-based PrEP, but did not include cisgender women, and currently there are no on-demand oral PrEP regimens that have been approved for cisgender women. Studies have indicated that it takes longer for TDF/FTC to reach protective levels in vaginal versus rectal tissue¹⁸⁸, and a modelling study predicted that a minimum of six of seven doses a week were required to maintain protective levels in vaginal tissue, whereas only two of seven doses per week were required for colorectal tissue¹⁸⁹. This indicates that there may be a greater need for cisgender women to maintain adherence to daily PrEP. Although not being able to use TDF/FTC as on demand-PrEP highlights an inequality for cisgender women, it is not in itself an inequity, as in this case it is not necessarily unavoidable, but due to biological differences in how long it takes for the medication to reach protective levels in different tissues. Current biological data suggests that event-based PrEP is not effective in women given the current PrEP formulations and delivery systems, however, I would argue that a lack of research into event-based or on-demand PrEP options for women (including alternative formulations, modalities, or dosing regimens) could constitute an inequity, particularly if there is a preference or demand from women for an on-demand modality of PrEP.

3.4.3 Awareness and willingness to use PrEP

A lack of awareness among women is commonly cited as a barrier to PrEP use^{190–192}. Studies conducted within six years after FDA approval of Truvada estimated awareness among women in the USA to be between 0%-33%^{14,193–196}. Although

more recent studies indicate that PrEP awareness is increasing with time, with early results from an ongoing survey in the USA reporting 71% of respondents were previously aware of PrEP¹⁹⁷, increased awareness has yet to lead to increased PrEP use among women¹⁹⁸. Low levels of PrEP awareness among women have also been reported in the UK. A recent review of barriers and facilitators to PrEP for cisgender and transgender women in the UK reported that in multiple studies conducted with women less than 20% of participants had heard of PrEP¹⁶. The Women and HIV Invisible No Longer report contained a survey in which 71% of respondents had previously heard of PrEP, but this was in a sample of HIV-negative women who had experienced concern around HIV¹⁶², and there was no data collected on the extent of women's PrEP knowledge (e.g., who could take PrEP, PrEP eligibility criteria, etc.).

Barriers to PrEP awareness include low HIV risk perception^{199,200}, a lack of information on PrEP^{192,200}, and a lack of policies supporting PrEP use in women. It will be important to address these barriers to awareness, as studies have indicated that once made aware of PrEP, women are often interested or enthusiastic about PrEP. For example, a systematic review of literature looking at PrEP implementation for women in the USA reported that across studies, women showed consistency in willingness to use PrEP (between 51% - 97% in quantitative studies) and were generally favourable towards PrEP in qualitative studies¹⁴ once they were made aware of it. Similar findings have been reported for women in the UK^{200–202}. In some instances, women who took part in qualitative studies on PrEP expressed concern or anger that they had not heard about PrEP before taking part^{194,203,204}.

There have been efforts and campaigns to increase PrEP awareness and knowledge among women in the UK, such as PrEPster's "PrEP4Women" campaign²⁰⁵.

However, campaigns to increase PrEP engagement among women are often organised and carried out by non-governmental organisations or community-based groups¹⁹², and a lack of sustained funding can hamper these efforts.

3.4.4 Social and interpersonal barriers to PrEP

Stigma related to sex and HIV-related stigma are often cited as barriers to PrEP use by women. For example, in qualitative studies, women have expressed concern that taking medication associated with HIV would mean they would be perceived as living with HIV^{193,194}, or as promiscuous²⁰². Stigma occurs at both the personal level (e.g.,

how an individual feels about HIV and by extension assumptions around HIV and who is susceptible, how they feel about discussing their sexual health needs), and at the interpersonal and community level (e.g., how partners, friends, family, and community members perceive HIV and prevention methods)²⁰⁰.

In some cases, women are unsure how PrEP would fit into relationships with their intimate partners. For example, women have expressed concerns that using PrEP would result in mistrust or suspicion of infidelity within their relationships^{193,194}.

3.4.5 Structural barriers to PrEP use

Healthcare infrastructure and a lack of women-specific PrEP guidelines or programmes are other commonly cited barriers to PrEP access among women. In most European countries, PrEP provision focuses on key populations, which vary from country to country. In 2019, a survey found that PrEP was available in 30 WHO European countries, only 18 reported that PrEP was available to anyone considered at risk of HIV acquisition, irrespective of gender or sexuality, and only 6 countries had specific PrEP recommendations for women¹⁹². When PrEP is available for women, concerns around cost is a commonly cited barrier to access^{192,206}.

A narrative review of PrEP and women in the U.S. found that women's preferences for PrEP provision were locations that were convenient, familiar, and accessible. In the same review, it was reported that PrEP knowledge and beliefs among healthcare providers (HCP) influenced women's awareness and interest in PrEP and that some providers were hesitant to prescribe PrEP to both cisgender and transgender women²⁰⁶. A study of PrEP implementation in Scotland found that some sexual HCPs had difficulties identifying PrEP candidates due to difficulties operationalising the PrEP eligibility criteria²⁰⁷. In a study from the USA, HCP revealed that the practice norms meant PrEP would only be discussed in response to patient requests, and therefore there may be missed opportunities to discuss PrEP with patients who are not aware of it or who may be hesitant to bring it up during a consultation²⁰⁸. HCP assumptions about a patient's risk of HIV acquisition can be influenced by patient age, ethnicity, and sexuality^{208,209}, and these biases may act as a barrier to conversations around HIV prevention and PrEP.

Medical mistrust, in particular among racially-minoritized women²¹⁰ and transgender women²¹¹, can impact both willingness to use PrEP and comfort discussing PrEP with a HCP. In qualitative PrEP studies from the UK, black women have reported experiences of institutional racism in the NHS, and these experiences resulted in a reduction in healthcare engagement^{200,212}.

3.5 Study rationale

Much of the available research and information on PrEP engagement among women in high-income countries comes from the USA where HIV epidemiology, PrEP provision, and the healthcare system are significantly different to England. While some of the barriers to PrEP access are likely to be similar between these two settings, for example, the underrepresentation of women in PrEP research and HIV stigma, there will be other unique factors that warrant investigation. For example, PrEP is currently available from a number of healthcare settings in the USA, whereas in England it is currently only available from SHS. PrEP has been routinely commissioned and freely available in the UK since 2020, whereas in the USA cost may be an issue for people trying to access PrEP if they do not have adequate health insurance coverage.

The HIV Action Plan for England⁹ acknowledges inequities in PrEP access for women and trans populations, but a lack of research on women means that little is known about women's PrEP knowledge, preferences, and whether current PrEP provision meets their HIV prevention needs. This means there is little guidance on how to design interventions to improve women's engagement with HIV prevention and PrEP or identify and address missed opportunities to engage with PrEP and prevention more generally. The lack of research on PrEP and women was highlighted in a recent narrative review on the barriers and facilitators to PrEP for women in the UK¹⁶. Most studies included in the review were qualitative and/or studies with small sample sizes, which limit generalisability. There is a need for research that focuses on women, as previous research often aggregates women into other groups (e.g., heterosexual people, people of black African heritage). Much of the research on PrEP and women has focused on black African, or black women more generally. Although HIV disproportionately affects black women in the UK, this

singular focus may perpetuate stigma and miss out other groups of women at risk of acquiring HIV²¹³.

Currently, there is little insight into how other factors that influence health equity, such as education, geographic location, and socioeconomic status might influence or drive disparities in PrEP and HIV prevention among women. While existing surveillance data has shown inequities in PrEP coverage for women, other data sources, such as community-based surveys, could be utilised to explore other factors associated with PrEP delivery that are not currently captured through national surveillance data¹⁵⁰.

Ensuring that women have the tools and information to make choices about their health, including which HIV prevention strategies they want to use, is an important equity issue and PrEP delivery should be optimised to meet the needs of women²¹⁴. Addressing the research gap and developing our understanding of PrEP awareness, knowledge, and preferences among women in England, will provide insight into how PrEP coverage and HIV prevention services for women can be improved.

3.6 Overall aim

The overall aim of this thesis was to investigate awareness, knowledge, and perceptions of PrEP among women in England through an equity lens.

3.7 Conclusion

In this chapter, I first introduced inequities in HIV that are experienced by women globally, and in England, followed by a discussion of the known barriers to PrEP use for women. I have demonstrated a lack of research focusing on PrEP engagement among women in England and provided the rationale for the studies included in this thesis. In the next chapter, I describe the thesis aim in more detail and introduce the research methodology that was undertaken to conduct the research detailed in this thesis.

Chapter 4 Methodological approach

4.1 Chapter overview

In this chapter, I outline the methodological approach that was taken in this thesis. I begin by restating the thesis aims and research questions, and introduce the thesis objectives, followed by a description of the methods that were used to address each objective. I then discuss the rationale for taking a mixed methods approach, introduce the “equity lens” through which this research is interpreted, and discuss the role of patient and public involvement in the thesis. Although the individual methods used in each study are introduced, they will be described in further detail in subsequent chapters.

4.2 Aim, research questions, and objectives

As described in Chapter 1, the overall aim of this thesis was to investigate awareness, knowledge, and perception of PrEP among women in England using an equity lens. Specifically, the research questions that this thesis addresses are:

1. What are the current levels of PrEP awareness, interest, and knowledge among women in England?
2. How can gaps in women’s PrEP awareness and knowledge be addressed?
3. What are women’s perceptions of PrEP provision in England?
4. How can PrEP provision be made more acceptable and accessible to women?

To address these research questions, this thesis aimed to achieve the following objectives:

1. Describe how the PrEP outcome measures “awareness” and “interest” are defined and reported in real-world settings in high-income countries
2. Qualitatively explore levels of PrEP awareness, knowledge, and interest, and preferences for PrEP provision among a sample of women in England
3. Quantitatively describe the levels of PrEP awareness and interest, and preferences for PrEP provision among a sample of women in England

4. Identify potential barriers and enablers to women's PrEP engagement (i.e., PrEP awareness, interest, knowledge, and use)
5. Employ an equity lens to consider the implications of these findings for public health policy and practice

4.3 Thesis methodology

I employed a mixed methods approach to address the thesis aims, research questions and objectives.

To address objective one, I conducted a PRISMA-E systematic review of scientific literature published between 2012 – March 2020. This review included quantitative, observational studies that assessed PrEP awareness or interest for populations in high-income countries. Data was extracted on how awareness and interest were assessed, and whether factors known to influence health equity were reported when describing the baseline population and when reporting PrEP awareness and interest. The full methods and results for this review are presented in Chapter 5.

To address the second, fourth, and fifth objectives, I conducted qualitative semi-structured, one-to-one interviews with women resident in England. I interviewed 18 women and used thematic analysis to identify patterns and develop themes to represent the data from these discussions. The full methods and results of the qualitative interviews are presented in Chapter 6.

To address objective three, and to provide further insight into objectives four and five, I conducted a quantitative online, self-completion, convenience survey among women resident in England. Over 900 women participated in the study and, where possible, the sociodemographic characteristics of the sample were compared to the most recent census data for England. Logistic regression was used to identify associations between sociodemographic and other factors known to influence health equity and PrEP awareness and interest. The full methods and results of the qualitative survey are presented in Chapter 7.

Chapters 5, 6, and 7 also each include a set of method-specific objectives, which better illustrate how each method contributes to addressing the thesis research questions and objectives.

As discussed in Chapter 1, the systematic review was originally designed to develop and evaluate a framework for measuring health inequities in PrEP implementation. The review searches, data extraction, and preliminary analyses were completed before the research focus of the thesis changed direction. The qualitative and quantitative research were largely conducted concurrently, however, initial findings from the systematic review (Chapter 5) were used to inform the development and analyses for both the qualitative and quantitative research (Chapters 6 and 7, respectively).

The findings from all three studies were then collated and synthesized in an integrated discussion and interpretation of the results²¹⁵ (Chapter 8). In the integrated discussion, the findings from each individual study are first summarised, before being considered together to address the thesis aim. The final thesis objective is then addressed in greater detail by discussing the implications of the research findings on healthcare and HIV prevention policy and practice, and research, and recommendations for future research directions are made.

4.4 Mixed methods as an approach to research

In mixed methods research, both qualitative and quantitative data are collected, analysed, and integrated to address the same research question or aim^{216,217}. “Integration” can occur at the design, analysis, or presentation stage of the research, and is a key component to conducting mixed methods, rather than “multiple methods” research²¹⁷ where qualitative and quantitative studies address the same research question independently.

Traditionally, quantitative and qualitative research methods were not thought to be compatible, or complementary methods, as they were considered to be guided by different philosophical (i.e., ontological and epistemological) positions²¹⁸. Ontology is the branch of philosophy that is concerned with describing the nature of reality and what exists²¹⁹, whereas epistemology is the branch of philosophy that is concerned with the nature of knowledge, including the justifications and limitations of knowledge²¹⁹. Epistemology can be thought of as ‘a way of understanding and explaining what we know’^{220(p10)}, and epistemological positions ‘reflect assumptions about what constitutes meaningful and valid knowledge, and how such knowledge

can (and should) be generated'^{220(p3)}. In other words, ontologies and epistemologies provide the basis for philosophical positions that guide decisions on what reality is, what it is possible to know about this reality, how that knowledge is generated, and whether that knowledge is both accurate and legitimate.

Quantitative research is grounded in a (post)positive position, which asserts that an objective reality exists, that this reality can be known exactly (or in the case of post-positivism, approximately), and that it is possible to generate objective knowledge of this reality through the application of scientific methods²²¹, such as hypothesis testing, logical reasoning, observation, and experimentation. Knowledge of this objective reality exists independently of the researcher and their personal values and biases²²². Conversely, qualitative research is grounded in an interpretivist or constructionist position, wherein knowledge is produced through the exploration of the social world that we inhabit²²². Knowledge, and therefore reality, is constructed from the interactions between humans and their environment and is dependent on social context^{220(p42)}. The constructionist position posits that knowledge does not exist independently of the researcher who generates it, and thus value- or bias-free research is not possible. Here, knowledge is produced through methods such as interviews, focus groups, and participant observation.

In health research, quantitative methods can be used to examine trends in health, monitor healthcare usage, estimate the prevalence and incidence of disease, determine predictors of poor health, and identify differences in health outcomes between different groups of people, whereas qualitative methods can be used to explore the lived experiences of people, the impacts and meaning of illness and health, provide in-depth accounts phenomena in relation to local contexts and describe how factors influence individual's decisions around their health and healthcare engagement²¹⁸. Each method possesses strengths and limitations. For example, quantitative research can generate findings that are difficult to apply or operationalise in a meaningful way²²³, while qualitative research cannot produce findings that are statistically generalisable to the wider population²²¹.

Increasingly, there is recognition that, rather than being incompatible, the two methods can be complementary. Mixed methods approaches can benefit from the

strengths of both methods and produce findings that provide a more complete understanding of the population(s) or phenomena that are being studied²²³.

4.4.1 Rationale for taking a mixed methods approach

As discussed in Chapter 3, there is a lack of research on women's PrEP engagement in England, and majority of research that does exist is qualitative. Little is known about the level of PrEP awareness and knowledge, or preferences for PrEP and its provision among women outside of these qualitative samples. The PrEP monitoring and evaluation framework¹⁵⁰ suggests that community-based surveys are used to enrich and complement routinely collected survey data, in order to gain further insight into PrEP use (and non-use) in different populations. However, to my knowledge the majority of community surveys that include questions on PrEP have included current or previous PrEP users¹³⁹ and/or have focused on GBMSM²²⁴. To address this gap in the research, I decided to run a community-based survey, to provide a benchmark of PrEP awareness and identify potential drivers of PrEP inequity among a sample of women resident in England.

However, I felt that taking a purely quantitative approach would limit our insight into women's perceptions of, and preferences for PrEP, and how PrEP fits into women's engagement with HIV prevention (if at all). I also recognised that, although PrEP is a biomedical innovation, it is learned about, administered, and taken within a social context; an individual's decision whether to use (or not use) PrEP can be influenced by their interactions with HCP, their peers, social norms, and their own values and perceptions of risk. This was demonstrated in the clinical trials that were designed to assess the efficacy of PrEP, such as the VOICE trial, where a lack of PrEP efficacy in the trial was due to low adherence among study participants, rather than the ability of the medication to prevent HIV¹⁶⁹. Subsequent qualitative studies highlighted that concerns about side effects, HIV stigma, difficulties taking medication, and influences from peers and sexual partners could act as barriers to adhering to PrEP regimens^{170,225}.

By taking a mixed methods approach, I aim to provide a more complete picture of PrEP awareness, knowledge, and (non)use among women, identify potential barriers to PrEP engagement in this population, and improve our understanding of women's experiences and motivations in relation to HIV prevention.

4.4.2 Choice of a convergent mixed method design

Typically, mixed method research follows three main research designs^{xv}: explanatory sequential, exploratory sequential, and convergent^{217,221}. In an explanatory sequential design, quantitative data is collected and analysed first, and the findings are used to inform the collection and analysis of qualitative data²¹⁷. In explanatory sequential studies, the qualitative research is used to address “how” and/or “why” questions that arise from the quantitative research²²¹. Conversely, in an exploratory sequential design, the opposite approach is taken; qualitative data is collected and analysed first, and the findings are used to inform the collection and analysis²¹⁷. In exploratory sequential studies, the quantitative research is used to answer epidemiological questions that arose from the preceding qualitative research²²¹. In a convergent design, qualitative and quantitative research are conducted concurrently, and the findings are brought together and integrated at the interpretation stage²¹⁷.

For this thesis, a convergent mixed methods design was taken. The reasons behind this design were mainly pragmatic. As research on awareness, knowledge, and preferences for PrEP among women in England is scarce, either an exploratory sequential, explanatory sequential, or convergent design would have been appropriate. However, this thesis was an independent research project; I was responsible for designing, conducting, and analysing each of the studies, and due to time and resource constraints, it was necessary to conduct the final analysis of the systematic review and the qualitative and quantitative studies concurrently (i.e., it was not feasible to fully complete the analysis of one study before designing and carrying out the next study), particularly as both the qualitative and quantitative studies involved primary data collection and ethical approvals. Taking a convergent, rather than sequential study design meant that no formal analysis of one method was complete before starting the design and analysis of another, however, I do acknowledge that the learning from each method informally influenced the ideas for, and designs of, the other method(s). The strengths and limitations of taking a convergent mixed method study design are included in the discussion chapter (Chapter 8).

^{xv} Other mixed method designs do exist, but it is beyond the scope of this thesis to discuss them here

4.5 Applying an “equity lens” to the research

In Chapter 3, I identified inequities in PrEP for women in England, both in terms of women’s engagement with PrEP, and the lack of research focused on women and PrEP. However, as noted, women are a diverse population. As in the general population, each individual woman may possess multiple, identities (e.g., ethnic or cultural identity, gender identity, sexual identity), and circumstances (e.g., education level, socioeconomic status) that can drive further inequities. To reduce health inequities, interventions such as PrEP must be effective in, acceptable to, and used by, those who are most disadvantaged²²⁶. By identifying inequities in women’s PrEP engagement, and the underlying factors that drive them, it may be possible to address implementation gaps and improve access.

Currently, it is not well characterised whether PrEP engagement among women is low generally, or if there are different levels of engagement among different groups of women. Therefore, in addition to taking a mixed methods approach, I have applied an “equity lens” to the studies in this thesis, as a way of identifying factors that may be driving inequities in PrEP engagement for women in general, and for specific populations of women.

In practice, applying an “equity lens” means that the studies have been developed to not only explore awareness, knowledge, and perceptions of PrEP among women, but also investigate whether and how characteristics known to impact health equity impact women’s engagement with PrEP. To ensure that an equity lens was applied to this thesis, health equity was considered in the design, analysis, and discussion of each study.

4.5.1 Health equity frameworks

There are a number of frameworks that have been developed to further the field of health equity; some are used to improve understanding of how disparities in health develop, while others allow for the identification of how interventions and programmes can be designed, implemented, and evaluated to identify and dismantle both systemic and specific health inequities^{227(p39)}. Often, multiple health equity frameworks and models are used in parallel to examine health disparities. The research design and analysis in this thesis were guided by three main

frameworks/models: the Social Determinants of Health Framework²²⁸, The Social Ecological Model²²⁹, and the PROGRESS-Plus Framework²³⁰.

4.5.1.1 The Social Determinants of Health Framework

The WHO defines social determinants of health (SDOH) as “the non-medical factors that influence health outcomes”²³¹. SDOH include the conditions across a person’s life course; where they are born, grow up, work, and age; and the wider forces and systems that influence and shape their daily lives, such as social norms, political systems, and social and economic policies.

In 2020, the US Office of Disease Prevention and Health Promotion’s Healthy People 2020 Framework conceptualised the SDOH Framework as five domains that affect a wide range of health and quality of life outcomes²²⁸. The five domains are: economic stability, education access and quality, health care access and quality, neighbourhood and built environment, social, and community context.

4.5.1.2 The Social Ecological Model

The Social Ecological Model (SEM, also known as Bronfenbrenner’s Social Ecological Model)²²⁹, is a multi-level model that explores how the beliefs and behaviour of an individual are influenced by, and interact with, the broader cultural, geographic, and social context. The levels of the SEM are individual (e.g., personal behaviours and beliefs), interpersonal (microsystem; interactions between the individual and others, e.g., partners, family members, or friends), community (macrosystems; connections between different microsystems, e.g., schools and churches), organisational (exosystem; factors that influence mesosystems, e.g., local politics), and environment (macrosystem; factors such as cultural values, norms, and policies that affect the entire system in which the individual lives)^{227(pp46-47)}.

4.5.1.3 The PROGRESS-Plus framework

The PROGRESS framework was introduced in 2003 by Evans and Brown²³⁰ to describe a sample of socially stratifying factors that drive disparities in health. The acronym PROGRESS refers to **P**lace of residence, **R**ace/ethnicity/culture, **O**ccupation, **G**ender/sex/sexual identity, **R**eligion, **E**ducation, **S**ocio-economic status,

and **Social capital**^{xvi}. Subsequently, the framework was expanded to “PROGRESS-Plus”²³³; the “Plus” suffix includes additional categories that can attract discrimination for consideration: personal characteristics (such as age or having a disability), features of a relationship (such as being excluded from school or having unpaid care responsibilities), and time-dependent relationships (such as leaving hospital or respite care) (Figure 1). Each factor can influence health equity in a positive or negative way.

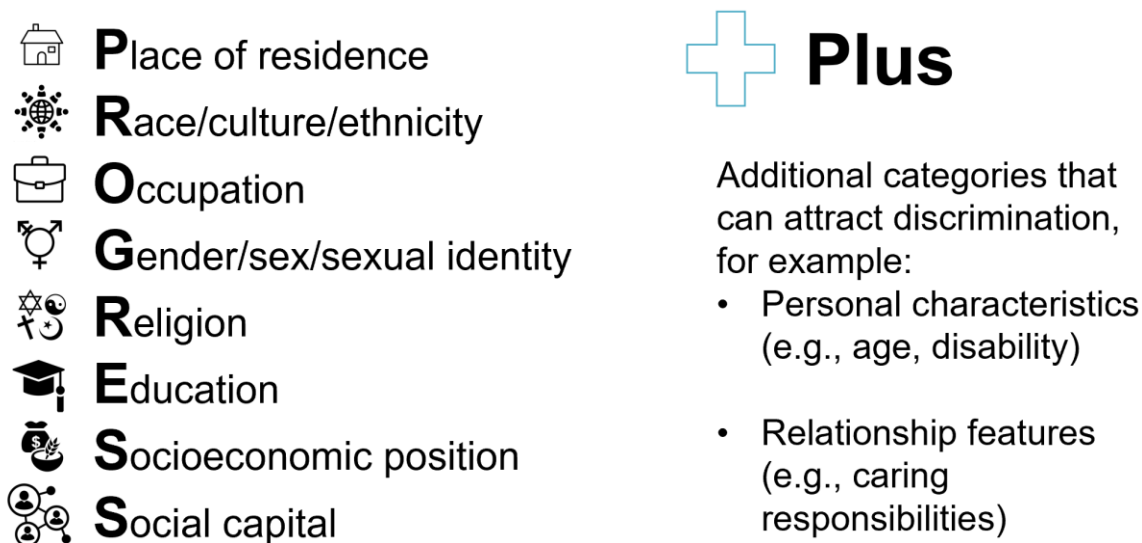


Figure 1: The PROGRESS-Plus framework

The framework is not meant to be an exhaustive list of factors that impact health equity, and not every factor will have an impact on health equity in every intervention or scenario. However, it does serve as an aide-memoire to help researchers decide what factors could be considered in research projects or when evaluating interventions²²⁶. Each element’s inclusion in the original PROGRESS framework has been justified by demonstrating its effect on burdens of disease²²⁶, although careful consideration must be paid to each characteristic’s definition and classification, as these may differ between settings and projects. The entire acronym has been tested in both systematic reviews of healthcare interventions²³⁴, and it is endorsed and

^{xvi} Social capital is a complex concept that describes the nature and extent of our connections with others, both individually and at a community level²³². It will be discussed in more detail in subsequent chapters.

recommended by the Campbell and Cochrane Equity Methods Group for use in the reporting guideless for systematic reviews with an equity focus²³⁵.

4.5.2 Health equity in the study designs

In this thesis, the PROGRESS-Plus framework was used in the design of each study to ensure that factors known to influence health equity were considered. This framework was chosen as it includes factors from the SDOH Framework that operate at different levels of the SEM and it provides explicit categories that can be explored both quantitatively and qualitatively. Further details will be discussed in the methods section for each study (Chapters 5 – 7).

4.5.3 Health equity in the study analyses, findings, and interpretation

Although the PROGRESS-Plus framework was employed to design each study, health equity was considered more broadly in the study analyses, findings, and interpretations, drawing on elements of both the SDOH and SEM. For example, where appropriate, the systemic and/or political roots of inequity are considered and discussed. Further details are included in the discussion section of each study (Chapters 5 – 7).

4.6 A brief note on intersectionality and syndemics

As discussed in Chapter 3, women have been identified as a group that is experiencing inequity regarding PrEP engagement. I recognise and appreciate that diversity exists within this population, and that each individual woman or female can possess multiple, identities and circumstances that may impact how they interact and engage with health services and HIV prevention. As discussed in Chapter 2, the experience of belonging to multiple marginalised groups may contribute to an increased risk of acquiring HIV¹³², and this is often explored by employing intersectionality and/or syndemic theories.

The term “intersectionality” was coined in 1989 by Kimberle Williams Crenshaw, an American critical legal race scholar. According to Crenshaw, “intersectionality is a metaphor for understanding the ways that multiple forms of inequality or disadvantage sometimes compound themselves and create obstacles that often are

not understood among conventional ways of thinking”²³⁶. Initially focused on race and gender, intersectionality theory has since been expanded to include all of the dimensions of a person’s identity, including (but not limited to) ethnicity, gender identity, geographic origin, and sexual orientation/identity²²⁷.

The term “syndemic”, or synergistic epidemic, originated in 1992 by Singer and Snipes, when describing the “synergistic nature of the health and social problems facing the poor and underserved”²³⁷. According to Quinn, “syndemic research examines the socio-structural contexts that create environments in which health conditions synergistically work together to amplify the burden of disease on a community or population”²³⁸, i.e., co-occurring health and social problems, such as poor mental health, substance use, and poverty, can compound in a way that synergistically increases vulnerabilities to other diseases, for example, HIV²³⁹.

Both intersectionality and syndemic theories examine the interactions of characteristics in relation to health, but key differences have been raised between them. Intersectionality examines the interlocking relationships between power, social position, and oppression, whereas syndemics emphasize the context in which disease dynamics occur, and how they work in concert to impact disease dynamics²⁴⁰. In spite of these differences, intersectionality and syndemic theory are both commonly employed to investigate vulnerabilities to, and inequity in, HIV for women^{241–243}.

While the work in this thesis has been designed and analysed through an equity lens, it is not formerly underpinned by either intersectionality or syndemic theory per se. PrEP awareness and interest among women in England are not well characterised, and so these studies are intended to be exploratory overall and provide insight into whether and how factors that influence health equity impact women’s engagement with PrEP.

Although I did not formally include either of these theories in the design and analysis of the studies, it is my hope that this work can lay the foundation for future research examining whether factors influencing health equity have a synergistic, rather than additive, impact on women’s engagement with HIV prevention and PrEP.

4.7 Patient and public involvement

Throughout this thesis, I sought input from PPI advisors to help identify research priorities, advise on study developments, provide input on study materials, and inform the interpretation of analyses.

4.7.1 The importance of Patient and Public involvement advisors

Sexual health and HIV prevention research often involves discussing stigmatised behaviours. As discussed in Chapter 2, HIV disproportionately impacts underserved populations, many of which are often under-represented in research. Early discussions in PrEP research called for community involvement²⁴⁴ and collaborative approaches, and the value of involving communities in HIV prevention research and services has been well documented²⁴⁵. When PPI is employed, research is conducted “with” or “by” members of the public, rather than “to” or “about” them²⁴⁶. Including the voices of the public and patients in research can help identify research priorities; ensure research outcomes and applications are meaningful, culturally and socially appropriate, and relevant to the populations of interest; and improve how research findings are communicated and disseminated²⁴⁷.

I felt that it was important to incorporate PPI in my research to help ensure that the studies were framed within the wider context of HIV prevention and sexual health access, thereby maximising the impact of research findings and recommendations.

Initially, when my project had focused on developing a health equity framework to evaluate PrEP implementation (as discussed in Chapter 1), I recruited a panel of PPI advisors. The panel was intended to provide feedback over the course of my PhD, with advisors providing input on the research priorities, proposed research methods, and interpretations of research findings. The panel was recruited from a number of community organizations that work with or have membership from populations that are disproportionately impacted by HIV and/or underrepresented in research on PrEP (e.g., the Africa Advocacy Foundation, which provides advice and support to people in the African diaspora community). The panel was made up of representatives from a number of different communities and backgrounds, including representatives with experience of sex work, people living with HIV, women, gender-diverse people, and people of black African ethnicity. The panel met in the autumn

2020 to discuss my research plans, priorities, and the initial findings from the systematic review. Details and outcomes from this meeting are included in Chapter 5.

When the focus of my PhD shifted to awareness, interest, and preferences for PrEP among women in England, as discussed in Chapter 1, the original panel was informed of the change, and subsequently disbanded. A new panel was formed to align with the new project direction; one of the original panel members was retained, and a new advisor was recruited from the Research Department of Primary Care and Population Health's Expert by Experience PPI group. The new panel provided input on the remaining studies, and the details and outcomes of their feedback are included in Chapters 6 and 7.

An evaluation was completed following each PPI activity (an example evaluation form is included in Appendix 1), and each PPI advisor had the opportunity to provide additional feedback, comments, or suggestions. When advisors made suggestions to alter or change elements of the studies, I in turn provided feedback on how those suggestions were incorporated and/or any changes to the study design or material that resulted. If a suggestion was not taken on board, I provided an explanation as to why not and provided the advisors with further opportunities to provide input or ask questions.

Pending adequate resources, further PPI activities will be carried out with the panel to advise on the dissemination and application of the thesis results.

4.8 Conclusion

In this chapter, I described the methodological approach that was taken, described the approach for conducting this research through an equity lens, and discussed the role of PPI in this thesis. In the next chapter, I present the methods and results from the systematic review.

Chapter 5 Systematic review

5.1 Chapter overview

In this chapter, I present the background, methods, and findings from a systematic review of literature reporting assessments of PrEP awareness or PrEP interest in high-income countries. In the review, I discuss whether PROGRESS-Plus factors were considered when describing study populations, and when reporting PrEP awareness and interest.

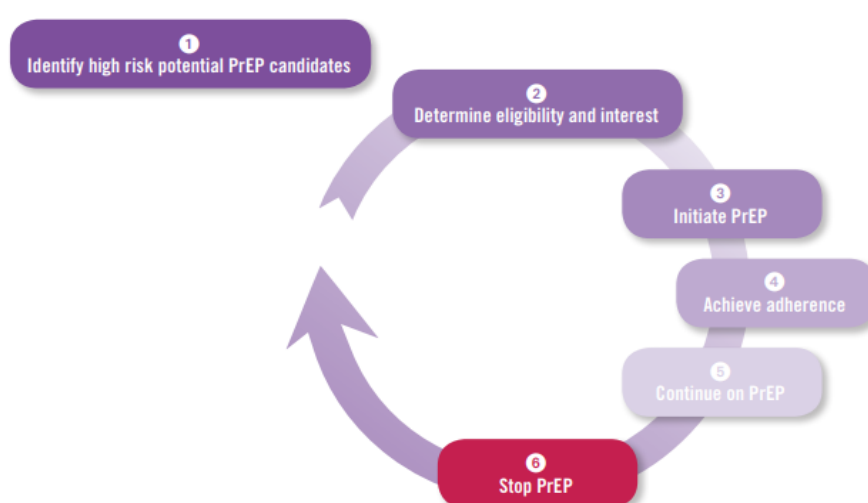
5.2 Background

Clinical trials have demonstrated the efficacy of PrEP (i.e., the ability of PrEP to prevent HIV when taken as prescribed), however, PrEP effectiveness (i.e., how well PrEP can prevent HIV in practice, or real-world settings outside of trials) depends on a number of factors, including whether people know about PrEP as a prevention option, how accessible it is to people who would benefit from it, and their ability to take it as prescribed for as long as it is relevant to them. PrEP implementation must be monitored to ensure that it does not contribute to existing disparities in HIV prevention, and so that where inequities exist, they can be identified and addressed.

Frameworks for evaluating and monitoring PrEP implementation have been developed, many of which take the form of care cascades, or continua of care, modelled on the HIV care continuum²⁴⁸. The HIV care continuum outlines the stages that people living with HIV go through from diagnosis, engagement in care, and receiving treatment, to viral suppression²⁴⁹. PrEP monitoring frameworks outline the stages that PrEP candidates go through, from the identification of PrEP need, through to receiving a prescription for PrEP and retention in PrEP care, so that gaps in PrEP engagement can be identified. Although there are non-specific HIV prevention cascades^{250,251} (which can be adapted to different HIV prevention technologies), there are also several PrEP specific care cascades, or PrEP continua of care (PCC) that have been developed^{17,150,252–256}.

In general, PCC and PrEP monitoring frameworks begin by identifying the population at risk of HIV (and, by extension, the population who may benefit from taking PrEP),

and follow this population through different stages of PrEP engagement. For example, the WHO Implementation tool for PrEP⁶ (Figure 2) starts by identifying the population of people considered at high risk of HIV acquisition, then moves to determining who in this population is eligible and interested in PrEP. Then, among those who are both eligible and interested, who initiates PrEP, followed by who achieves adherence on PrEP and who continues to take PrEP for as long as it is relevant to them.



Source: Adapted from Liu et al. (2)

Figure 2: The PrEP Cascade from the WHO Implementation tool for PrEP⁶, adapted from Liu *et al.*²⁵⁷

Both the PCC and HIV care cascades begin by identifying the population that will move through the cascade, i.e., those considered at risk of HIV acquisition who may benefit from PrEP and people living with HIV, respectively. However, in the HIV care cascade, this population is easily defined; once a person enters the HIV care cascade, at present they will remain in the cascade for the duration of their life. With PrEP, individuals may experience “seasons of risk”, i.e., their risk of HIV acquisition (and consequently, their PrEP candidacy), may change depending on their sexual behaviour and/or circumstances. Hence, the population who may benefit from PrEP is not always easily estimated or defined.

Earlier versions of PCC, such as the first PCC presented by Liu *et al.*²⁵⁷ and Nunn *et al.*'s PrEP Care Continuum¹⁷ had not been applied to real-world PrEP implementation programmes at the time of their publication, meaning the adaptability, feasibility, and useability of the frameworks had not been explored. More recent monitoring frameworks have used real-world or routinely collected surveillance data to evaluate PrEP implementation, such as the PCC to assess implementation in Australia, which utilizes national behavioural surveillance data²⁵⁵, and a metric for evaluating PrEP programme effectiveness²⁵⁶, which uses routinely collected surveillance data from clinic visits, has been demonstrated using data from South Africa and Zambia. In England, the PrEP monitoring and implementation framework¹⁵⁰ defines seven indicators to support the delivery of PrEP using existing, routinely collected surveillance data from SHS. The indicators are intended to support service delivery and identify ways to reduce inequities in PrEP provision and engagement and are grouped under two themes: service delivery evaluation and epidemiology of HIV and STIs among PrEP users (Figure 3). The service delivery evaluation indicators follow a PCC structure, i.e., they start by identifying the number of people with a PrEP need among HIV-negative individuals accessing specialist SHS, then report initiations or continuations among that population and so forth through to PrEP discontinuation. Conversely, the epidemiological indicators provide data on the number of HIV seroconversions and STI diagnoses among people in receipt of PrEP.

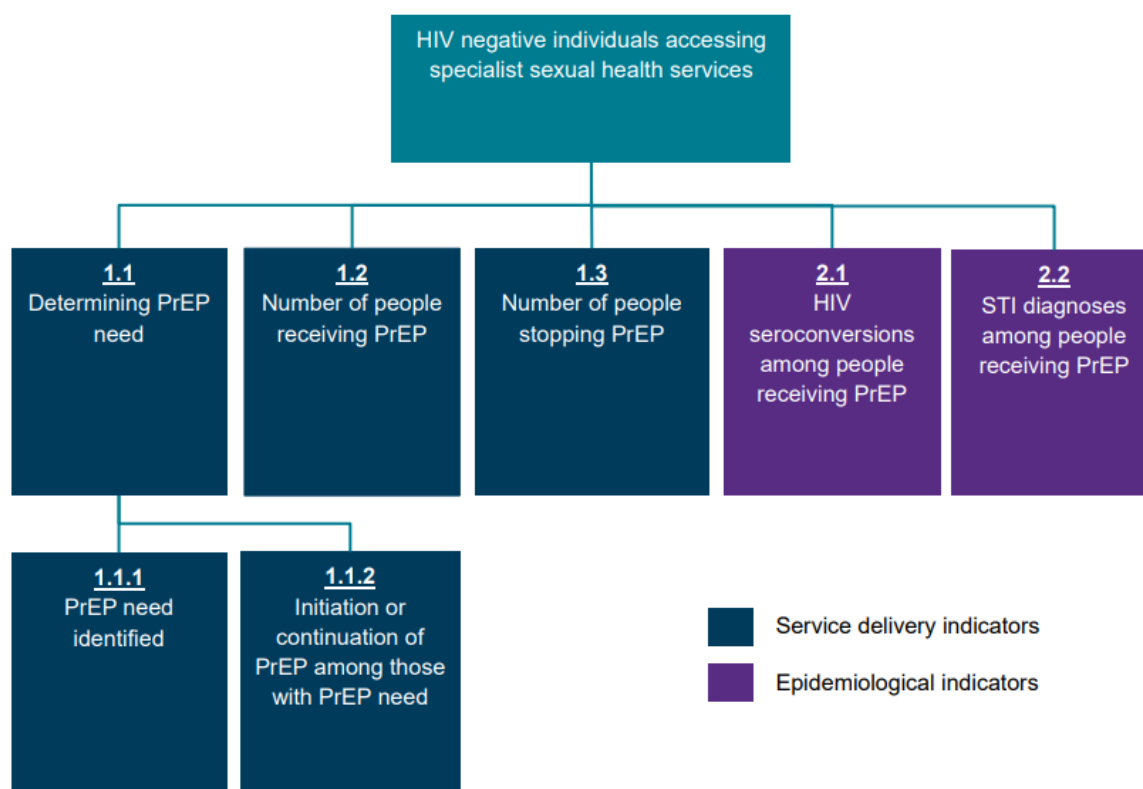


Figure 3: United Kingdom Health Security Agency's PrEP monitoring and evaluation framework overview

The PrEP monitoring and evaluation framework has identified populations with low PrEP initiation (stage 1.1.2) relative to PrEP need (stage 1.1), for example, women (as discussed in Chapter 3), however, the framework indicators only capture people who are attending SHS, and so the population with a PrEP need may be underestimated. Furthermore, current surveillance data does not capture information on other factors that may be important for PrEP engagement that are captured in other PCCs, such as awareness of¹⁷ and interest in PrEP^{17,253}. Awareness is an important early stage in both health promotion and implementation science; for an intervention such as PrEP to be successful, those who can benefit from it must first be aware that it exists²⁵⁸, and a lack of PrEP awareness has been cited as a barrier to PrEP uptake^{190–192}. PrEP interest is important for planning service delivery, to ensure that adequate resources (e.g., clinical staff, medication supply etc.) are available to meet demand. Furthermore, identifying people who are eligible for, but not interested in taking PrEP, may allow for the development of bespoke

interventions to support them in engaging with their preferred HIV prevention methods and services.

Monitoring outcomes such as PrEP awareness and interest are not only important for evaluating the overall success of implementation programmes. By considering health equity characteristics when evaluating these outcomes, it may allow us to identify groups with low engagement and better ensure that PrEP provision programmes do not contribute to health inequities among at-risk populations.

To my knowledge there are no standard definitions for assessing PrEP awareness and interest, and how these outcomes have previously been measured is not well characterised. Additionally, little is known about how factors that influence health equity, such as those in the PROGRESS-Plus framework, have previously been considered when reporting PrEP awareness and interest.

5.3 Systematic review aims and objectives

This systematic review was carried out to address the first thesis objective described in Chapter 4 (i.e., Describe how the PrEP outcome measures “awareness” and “interest” are defined and reported in real-world settings in high-income countries”). Specifically, the review aims to characterize how PrEP awareness and interest have previously been assessed in published scientific literature, and to describe whether PROGRESS-Plus characteristics have been considered in studies reporting PrEP awareness and interest in high-income countries.

The objectives of this systematic review are:

1. To identify and collate assessments of awareness and interest in PrEP in real-world settings in high-income countries.
2. To describe the baseline populations in studies reporting PrEP awareness and interest
3. To explore how these studies consider PROGRESS-Plus characteristics for the baseline populations, and when reporting PrEP interest and awareness

Although this review aims to collate and describe how awareness and interest are assessed, and how factors that influence health equity are considered, it is not intended to comment on the level of PrEP awareness and interest in high-income

countries, summarise or identify inequities in PrEP awareness and interest, nor comment on the effectiveness of specific PrEP programmes at reducing inequities in awareness and interest.

5.3.1 Adaptation of the original systematic review

As discussed in Chapter 1, this systematic review was initially designed for a thesis project focused on developing and evaluating a framework for measuring health inequities in PrEP implementation. The original review aimed to identify and collate assessments of five stages of the PrEP care continuum: awareness, interest, uptake, adherence, and retention. Once the research focus of the thesis changed to awareness and interest in PrEP among women in England, the systematic review was adapted to better reflect this new direction. For the adapted review, only studies reporting a definition of awareness or interest were included. Studies including a definition of PrEP uptake, adherence, or retention were not included, as these stages of the PrEP care continuum were not explored in detail in the subsequent studies. Additionally, although the new thesis direction focused exclusively on women, the included studies were not restricted to those whose population included women (i.e., studies with participants of any gender were retained). As the review collated *definitions* of awareness and interest, rather than the *level of* awareness and interest in the included studies, I felt that it was important to describe how these stages were reported in the literature more generally as the searches returned relatively few studies that focused on women.

The searches, data extraction, and preliminary analysis (e.g., tabulation of study characteristics, outcome measure definitions, and PROGRESS-Plus characteristics) were completed before the thesis direction changed, however, only results relevant to awareness and interest have been included in this chapter. The full study protocol has been published¹⁸, and is included in Appendix 2. The aims and objectives that are presented above reflect the adapted review, and the methods, results, and discussion for the adapted review are presented below.

5.4 Method

This systematic review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement guidelines²⁵⁹ and the 2012 Preferred Reporting Items for Systematic Reviews and Meta-Analyses Equity extension²³⁵, which provides guidance for reporting systematic reviews with an equity-focus. It was registered with the PROSPERO international prospective register of systematic reviews (CRD: 42020169779).

5.4.1 Search strategy, including databases searched

Five electronic databases were searched: Medline (via Ovid), Embase (via Ovid), PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL) (via EBSCO Host) and Applied Social Sciences Index and Abstracts (ASSIA) (via ProQuest). The full search used for Medline/Embase is included in Appendix 3.

5.4.2 Study inclusion and exclusion criteria

Inclusion and exclusion criteria were defined using PICOS (Population, Intervention, Comparison, Outcomes, Study design). A summary of the inclusion/exclusion criteria is included in Table 2.

In brief, included studies had to report an assessment of either PrEP awareness or interest within the context of a real-world setting (i.e., where the study population had the opportunity to access PrEP from an implementation trial, demonstration project, or national programme). In an effort to minimise heterogeneity, only studies including data from high-income countries were included. Although factors influencing health equity in high-income countries are likely to be similar to those in low-income and middle-income countries, how PrEP programmes are monitored and the way vulnerable populations experience health inequity, will likely differ between these settings.

Quantitative observational studies were included in the review. Mixed methods studies were included where an assessment of PrEP awareness or interest from quantitative data was included and reported. Qualitative studies, review articles, case studies, studies not involving oral FTC/TDF PrEP, and commentary or opinion pieces that did not contain a definition for PrEP awareness or interest were

excluded. RCTs that focused on PrEP safety and efficacy were excluded, and other RCTs were only included if the intervention studied was not targeted at PrEP interest or awareness.

Articles were included if they were published in English between 2012 – March 2020, when the initial searches were run. Studies with data collection that took place prior to 2012 were excluded on the basis that real-world implementation projects in high-income countries were not likely to be common before FDA approval of emtricitabine/tenofovir disoproxil fumarate for PrEP. Retrieved records were also excluded where the study population was exclusively people living with HIV, as this is not a group that is eligible to use PrEP.

Table 2: Systematic review inclusion and exclusion criteria

PICOS category	Inclusion criteria	Exclusion criteria
Population	People resident in high-income countries with a national PrEP provision programme (i.e., where the national governing body has approved PrEP for use and it is available from health care facilities and/or bespoke initiatives) or demonstration/implementation project, regardless of sexual orientation/identity, age, gender identity, or occupation	People resident in countries without a national PrEP provision program or demonstration/implementation project; people resident in low- or middle-income countries.
Intervention	Studies reporting an assessment of PrEP awareness or interest	Studies that do not report an assessment of PrEP awareness or interest
Context	Studies conducted in high-income countries, as defined by the World Bank country classifications ²⁶⁰ .	Studies conducted in low- or middle-income countries.
Outcomes	Primary outcome: Definition for at least one of PrEP awareness or PrEP interest Secondary outcome: Whether (and how) PROGRESS- Plus characteristics were considered in reporting the baseline population, PrEP awareness or PrEP interest	Outcomes not in the inclusion criteria

Study Design	Quantitative research studies including non-experimental observational studies	Qualitative studies, review articles, case studies, studies not involving oral emtricitabine/tenofovir disoproxil fumarate as PrEP, randomised controlled trials focused on PrEP efficacy or safety

5.4.3 Study selection

Records were extracted into EndNote for duplicate checking and title and abstract screening. Records included at the first stage were exported to a bespoke Microsoft Access database for full text screening and data extraction. I carried out all title, abstract and full text screening for all results, and another PhD candidate carried out secondary screening (title, abstract, and full text) of 20% of the search results. Disagreements between the two reviewers were resolved by discussion, with LMD acting as arbitrator in case of disagreements.

5.4.4 Data extraction

Data was extracted into a pilot tested, bespoke Microsoft Access database. The following data items were extracted:

- Bibliographic information (first author, year of study, country of study)
- Study aims and design (including descriptions of the study population and data collection methods)
- Participant demographic and PROGRESS-Plus characteristics
- How PrEP awareness and/or PrEP interest were assessed
- Whether the study considered PROGRESS-Plus characteristics for the baseline population and when reporting PrEP awareness and interest

An expanded data form was used to extract data detailing how PROGRESS-Plus characteristics were considered. e.g., as a descriptive category, or as an explanatory variable in a multivariate analysis. For the purpose of this review, the “Plus” category characteristics that were extracted included characteristics that are considered relevant to HIV transmission risk²⁶¹ by the WHO. Where a characteristic could be considered as part of a “PROGRESS” category, but carried a known risk of HIV transmission, it was extracted as a “Plus” category- e.g., current or former experience of sex work was considered and extracted as a “Plus” category, rather than as an “occupation”. Table 3 includes an example of PROGRESS-Plus categories that were extracted.

Data was extracted on how PROGRESS-Plus characteristics were considered in reporting awareness and interest; studies were classified as “analytical” if

PROGRESS-Plus categories were used to estimate an exposure-outcome association, or were adjusted for in these estimations (e.g., as confounders). Otherwise, studies were classified as “descriptive”.

Table 3: PROGRESS-Plus categories for data extraction

PROGRESS-Plus Category	Example
Place of Residence	Rural/Urban, country/state/city, housing characteristics
Race/ethnicity/culture	Ethnic background, country of birth
Occupation	Employment status, employment type (e.g., Professional, skilled, etc)
Gender/sex/sexual identity	Gender identity, sexual identity, sex, Male, Female, gender Non-Binary, Transgender,
Religion	Religious background
Education	Years in/left of education, highest level of education attained, school type
Social capital	Neighbourhood/community/family support
Socio-economic position	Income, means tested benefits, affluence measures
Plus	Age
	Physical or mental/emotional disability
	Other vulnerable groups: Experience of sex work (current or former)
	Other vulnerable groups: Experience of homelessness or unstable housing (current or former)
	Other vulnerable groups: History of incarceration
	Other vulnerable groups: Experience of intimate partner violence
	Other vulnerable groups: Substance users/substance use

5.4.5 Risk of bias assessment

Risk of bias assessment (also called critical appraisal, or quality appraisal) is the systematic assessment of a study's methodological rigour. In a systematic review, it helps researchers to assess the credibility of the research that underpins the findings of a set of studies²⁶². In other words, risk of bias is carried out to assess the validity of each study's findings²⁶³. Threats to the validity and precision of study findings include systematic errors (e.g., confounding, selection, or reporting bias), and random errors (e.g., inadequate study sizes, or a lack of study efficiency)²⁶³.

The focus of this review was to 1) describe and collate definitions of PrEP awareness and interest and 2) describe whether equity characteristics were considered in studies. The review was not meant to evaluate the results of studies reporting PrEP awareness or interest, nor identify inequities in these outcome measures. Additionally, commenting on the quality of the outcome measure definitions (e.g., ranking definitions of outcome measures), was also beyond the scope of this review. As such, no formal assessment of risk of bias was conducted, as sources of bias in quantitative studies (such as non-response rate, or representativeness of the cohort) would not impact the outcomes extracted in this review (i.e., outcome measure definitions).

There is precedence for not conducting a risk of biases assessment in reviews where the focus is to describe, rather than evaluate, a phenomenon of interest. A 2021 review of approaches for combining primary care electronic health records data from multiple sources took a similar approach to data synthesis and did not conduct a risk of bias assessment²⁶⁴.

5.4.6 Data synthesis

I conducted a narrative synthesis²⁶⁵ of the extracted data to address the aims of this review, as a meta-analysis was not possible for several reasons. There was considerable heterogeneity across the studies in terms of how awareness and interest were assessed, study populations, and inclusion of PROGRESS-Plus characteristics. Additionally, this review aimed to collate definitions of how PrEP awareness and interest were assessed, rather than the level of awareness and interest, therefore, it was not appropriate to pool the data for analysis.

To conduct the narrative synthesis, definitions for PrEP awareness and interest were extracted and tabulated. Definitions were compared to identify patterns and differences in how these outcomes were assessed between studies. Similarities and differences between these definitions were explored and discussed, taking into account differences in study population, study design, and data collection. Baseline participant characteristics were mapped to PROGRESS-Plus characteristics where appropriate, and data was extracted as to whether PROGRESS-Plus characteristics were considered in reporting PrEP awareness and interest. Reporting of PROGRESS-Plus characteristics was tallied, and how these characteristics were considered in each study was explored and discussed.

5.4.7 Patient and public involvement

A PPI panel meeting was held with advisors to discuss the review protocol and preliminary results in November 2020. Advertisements for panel members were distributed via email to community organisations who worked with or served populations that are disproportionately impacted by HIV and/or are underrepresented in HIV and PrEP research (e.g., women, people from rural communities, people from minority ethnic communities, and people who identify as a gender or sexual minority). Interviews were held with interested candidates, and four PPI advisors were recruited. The panel had representation from cisgender men and women, trans non-binary people, people of black African ethnicity, people living with HIV, and people with past and current experience with sex work.

The PPI advisors gave feedback on the original systematic review protocol and preliminary results (which included uptake, adherence, and retention stages), however, they did emphasize the importance of exploring PrEP awareness and interest as a way to improve engagement downstream stages of the PrEP care continuum. The advisors also felt that the PROGRESS-Plus characteristics were appropriate for discussing inequities that may impact engagement with PrEP.

5.5 Results

5.5.1 Characteristics of included studies

Of 11,264 records identified, 5,815 unique records were identified for title and abstract screening. Of these, 573 (9.9%) full texts were assessed for eligibility. Three hundred and thirty-six articles were excluded at the full text screening stage; the majority of excluded studies were conference abstracts (n=233). Other reasons for exclusion were no outcome measure definition reported (n=38) and only including data collected before 2012 (n=32). This left a total of 237 studies. As discussed above, the systematic review was originally designed to investigate outcome measures across the entire PCC, from awareness through to retention. For this adapted review, only studies including a definition of awareness or interest were relevant, excluding a further 77 studies.

Of the remaining 160 studies that had a definition for either awareness or interest, eight were excluded as the data collection took place before there was a national PrEP demonstration or implementation programme, and one was excluded for being an experimental, rather than observational study. This left a total of 151 articles that were included. Figure 4 shows the PRISMA flow diagram, and the results tables for the included studies are located in Table 19 (Appendix 4).

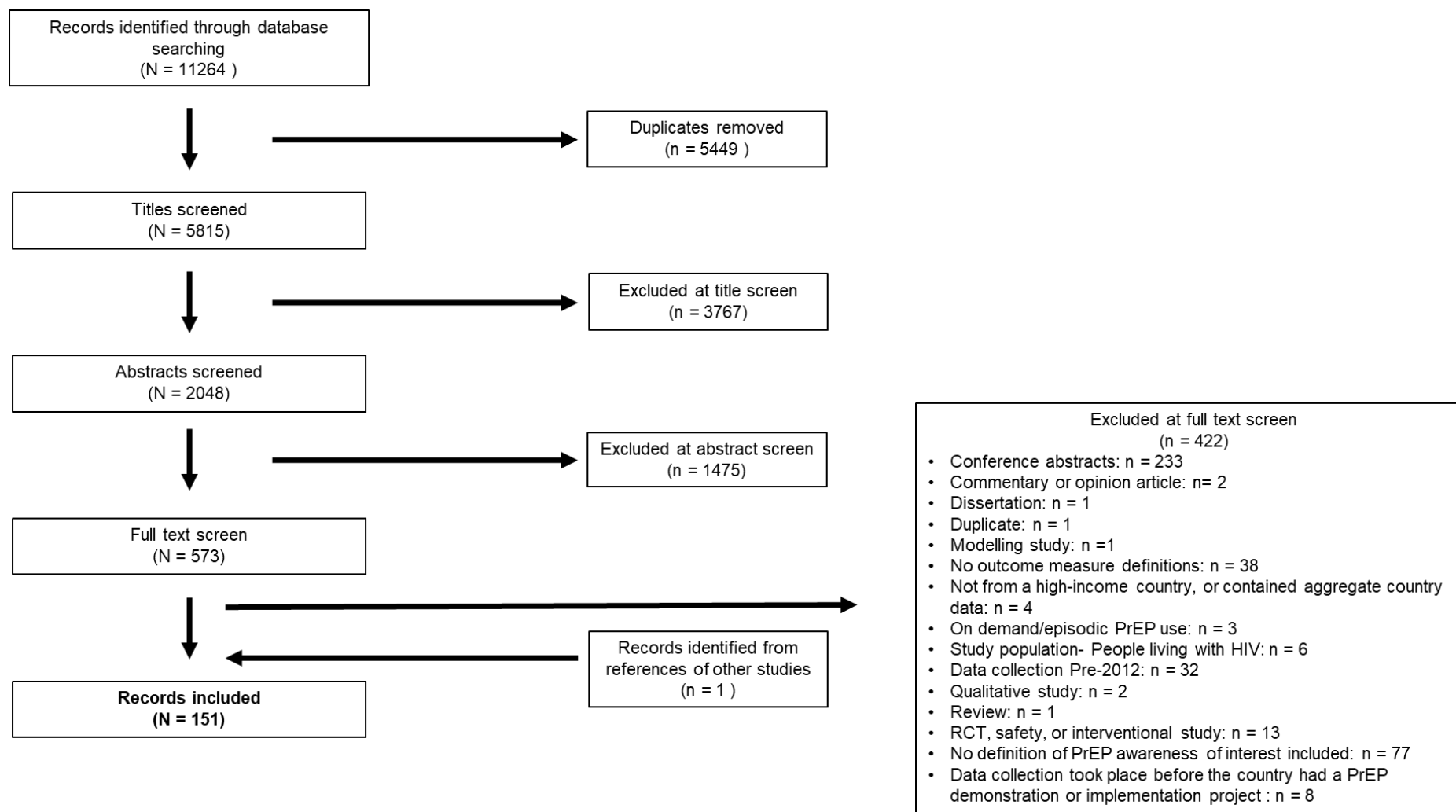


Figure 4: Prisma Flow diagram for the systematic review

5.5.1.1 Study characteristics

The majority of studies were conducted in the USA^{190,199,211,266–384} (80.1%, n= 122), followed by Canada^{385–392} (5.9%, n=9), Australia^{255,393–396} (3.3%, n=5), France^{397–400} (2.6%, n=4), and England^{401,402} (1.9%, n=2). Two studies were conducted in each of Spain^{403,404} and Taiwan^{405,406}, and one study in each of Belgium⁴⁰⁷, Korea⁴⁰⁸, New Zealand⁴⁰⁹, and Switzerland⁴¹⁰.

5.5.1.2 Study design

Over 70% of included studies had a cross-sectional design^{190,199,202,211,255,266–271,273–277,279–282,286,289,290,292–295,297,299–301,303,306,307,309–312,314–316,318–320,322,324,326–328,330–335,337–341,344,345,349–357,360,362–364,370,371,373,375,377,379,380,382,384–388,390–392,394–408,410–413} (n=110), 16% (n=25) were cohort studies, and 8% (n=12) were from an ongoing behavioural surveillance program in the United States (National HIV Behavioural Surveillance (NHBS))^{272,283,288,308,336,342,346,348,359,361,365,366}, and 2.6% (n=4) were baseline data from HIV prevention trials^{278,305,347,358}. Three of the cohort studies were retrospective cohort studies which reviewed medical records^{285,304,414}, and the remainder were prospective cohort studies^{296,298,302,313,323,329,367–369,372,374,378,383,389,409,415}.

5.5.1.3 Study population

The included studies fell into two main categories: studies which recruited populations based on gender or sexual identity characteristics (n=118), and those which did not (n=33). Of the studies that recruited samples based on gender and/or sexuality, most of the studies recruited men or

GBMSM^{255,267,271,272,274,275,277,279,288,290,294,298,300,301,305,307,309,312,316,317,320–323,327,333,334,338–340,342,344–346,349,351,353,354,356,357,359,361–363,365,366,368,370,372,373,375,378,380,383,385–395,397–403,406,407,409,410,412,414–416} (n=80), while

seven studies recruited GBMSM and transgender women^{310,313,332,343,371,377,404}.

Seven studies recruited transgender women^{211,266,270,282,297,311,330} exclusively, and one study recruited transgender men³¹⁴. Some studies recruiting GBMSM and transgender people included additional eligibility criteria such as a history of substance use, or identifying as a particular ethnicity (e.g., black, African American, Latino).

Eighteen studies recruited cisgender

women^{190,278,280,281,283,285,286,295,315,318,319,326,329,335,350,358,369}, and one study recruited both cisgender and transgender women²⁹³. In studies recruiting women, additional eligibility criteria included women experiencing homelessness or housing instability³¹⁹, experience of sex work²⁸¹, injection drug use²⁸³, and identifying as black or African American^{280,328,358}. Five of the studies recruited women from either sexual health clinics, planned parenthood, or other healthcare providers^{285,295,315,318,335}. Four of the studies included a definition of PrEP eligibility^{285,286,329,369}.

Of the 33 studies that did not include gender or sexual identity eligibility requirements, twelve studies recruited participants who used drugs^{292,337,382,384} or injection drugs specifically^{273,336,341,355,396,411,417,418}, three recruited people of black/black African/African American ethnicity^{202,276,306}, three recruited young people^{269,352,367}, and one recruited partners of people living with HIV²⁹⁶.

In general, studies did not restrict participation to people who were “eligible” to take PrEP but reported populations as being at risk of HIV acquisition due to a particular characteristic (e.g., substance use, ethnicity, sexual behaviour).

5.5.1.4 Recruitment strategy

Only three of the studies recruited participants used a form of probability sampling^{276,306,321}, while the remainder used either respondent driven sampling, time-location sampling, and convenience sampling. One study did not report the recruitment strategy²⁸². For studies using NHBS data, the recruitment strategy depended on the population of interest; studies recruiting people who inject drugs^{283,336,418} and heterosexual people³⁴⁸ were recruited using respondent driven sampling, while studies recruiting GBMSM^{272,288,342,346,359,361,365,366} used time-location sampling.

Convenience samples were recruited from a range of locations, including sexual health services or other healthcare providers, geosocial networking apps (e.g., Grindr), and gay social venues, such as Gay pride events, and sexual health clinics.

Data collection periods were available for all but nine of the included studies^{202,211,290,297,299,352,353,367,370}. The majority of studies completed data collected between 2014 – 2017.

5.5.2 Assessment of PrEP awareness and interest

Of the 151 included studies, 119 (78.8%) included an assessment of PrEP awareness^{190,202,211,255,266,266–268,270,274–277,279–283,285–290,292,294,295,297,298,300–303,305–307,309,311–322,324,326,329–334,336,338–349,351,353–357,359,360,362–373,377,382–392,395–403,405–408,410,412,413,417,418}, 109 (72.1%) included an assessment of PrEP interest^{190,199,211,255,266,267,269–276,278–282,286,289–295,297–299,302–307,309–312,315,318,319,322–324,326–330,335,337–339,341,342,344,349,350,352–356,358–361,363,367–371,373–375,378–380,382,383,386–388,390,391,393,394,396–404,406–411,413–415,417}. Seventy-seven studies (51.1%) included an assessment of both PrEP awareness and interest^{190,211,255,266,267,270,274–276,279–282,286,289,290,292,294,295,297,298,302,303,305–307,309,311,312,315,318,319,322,324,326,329,330,338,339,341,342,344,349,353–356,359,360,363,367–371,373,382,386–388,390,391,396–403,406–408,410,413,415,417}.

5.5.2.1 Awareness

In some studies, the terms “awareness” and “knowledge” were used interchangeably, however, for this review I have made the following distinction: “awareness” is used to denote when a study assessed whether a participant knew about the existence of PrEP, without asking or reporting any further details about PrEP, whereas “knowledge” is used for studies that assessed how much information participants knew about PrEP (e.g., PrEP efficacy, PrEP availability, PrEP candidacy). Knowledge could be quantified (e.g., participants’ PrEP knowledge was assessed through a series of true/false questions) or perceived (e.g., participants report their perceived level of PrEP knowledge).

PrEP awareness was assessed in all but twelve studies^{211,275,276,305,306,320,321,324,331,367,395,413}. In general, there were two ways that awareness was assessed; participants were either asked whether they were aware of PrEP (with no preamble) or were given a brief description or definition of PrEP and asked if they were aware of it.

A of total fourteen studies assessed participants' knowledge of PrEP, either through True or False questions^{211,275,306,331}, or by asking participants how much they knew about PrEP^{305,320,321,324,367,385,389,395,413}. Where true/false questions were asked, participants' actual knowledge was assessed, rather than their self-perceived knowledge. True/false questions used to assess PrEP knowledge included questions around PrEP candidacy, and PrEP efficacy. In one study, multiple questions were asked to assess PrEP knowledge, and participants were given an overall score for their knowledge of PrEP²⁷⁵.

Two studies included an assessment of both participants' PrEP awareness and PrEP knowledge^{385,389}.

5.5.2.2 *Interest*

Studies reported assessments of interest in a number of ways, and for this review, I have classified them into three categories: interest in or willingness to take PrEP, intention to use or likelihood of using PrEP, and acceptability of PrEP. Although each of these categories may be important in predicting service use and assessing PrEP demand, I did not feel that they were directly comparable. Intention to use or likelihood of using PrEP may be a better representation of whether an individual will seek out PrEP than interest or willingness, whereas acceptability explored participants' perceptions of PrEP as a method for preventing HIV. The difference between "hypothetical willingness" and behavioural "intention" to take PrEP has previously been investigated, and the distinction between them was found to be "meaningful"²⁹⁸. I felt that it was important to capture these differences, particularly as several studies assessed multiple categories of interest.

Eighty-four papers reported an assessment of PrEP interest or willingness^{190,199,211,255,266,269–273,275,276,281,282,286–293,295,297,298,302–306,309,311,312,315,319,322–324,326–328,330,335,337–339,341,342,349,350,352–356,359,361–363,367,370,371,374,375,378–380,382,383,386–388,390,394,396,402–404,407,409,410,413,414,417}. For the most part, studies assessed whether participants were interested in or willing to taking PrEP, however, eight studies assessed whether participants were interested in learning more about PrEP^{190,295,304,323,339,369,410,415}. Interest or willingness was assessed with either a yes or no question, or a Likert scale⁴¹⁹, which allows respondents to express their strength of agreement with a statement. Questions using Likert scales typically used

the statement “I am interested in taking PrEP”, and participants could choose from answers ranging from “strongly disagree” to “agree”. Likert scales were generally dichotomised into two categories, e.g., “interested” and “not interested” (or “willing” and “not willing”). Only one study used a validated instrument to assess willingness to take PrEP²⁵⁵. In this study, a 7-item scale to assess willingness to take PrEP- participants were classified as “willing to use PrEP” if they scored ≥ 4 on the scale.

Seventeen studies assessed participants’ interest in or willingness to use PrEP in hypothetical scenarios^{267,269,269,271,273,273,291,297,298,337,354,356,363,378,382,387,402,409,410}. The scenarios included questions around PrEP efficacy (e.g., would you be willing to use PrEP if it were 90% effective), side effects (e.g., would you be willing to use PrEP if it caused side effects), and cost (e.g., would you be willing to use PrEP if it were available for free).

Twenty-six studies assessed participants intention to or likelihood of taking PrEP^{278–280,294,295,298,307,318,329,344,358,368,369,373,391,393,397–401,406,408,411,413}. As with interest or willingness, intention or likelihood was assessed via a yes or no question or Likert scale, and when reporting intention or likelihood, the Likert scales were usually dichotomised (e.g., “likely” vs “not likely”). Eight studies^{278,310,344,358,391,397,400,411} assessed intention or likelihood of taking PrEP in hypothetical scenarios, for example whether participants would be likely to take PrEP if they had to attend SHS for regular testing, or likelihood at different price points or efficacy levels.

Five studies assessed PrEP acceptability^{269,271,337,402,409}, three of which assessed how acceptable participants found PrEP in different hypothetical scenarios^{269,271,337} (e.g., if PrEP was acceptable if it had side effects, acceptability of drug regimens, acceptability at different costs). One study assessed at whether participants felt PrEP was beneficial to them⁴⁰².

5.5.3 Consideration of PROGRESS-Plus categories

5.5.3.1 PROGRESS-Plus in the baseline population

All but two studies^{271,380} included at least one PROGRESS-Plus category when describing the baseline population. The most commonly reported PROGRESS category was race/ethnicity, reported in 81.5% of all studies

(n=124)^{190,199,202,211,255,266,269,270,272-275,277,279,281-283,285,286,288-300,302-307,309-316,318-321,323,324,326,327,329-332,334-339,341-343,345-350,352-357,359-362,364-375,378,379,382-385,388-392,394,396-403,407,409-411,413,414,417,418}, followed by gender or sexuality, included in 71.7% (n=109)^{202,211,255,266-270,272,273,275-277,282,283,288-296,298-306,309,310,313,314,316-321,323,324,326-328,331-334,336-339,341,344-348,350,352,354-356,360,363,364,367-369,371-375,377,378,382-385,387-389,391-394,396-406,411,413,415,417,418}. The least commonly reported category was religion, which was only included in one study³⁴⁹, followed by place of residence^{266,267,273-275,277,280,282,286,288,291,293,298,300,305,306,313,314,317,318,321,324,330,339,343,352,354,355,362,363,366,367,373-375,378,385,387,388,391,394,395,402-404,407,410,413} and occupation^{199,255,266,268,270,272,275,279,291-293,295,301,305-307,318,320,328,332,337,338,340,343,344,347,349,352,353,355,363,369,371,373,377,384,390-392,394,395,397-401,403,405,411}, both of which were included in 32.2% of studies (n=49). Age was the most commonly reported PLUS category (80.9%, n=123)^{199,255,267-270,273,275-277,279-281,283,285,288-291,293,296,297,299-305,307,309-319,321-324,326-329,331-335,337-342,344-351,353-355,358-364,367-369,371,374,375,377-379,382-385,388-392,394-406,408,410-415,417,418}, followed by substance use (30.0%, n =41)^{272,281,283,286,291,292,296,298,299,301,306,307,311,314,317,327,330,336-338,341,348,349,355,360,363,368,373,375,382-384,386,390,394,396,402,411,412,417,418}. Only six studies (3.9%) included a history of IPV when describing the baseline population^{281,303,328,346,369,373}.

In general, age, gender, ethnicity, occupation, and sexual identity were reported consistently across studies, however, other PROGRESS-Plus categories varied widely between studies. For example, socioeconomic position was defined in several ways, including (but not limited to) household income, medical insurance status, and relative need (e.g., participants feeling that they had adequate income to cover their basic needs and expenses). Studies conducted in the United States commonly reported medical insurance status, and this was included as a measure of socioeconomic position. Social capital was usually only reported as a participant's relationship status, and other definitions (e.g., feeling involved in local community), mainly featured in studies where the population of interest was a gender or sexual minority.

5.5.3.2 PROGRESS-Plus in awareness

Of the 119 studies assessing awareness, 85 included at least one PROGRESS-Plus category when reporting the level of awareness among the sample. In 25.9% of

studies (n=22), PROGRESS-Plus categories were reported for descriptive statistics only^{202,211,280,295,297,302,306,313,320,324,329–331,336,339,346,371,372,391,403,408,412}, and in the remaining 74.1% (n=63), they were included as explanatory variables or confounders in analytical models^{255,267,268,274,277,281,283,285,288–290,294,296,300,303,305,309,311,312,316,321,326,332–334,338,340,342,345,347–349,351,353,354,357,359,360,362,364–366,369,370,373,377,385,388–390,392,395–401,406,407,410,413,418}.

As in the baseline population, the most commonly included PROGRESS category was race/ethnicity (45.4%, n=54)^{274,277,281,283,285,288–290,294–297,300,303,305,309,311,312,316,320,321,326,330–332,334,339,342,345–347,349,354,357,359,360,364–366,369,371,372,385,388–390,395–399,403,410,418}, followed by gender/sexuality (35.3%, n=42)^{267,268,277,283,288–290,294,296,303,305,316,320,321,330,331,333,338,339,345–348,360,362,364,369,372,373,377,385,388,389,392,396–399,403,406,413,418}. No studies included religion, and only 16 (13.4%) studies included occupation^{268,303,305,320,332,338,347,349,369,372,377,390,395,398,399,403}. Age was the most reported PLUS category (45.4%, n=54)^{202,267,268,274,277,280,281,283,285,288–290,296,300,303,305,309,311,312,316,321,326,330–334,338,342,346,347,349,351,354,359,362,364,369,377,385,388,389,392,395–399,402,403,406,410,413,418}, followed by substance use^{281,283,296,311,330,332,338,349,362,373,396,412,418}. Four studies included each of having a disability^{281,351,362,373}, a history of incarceration^{281,283,354,373}, or a history of transactional sex^{281,283,338,418}.

5.5.3.3 *PROGRESS-Plus in interest*

Of the 109 studies assessing awareness, 83 included at least one PROGRESS-Plus category when reporting the level of interest among the sample. In 21.7% of studies (n=18), PROGRESS-Plus categories were reported for descriptive statistics only^{211,269,274,280,282,295,297,307,310,349,361,378,382,386,391,396,407,413}, and in the remaining 78.3% (n=65), they were included as explanatory variables or confounders in analytical models^{199,255,266,267,270,272,273,275,276,281,286,290,292,294,298,299,303,306,309,311,318,322,323,327–329,335,339,342,344,350,354–356,359,360,363,368,368–371,373,374,379,380,383,387,388,390,394,397,398,400–406,409–411,414,415,417}.

As in both the baseline population and awareness, race/ethnicity was the commonly included PROGRESS category (41.2%, n=45)

199,255,266,269,270,274,275,281,282,292,295,297,298,307,309,311,322,323,327,335,342,354–356,359,361,369,374,378,379,382,383,388,390,396,398,402,410,411,413,414,417, however, the next most common was education (38.5%, n=42)^{255,270,272,274–276,281,282,290,292,295,298,307,309,310,322,327,342,344,349,350,354–356,359,363,369,371,374,379,380,382,383,387,388,390,402–404,406,411,417}. Sixteen studies (14.7%) included occupation^{199,255,270,272,275,292,295,306,307,349,355,363,390,398,403,411}, and no studies included religion. Age was the most reported PLUS category (41.3%, n=45)^{199,255,267,269,270,272,274–276,280–282,298,304,306,307,309,311,322,323,327,335,342,344,354,355,359,369,374,379,380,382,383,387,388,396,398,403–405,410,411,413,414}, followed by substance use (11.9%, n=13)^{281,292,298,307,311,327,355,373,380,381,383,396,402}. The least commonly included PLUS categories were having a disability^{281,292,306,355,373} or a history of transactional sex^{266,270,281,282,405}, each reported by five studies (4.6%).

5.6 Discussion

5.6.1 Summary of findings

In this systematic review, I described how assessments of awareness of and interest in PrEP have been reported in the literature and whether factors influencing health equity have been considered in reporting these measures. The findings of this review suggest that there are not standard definitions for PrEP awareness and interest and that although health equity characteristics included in the PROGRESS-Plus framework are often considered, not all characteristics are well-represented.

5.6.2 Paper characteristics

Despite global scale-up of PrEP availability between 2012-2020, the majority of included studies were from the USA. In the USA, healthcare is provided through a combination of private health insurance and public health coverage (e.g., Medicaid). This may influence how outcome measures are interpreted, for example, PrEP cost or insurance status may influence an individual's interest in PrEP²⁷¹. This also influences how PROGRESS-Plus categories are reported; in studies conducted in the USA, measures of socio-economic status may include insurance coverage,

whereas measures from countries with universal or single payer healthcare (such as Canada or the UK), this will not be as relevant.

Few studies focused on cisgender women or trans people, indicating a need for more research to be conducted with these populations. Qualitative studies with women have shown low awareness of PrEP before participation, but enthusiasm for PrEP as a prevention option once made aware of it^{194,420}. Transgender women were often included in studies with GBMSM, where their recruitment numbers were generally low. Transgender women face unique barriers to healthcare access from GBMSM, such as stigma related to their gender identity and the absence of providers who are culturally competent or knowledgeable about transgender issues⁴²¹, and a lack of gender-affirming language in these studies reinforces stigma and may prevent future participation of transgender women in PrEP studies.

Although most PCC and monitoring and evaluation frameworks define their population of interest as those at high risk of HIV or eligible for PrEP^{17,150,252–256}, awareness and interest were rarely reported as the proportion of those eligible/at risk who were aware of/interested in PrEP. Given challenges estimating PrEP eligibility in a population⁴²², this is not surprising. Assessing awareness and interest among general populations, as opposed to only “high-risk” or PrEP-eligible populations, may still be valuable for identifying disparities in PrEP awareness and knowledge, and for planning service provision. For example, the PrEP impact trial initially had 10,000 places, but this was raised to 26,000⁴²³ due to PrEP interest exceeding initial estimates of PrEP eligibility¹⁸¹ and interest. An individual’s risk of HIV acquisition may fluctuate over time, therefore monitoring awareness in a more general population, rather than just for those who are eligible for PrEP at a given time, may give more insight into inequities in PrEP awareness and give a better indication of how education and awareness campaigns should be designed and delivered. This in turn means that an individual may be more able to recognise when PrEP is appropriate or relevant to them as their risk changes⁴²⁴.

Data on PrEP awareness and interest was collected from cross-sectional studies, the majority of which recruited convenience samples. Only twelve studies used data from routinely collected behavioural surveillance, and all of which were part of the NHBS in the USA. Awareness and interest are currently not part of routinely

collected clinic surveillance data in the UK, and therefore, these items must be collected purposefully from other sources, such as community surveys, to enrich and complement data from downstream PrEP indicators, such as uptake and retention in care.

5.6.3 PrEP awareness and interest

PrEP awareness was assessed similarly across most studies. Although the terms “awareness” and “knowledge” were often used interchangeably, most studies asked whether participants knew about the existence of PrEP, rather than what, or how much, information participants knew about PrEP. Although knowing the level of PrEP awareness in a given setting is the first step in mitigating inequities in awareness, it does not provide an indication as to whether an individual understands PrEP candidacy, PrEP regimens, or how to access PrEP. Few papers assessed participant’s knowledge of PrEP, which may be important for identifying barriers to downstream stages of PrEP engagement. For example, in populations where PrEP uptake is low, assessing both PrEP awareness and knowledge may indicate whether this is due to an individual not being aware of PrEP, not knowing they could take PrEP, or whether it is due to other structural or personal barriers (e.g., inaccessibility of clinics, HIV related stigma), each of which requires its own bespoke intervention.

There was more heterogeneity in the reporting of PrEP interest and intention. Several studies reported whether participants were interested in learning more about PrEP, rather than asking about interest generally, or interest in taking PrEP specifically. Although only eight papers included this as a measure, it may be an important indicator for highlighting gaps in PrEP knowledge, and therefore planning of PrEP educational campaigns. Just under one-third of studies asked participants about their likelihood of or intention to take PrEP. Intention may be important to assess alongside PrEP need, in order to plan service delivery that can handle PrEP demand. Additionally, investigating interest alongside PrEP eligibility may identify individuals who could benefit from PrEP but do not want to take it. In these instances, interventions to support engagement with other HIV prevention methods may be more appropriate than those targeted at increasing interest.

5.6.4 Recommendations for reporting PrEP awareness, knowledge, interest, and intention

Based on the results of this review, I recommend that standard definitions are used when describing PrEP awareness, knowledge, interest, and intention. Possible definitions are included in Table 4. To decrease heterogeneity between studies and allow for better comparisons between settings, locations, and populations, studies should be explicit about which measure is being reported, rather than using the terms interchangeably as was observed in this review. This will also us to better identify and address disparities in PrEP engagement. For example, interventions to improve PrEP knowledge may benefit from a different design and implementation to those targeted at improving PrEP awareness, and there may be different barriers and facilitators for each of these outcomes that need investigating and addressing.

Table 4: Proposed definitions for outcome measures in the early stages of PrEP engagement

<i>Outcome measure</i>	<i>Proposed definition</i>
Awareness	Whether the population of interest knows about the existence of PrEP
Knowledge	How much the population knows about PrEP
Interest	Whether the population expresses an interest in taking PrEP or learning about PrEP
Intention	Whether the population expresses an intention to use PrEP

I recognise that there may be nuances within these categories, for example, whether participants express a “hypothetical” interest, or the exact category of PrEP knowledge being assessed (e.g., PrEP candidacy, effectiveness, regimens), and these specifics should also be made clear in reports.

Although this review focused on the early stages of the PrEP care continuum, I would recommend that consistent definitions should be adopted for the other outcome measures used to evaluate PrEP implementation programmes: uptake, adherence, and retention.

5.6.5 PROGRESS-Plus equity characteristics

PROGRESS-Plus categories were frequently used to describe the baseline demographics of populations. Age, gender/sexuality, and ethnicity were well

represented in describing participants' baseline demographics, and when reporting awareness and interest. Other factors, such as social capital, were less well represented, which may limit our understanding as to whether factors that influence health equity may be driving disparities in PrEP awareness and interest. For example, qualitative studies with women have shown that social networks, support from romantic/sexual partners and community support are important for normalising HIV prevention methods and cultivating interest in PrEP^{200,425,426}, but this has not been investigated in depth in quantitative studies. Only one study included a measure of religion for the baseline population, and no studies included religion when reporting awareness or interest. Religion is known to influence how some communities view and engage with, HIV prevention and services^{425,427}. In England, HIV prevention charities and advocacy groups work with faith leaders to facilitate outreach and knowledge of HIV and HIV prevention⁴²⁸, and so it may be beneficial to explore how religion, or belonging to a religious community, can influence an individual's engagement with PrEP.

5.6.6 Strengths and limitations

To my knowledge, this review is the first to collate assessments of PrEP awareness and interest and to describe how factors that influence health equity are considered when reporting these measures. The review has highlighted differences in how PrEP awareness and interest are defined and identified populations and health equity factors that are not well-represented in the current scientific literature. These findings may help inform how measures of awareness and interest can be used to complement existing PrEP monitoring and evaluation frameworks, and how in order to identify inequities in implementation, the drivers of inequity must be investigated in the first place.

There are several limitations to this study. Only English language articles were included, which may have introduced systematic bias. It is possible that articles were not identified in the original search, and the volume of papers included meant that it was not feasible to systematically go through the references of each included study to identify missed studies. In the same manner, it was not possible to include grey literature, which may have uncovered additional PrEP monitoring and evaluation frameworks that included definitions of PrEP awareness and interest. The volume of

included studies also meant that it was not feasible to include qualitative studies, which may have identified more studies featuring underrepresented populations, such as women¹⁶.

The volume of studies also meant that the screening, data extraction, and analysis were very resource intensive. There were several additional analyses that I had planned, but decided not to complete, given the time constraints of a PhD project. For example, I had intended to discuss and compare how each PROGRESS-Plus factor was defined in each study in further detail. Additionally, for studies that included the population “at risk of HIV”, I intended to collate how these populations were defined. I still feel that this is an area that is worth investigating, particularly for populations for whom this concept is less well characterised, e.g., women, however, it would need to be done as a dedicated piece of work, rather than as part of this systematic review.

The majority of studies completed data collection between 2014 – 2017, and the searches were completed in March 2020, therefore, this review would need to be updated to capture recent developments as PrEP availability and use continues to increase. Data in all of the studies was collected prior to the global COVID-19 pandemic, which had a drastic impact on healthcare access and provision and may have introduced additional sources of inequity in PrEP engagement.

5.7 Conclusions

In this chapter I have shown that the majority of studies investigating PrEP awareness and interest in high-income countries are focused on GBMSM and/or originate from the USA. I have highlighted the differences between PrEP awareness and knowledge, and interest and intention, and made recommendations for standard definitions of these measures of PrEP engagement.

5.8 Implications for the rest of the thesis

The research in Chapters 6 and 7 aims to address one of the gaps in the scientific literature that were highlighted by the review, i.e., the lack of research focused on PrEP awareness and interest among women. Chapter 6 presents qualitative research exploring PrEP awareness and knowledge among women living in

England, and Chapter 7 presents a quantitative study of women's PrEP awareness and preferences from a non-probability, online convenience survey. Both studies apply the recommendations from this review, namely clearly defining what outcome measure it being reported in each study, according to the definitions presented above. These studies were also designed to investigate the impact of PROGRESS-Plus factors, including less well-represented factors such as social capital and religion, on these outcome measures.

Chapter 6 Qualitative exploration of women's awareness and knowledge of PrEP

6.1 Chapter overview

In this chapter, I present the methods and findings from qualitative interviews investigating awareness, knowledge, and perceptions of PrEP among women in England. The data was collected from 18 semi-structured interviews that were conducted by telephone, or online via Microsoft Teams, and the data were analysed using thematic analysis. Three overarching themes were developed, and barriers to the delivery of PrEP information and PrEP services, as well as potential solutions to improve PrEP knowledge and access for women, were identified.

6.2 Background

In Chapter 5, I presented the results from a systematic review that characterized how awareness of and interest in PrEP had previously been assessed in scientific literature and described where PROGRESS-Plus characteristics had been considered in studies reporting PrEP awareness and interest in high-income countries. Overall, few of the studies included in the review were focused on women, and even fewer were focused on women in the UK. The lack of research on women and PrEP in the UK was also highlighted in a 2023 review by Whelan *et. al.* exploring the barriers and facilitators for PrEP access for women¹⁶. In the UK, existing research on women has mainly focused on black African women^{200,202,213}. While this group are disproportionately affected by HIV, it has been suggested that this focus not only perpetuates stigma²¹³, but also means less is known about PrEP knowledge, preferences, and access among other populations of women¹⁶.

The systematic review also highlighted the distinction between PrEP awareness (i.e., knowing that medication called PrEP exists), and PrEP knowledge (e.g., knowing how PrEP works, when to take PrEP, and who can take PrEP). Low PrEP awareness and knowledge have been identified as barriers to accessing PrEP for women in the UK^{16,200,202}, but further research is needed with cisgender women more

generally, and even less is known about women's preferences for PrEP provision and modality.

As discussed in Chapter 3, there are known inequities in PrEP provision among women, and the review by Whelan et. al.¹⁶, identifies barriers to the use of PrEP for women, with a focus on health equity. However, it is worth exploring whether and how factors influencing health equity influence PrEP awareness. As discussed in Chapter 5, individuals who could benefit from taking PrEP must first be aware that it exists before they can seek it out²⁵⁸, and by identifying drivers of disparities in awareness, it may be possible to design bespoke information campaigns or other interventions to address these disparities.

In Chapter 2, I discussed that the availability of PrEP has differed between the devolved nations of the UK, and to my knowledge, there has been little research focused on women in England since PrEP was made routinely available on the NHS in 2020.

6.3 Research aims and objectives

The qualitative interviews were carried out to address the second, fourth, and fifth thesis objectives described in Chapter 4 (i.e., qualitatively explore levels of PrEP awareness, knowledge, and interest, and preferences for PrEP provision among a sample of women in England; identify potential barriers and enablers to women's PrEP engagement (i.e., PrEP awareness, interest, knowledge, and use); and employ an equity lens to consider the implications of these findings for public health policy and practice). Specifically, this research aims to explore PrEP awareness and knowledge and perceptions of current PrEP provision in England among a diverse sample of women. The specific objectives are to:

1. Improve our understanding of women's awareness and knowledge of PrEP
2. Explore women's perceptions of and preferences for PrEP provision
3. Apply an equity lens to identify barriers and enablers to PrEP awareness, interest, knowledge and access for women in England

6.4 Method

I conducted semi-structured interviews with a sample of women living in England. The data were analysed using thematic analysis to develop themes that addressed the study aims.

6.4.1 Study design

Although there are many methods for collecting qualitative data, two of the most common are interviews and focus groups⁴²⁹. Typically, interviews are one-on-one “conversations with a purpose”^{430(p136)}, wherein the interviewer leads a participant in a conversation that focuses on questions related to a research study^{431(p55)}. In these conversations, the interviewer leads the participant in a conversation about their personal feelings, experiences, and perspectives, in relation to the research study aims. In contrast, focus groups are discussions that occur in a group setting among a number of participants, with the discussion guided by a moderator^{430(pp113-114)}. Data from focus groups are socially constructed within the interactions of the group and participants may refine their views in the discussions^{430(p114)}.

Although both interviews and focus groups are appropriate methods for generating qualitative data, in this study I decided to use interviews. There were several reasons behind this decision; firstly, in this study, participants would be asked to discuss topics of a sensitive nature, including their sexual behaviour and experiences with HIV prevention. Although focus groups are an appropriate methodology for researching sensitive subjects, including sexual health⁴³², as group dynamics can at times facilitate the discussion of sensitive topics, they may not be suitable for individuals and populations for whom discretion is important⁴³³. The eligibility criteria meant that the study was open to women of any HIV status^{xvii}, and I wanted the participants to be able to discuss their experiences without having to share their HIV status with other participants if they did not want to. Secondly, in focus groups, the data is formed by the group dynamic, and this format does not always allow for the opportunity to follow up on participant’s views or experiences. And finally, focus

^{xvii} NB: the decision to include women of any HIV status is discussed further in section 6.4.4.1

groups can give a more general, or breadth of understanding of the area under study, whereas interviews may allow for more in-depth investigations⁴³⁴.

6.4.1.1 Semi-structured interviews

Qualitative interviews are typically less structured than those used in quantitative studies, and fall into two main categories: unstructured/informal interviews and semi-structured interviews^{430(p110)}. In-depth interviews are loosely structured and consist of open-ended questions, used primarily in ethnography and case studies.

Conversely, semi-structured interviews are often used in healthcare research and include a mix of more and less structured questions⁴³⁵. A list of pre-prepared questions (known as the topic guide) is used to direct the conversation, however, the structure is not followed rigidly and allows for flexibility in the interview. In this study, I chose to use semi-structured interviews to accommodate the range of topics that I needed to cover to address the research aims. The loose structure of the interviews allowed me to ask participants both open-ended questions (e.g., Can you tell me what you know about HIV prevention?) and more specific questions (e.g., Would you ever be interested in using PrEP?), and provided the flexibility needed to explore the topics that were important to address the study aims.

6.4.1.2 Topic guide development

The topic guide was developed to address the research questions listed above and was informed by a literature review (Chapters 2 and 3), the initial results from the systematic review (Chapter 5), and feedback from PPI advisors (discussed below). In developing the topic guide, I also received input from my supervisory panel, which included clinical staff from primary care and sexual health, researchers in sexual and reproductive health, and experienced qualitative researchers.

As mentioned above, the study was open to women of all HIV statuses. Therefore, one topic guide was developed for people who were not living with HIV or reported their HIV status as “unknown” (Appendix 5), and one was developed for people living with HIV (Appendix 6). Both topic guides were designed to address the study aims, and only differed in the questions participants were asked about their HIV and HIV prevention knowledge and experiences.

6.4.1.3 Topic guide piloting and refinement

The topic guide went through several iterations and was further refined following a series of pilot interviews. A total of four pilot interviews were conducted with friends and colleagues. After each pilot interview, the topic guides were updated to reflect any feedback from the interviewees, for example updating and removing jargon and changing the wording of questions that were difficult to understand. The pilot interviews were also an opportunity for me to practice my interview skills and techniques and to familiarise myself further with the topic guide questions.

The topic guide continued to be re’line’ during the recruitment period. After conducting the first three interviews, I found that HIV knowledge varied among the participants, and more information on HIV (e.g., transmission routes, HIV prevention methods) was required before discussing PrEP. Therefore, in subsequent interviews, I added in the addition of a “5 HIV facts” poster⁴³⁶ (Appendix 7, Figure 11), a resource developed by the National AIDS Trust. During interviews, I would ask participants to read through the leaflet, before discussing its contents. For example, I would ask participants about information they knew prior to the study, versus what information was new. At this point I gave participants the opportunity to ask any questions about the information that we had just discussed.

6.4.1.4 Topic guide structure

The first section of the topic guide involved questions about the participant’s knowledge and experiences with HIV and HIV prevention. The next section focused on PrEP, including participant’s knowledge of PrEP, whether they would consider taking PrEP, and their (hypothetical or actual) preferences for accessing PrEP. The final section of the interview focused on factors that can influence health equity (i.e., PROGRESS-Plus factors), and explored participant’s experiences and opinions on how PROGRESS-Plus categories could impact access to sexual healthcare in general, and PrEP access specifically.

I anticipated that PrEP knowledge would vary greatly between participants, therefore, I developed an information leaflet to aid in the discussions around PrEP. The leaflet was adapted from a similar discussion aid that was used in a study exploring barriers and facilitators to PrEP among black African and black Caribbean

women in the UK²⁰⁰. The leaflet was reviewed by a sexual health clinician for accuracy, and by the PPI advisors for readability and accessibility of the information provided (Appendix 8, Figure 12).

To support the discussions of how factors that influence health equity could impact access to PrEP, participants were presented with a visual representation of PROGRESS-Plus factors (Appendix 9, Figure 13).

For all discussion aids, participants were asked to review them on their own, before discussing the contents with the interviewer. Participants were given the opportunity to ask questions or for clarification before resuming the topic guide questions.

6.4.2 Patient and public involvement

Input from PPI advisors was incredibly valuable for this study. For this study, the PPI panel consisted of two cisgender women; one advisor is a woman living with HIV with experience in HIV and PrEP charity work and activism, particularly for women, and the second advisor is experienced with supporting diversity and inclusion research. PPI advisors reviewed and provided feedback on all study materials, including the topic guide, demographics questionnaire, discussion aids, and recruitment advertisements. All documents were reviewed to ensure that the layouts made sense and that the language and content were acceptable and accessible. The representatives were particularly helpful in ensuring that person-first language was used in all the study materials, removing jargon and technical language where possible, and sense-checking the interview materials. Representatives also provided additional suggestions for support organisations to be included in the participant information leaflet (PIL).

6.4.3 Ethical considerations and research governance

There were several ethical considerations, due to the sensitive topics discussed during the interviews.

6.4.3.1 Privacy and data security

Participants were asked to discuss topics that were sensitive in nature, including their sexual behaviour and experiences with HIV prevention. The confidentiality and

anonymity of participants were therefore not only important as an ethical consideration but necessary to ensure that participants felt comfortable disclosing and discussing this information.

All participant information (including contact details and consent forms) was held on the UCL Data Safe Haven (DSH). The DSH is a service that provides a secure channel to upload, handle, and analyse identifiable data, ensuring only those with assigned access can view and manage the data. After consenting to participate in the study, participants were assigned a unique study ID that contained no identifiable information. The ID key was kept in a separate file on the DSH. All interview recordings, transcripts, and demographic information were stored using the unique study ID only. Participants sent copies of their consent forms electronically, and these were stored on the DSH.

All interviews were held over the telephone and recorded to an encrypted voice recorder, or online via Microsoft Teams and recorded using the inbuilt Microsoft Teams feature. During the interviews, participants gave verbal consent to being recorded with or without video, depending on their preference. Immediately following the interview, recordings were transferred to the DSH, checked for completeness, and deleted from the original device. Interviews were transcribed by a secure, confidential third-party transcription service, and recordings and transcripts were sent via the DSH file transfer portal. Transcripts were anonymised to remove any identifiable information discussed during the interviews (e.g., names, locations). Anonymised transcripts were transferred to the password-protected UCL secure network for analysis.

6.4.3.2 Safeguarding of participants

Safeguarding of participants was a priority during and after the interviews. Due to the sensitive nature of some of the topics that were discussed, it was possible that participants could find parts of the discussions upsetting or uncomfortable. A distress protocol (Appendix 10) was developed to ensure that a standard protocol was established should a participant show signs of stress or discomfort during the interviews. Participants were assured that they could pause or leave the interview at any time, or skip/decline to answer any questions. The PIL (Appendix 11) contained contact information for a number of sexual health, domestic violence, LGBTQ+, and

mental health charities and organisations. During the interviews, I checked in with participants at various points to ensure that they were happy to proceed. At the end of each interview, I reminded participants of the information on the PIL and offered to follow up with any questions or concerns they had.

6.4.3.3 Safeguarding of the researcher

A separate mobile phone was used for the study, to ensure that participants did not have my personal number. My supervisors were also available to debrief if I found any of the interviews distressing or difficult or to discuss any upsetting topics that might arise during the interviews.

6.4.3.4 Ethics approval and data governance

This study received ethical approval from the UCL Research Ethics Committee (Project ID: 20443/001). This research was also found to be compliant with the General Data Protection Regulation 2018 and received approval from the UCL Data Protection Officer. The Data Protection Registration number is Z6364106/2021/06/110.

6.4.4 Participants

6.4.4.1 Eligibility criteria

The target population was women, age 18 or over, who lived in England. Participation was open to anyone who identified as a woman, and this included anyone who identifies as female, including cis and transgender women, and those identifying within the gender-diverse umbrella who felt the study was applicable to them.

There was no upper age limit or requirements of previous sexual experience to take part in the study, and women of all HIV statuses were eligible to participate. As this study focused on women in general, rather than women who may be considered at elevated risk of HIV, I felt it was necessary to collect a diverse array of experiences and opinions. Although only people who are HIV-negative can take PrEP, I had several reasons for including women living with HIV in the eligibility criteria. Firstly, even though women living with HIV are not candidates for PrEP use, it is still

important to explore awareness and knowledge of PrEP among this population, as it may still be relevant to them, e.g., if they are currently in, or enter into a serodifferent relationship. Secondly, at one time, women living with HIV had HIV prevention needs that were not being met. Therefore, their experiences and preferences for improving awareness and access to HIV prevention services may help us identify barriers to engagement with HIV prevention methods such as PrEP and to design HIV prevention information and services that are more acceptable and accessible to women. This is particularly relevant to thesis objective four, described above in section 6.3. Lastly, PPI advisors felt that the inclusion of women living with HIV was important to addressing the study objectives and ensuring that the study results were relevant across a diverse range of women. For these reasons, I felt it was important for women living with HIV to have the opportunity to take part and share their experiences and opinions.

Women were ineligible to take part if they could not adequately understand verbal or written information in English, were unable to provide informed consent, or had special communication needs that could not be accommodated in online or telephone interviews.

6.4.4.2 Sampling strategy

Although the eligibility criteria for participating in the study were quite broad, I was keen to ensure that the interviews captured a diverse range of experiences and opinions. I was not only interested in the individual experiences of the women who took part, but also in identifying and developing any shared patterns that were identified across a heterogeneous sample. In this way, it may be possible to make general recommendations to improve PrEP access for women and identify subpopulations that might be experiencing specific inequity or disparities in regard to PrEP.

To achieve this, I used a purposeful sample design known as “maximum variation sampling”, or heterogeneity sampling⁴³⁷. In maximum variation sampling, key dimensions of variations (e.g., occupations, ages, experiences etc) are first identified, and then the sample is selected by finding cases that vary from each other as much as possible. This sampling design can allow the researcher construct a

holistic understanding of the research questions by identifying key features or core experiences that are shared among different contexts⁴³⁷.

I identified three key dimensions in which I wanted to achieve heterogeneity within the sample. The first dimension was geographic location, chosen because access to both general healthcare and sexual healthcare, varies greatly across different regions and locations in England. This was seen as particularly important, as currently, and at the time of the interviews, PrEP was only available from sexual health services, and access was likely to be very different depending on where participants lived. The second characteristic was ethnicity. The existing literature available on women and PrEP in England or the UK has focused on black African and black Caribbean women, and little research has included women of other ethnicities. The final characteristic was age. Women's sexual and reproductive healthcare needs and priorities may change and fluctuate over time. Women of different ages may have also had differences in their sexual and reproductive health education and different attitudes towards their sexual health, and I wanted to capture how that did or did not influence PrEP awareness and knowledge. To facilitate the sampling strategy, participants were asked to complete demographic questionnaires after enquiring about the project.

It is important to note that the sample was not meant to be representative, i.e., the sample was not meant to reflect the characteristics of the entire population of women, as qualitative research is framed in terms of rigorous process, and transferability (i.e., contextualised in a way that allows the reader to make judgements about whether the analysis can be transferred to another specific context or setting), rather than representativeness or generalisability²²².

6.4.4.3 Demographic questionnaire

The demographic questionnaire was designed to capture the demographic characteristics of the participants and select the interview sample (Appendix 12). The questionnaire collected information on a number of categories, including participants' age, ethnicity, gender identity, sexual identity, region of England, whether they lived in an urban or rural environment, and religious identity.

6.4.5 Recruitment

Participants were recruited online from three different sources: 1. Paid for advertisements on Facebook (now part of the Meta advertising platform), 2. A paid-for advertisement on the study recruitment website Call for Participants^{xviii}, and 3) dissemination via the study X (formerly Twitter) page (Women and HIV prevention research projects, www.twitter.com/whivpr). Examples of the study advertisements are included in Appendix 13, Figure 14. Interested parties could follow a link from the advertisements to the study landing page, which had more information on the study aims, eligibility criteria, and a form to leave contact details. My email address was also provided on the study landing page and the Call for Participants and Twitter advertisements so that I could be contacted directly to answer questions or provide more information. I then reached out to interested parties to provide more information on the study and to send them a copy of the PIL, consent form (Appendix 14), and demographic survey. Potential participants were asked to read through the PIL, sign and return the consent form, fill in the demographics survey, and choose an interview date from a list of available options.

Participants were offered a £20 Life:Style voucher as a gesture of thanks for their time and participation. Recruitment continued until “information power” was reached, i.e. the number of interviews conducted contained sufficient information to address the research questions. Information power is impacted by the study aim (broad study aims may require more participants and vice versa), quality of the dialogue, and the analysis strategy⁴³⁸. While aiming to achieve sufficient information power, recruitment was also restricted by pragmatic constraints, for example, data collection and analysis needed to be completed within the personnel and time constraints of a PhD timeline.

Two distinct recruitment drives took place. The first ten participants were recruited and interviewed between November 2021 – April 2022. In January 2022 I took a six-week interruption of study, and then embarked on a three-month internship at the Academy of Medical Sciences. One participant was recruited and interviewed during the internship. The second recruitment drive took place after the internship, and the

^{xviii} <https://www.callforparticipants.com/>

remaining eight participants were recruited and interviewed between July – September 2022.

6.4.5.1 Difficulties encountered in recruitment

During the second recruitment drive (July – September 2022), there was a dramatic increase in people signing up to take part via the study landing page. Often a large number of participants would sign up in quick succession^{xix}. To minimise the administrative burden of contacting everyone who signed up, I added a question asking potential participants why they would like to take part and did not contact anyone who did not provide an answer or provided an answer that did not make sense. I further excluded anyone who filled in the demographic questionnaire with answers that did not make sense, or that did not meet the eligibility criteria. Prior to starting each interview, I asked each participant to confirm a number of their answers from the demographic questionnaire. When a participant's answer did not match the demographics collected by the questionnaire, the interview was not conducted. This occurred in four scheduled interviews.

6.4.6 Data collection

All participants were offered the option of being interviewed either via telephone or Microsoft Teams. In online interviews, I used the screen share function of Microsoft Teams to go through the interview materials (e.g., the PrEP leaflet). In telephone interviews, the documents were sent via email before the interview. In one instance, a participant did not have access to a computer, and the interview materials were sent via post.

6.4.6.1 Recording and transcription

Online interviews were recorded using the “Record” function in Microsoft Teams. Both audio and visual were recorded, however, participants who did not want to appear on video could take part with their camera off. These recordings were automatically saved to my UCL OneDrive. Interviews that took place by phone were recorded using an encrypted voice recorder with an earpiece microphone.

^{xix} Submissions to the form on the study landing page were time stamped

Recordings were uploaded to the UCL DSH immediately after each interview and were deleted from OneDrive or the voice recorder once the uploaded recordings were checked. Interviews were transcribed by a UCL registered, secure, confidential third-party transcription service. Once received, transcripts were compared to the recordings to check for accuracy.

6.4.6.2 Field notes

I wrote field notes before and after each interview. These notes included: my feelings before and after the interviews, observations on the participant (e.g., if I thought they felt comfortable during the interview), thoughts on responses that were memorable or very similar/different to other participants, thoughts on how subsequent interviews could be improved, and my general thoughts on how the interview went. The field notes were referred to in order to provide additional context or information throughout the analysis.

6.4.7 Analysis

The data was analysed using a reflexive, inductive, thematic analysis approach^{222,439}. A thematic analysis approach consists of six stages: dataset familiarisation, generating initial codes from the data, initial theme generation, theme development and review, theme refining, defining, and naming, and writing up. Although these steps are presented linearly, thematic analysis is both iterative and recursive (moving back and forth and revisiting stages of the analysis), and stages can occur simultaneously (e.g., initial codes may be developed during the familiarisation stage)^{222(pp35-37)}.

In an inductive thematic analysis (sometimes referred to as “bottom up” analysis), the data coding and theme development are grounded in the data themselves, i.e. the analysis does not start from the position of a pre-existing explanatory framework or theory. This is in contrast with a deductive approach or “top down” analysis where coding and theme development are guided by pre-existing frameworks or theories. I chose to take an inductive approach, as the research was exploratory in nature. As discussed earlier, there is a paucity of research on women’s awareness and knowledge of PrEP in England, and I wanted the flexibility to develop themes without first having to structure them around preconceived notions or theories. However, I do

acknowledge that it is not possible to remove the knowledge of HIV and PrEP that I already possessed and that this knowledge could, in turn, influence the analysis and/or introduce bias. To mitigate this, I engaged in reflexivity. Reflexivity refers to the practice wherein the researcher critically interrogates their methods, assumptions, and motives, and how these impact and influence the research they undertake⁴⁴⁰. I discuss my reflexivity further below.

Data collection and analysis happened concurrently; i.e., transcripts were reviewed and preliminary analysis was undertaken while I was actively recruiting and interviewing participants. At all stages, the analysis was discussed with members of my supervisory team.

The below section, describing the analysis process, is adapted from “Introducing the six stages of reflexive thematic analysis” from *Thematic analysis: a practical guide*^{222(pp35-37)}.

6.4.7.1 Stage 1: Familiarisation with the dataset

Familiarisation involves immersion, reflection, and engagement with the dataset. It is an “active process” where the researcher immerses themselves in the data. To familiarise myself with the data, I first listened to the audio recordings before sending them off for transcription. I then listened to them again while checking over the received transcripts for accuracy. Next, I read and re-read the checked transcripts, at the same time revisiting field notes to consider any observations or candidate codes that had occurred to me at the time of the interview. During the familiarisation stage, I annotated the transcripts with my initial thoughts or any connections or contradictions that I identified from other transcripts.

6.4.7.2 Stage 2: Generating initial codes

The coding process involves working through the dataset systematically to identify pieces of data that are interesting, relevant, or meaningful in relation to the research questions. During the coding phase, I assigned short words or phrases to key sections of the data that were relevant to the research question to generate a list of “candidate codes”, i.e., an initial list of codes to be refined and collapsed. For the first pass, transcripts were coded sequentially. For re-iterations of coding, transcripts

were coded in a semi-random order. This allowed me to gain additional perspective and helped to better identify patterns or contradictions between interviews that were not conducted close together. A mixture of semantic (i.e., where the codes captured explicitly expressed meaning) and latent (e.g., where the codes captured more “implicit” meaning around concepts) coding was used.

6.4.7.3 Stage 3: Generating initial themes

Initial themes are generated by identifying patterns of shared meaning across the dataset. In this stage, I started by reviewing the initial code list and compiled “nodes”, or clusters of codes that had a shared meaning or concept. Nodes that were deemed relevant to the study aims were further developed into candidate themes, i.e., an initial list of themes that was to be reviewed and refined. In some cases, where a particular candidate theme was only present in one or two transcripts but was seen as being particularly important to women’s perceptions or experiences with HIV prevention, the candidate theme was retained. Concept maps were used as visual aids to collate codes and develop candidate themes. An example of a concept map that was used during the analysis process is included in Appendix 15, Figure 16. Data clinics were held with one of my supervisors to discuss my initial thoughts around the candidate themes that had been generated.

6.4.7.4 Stage 4: Developing and reviewing themes

Developing and reviewing themes involves revisiting the full dataset to see whether the candidate themes fit the data and to review the viability of the analysis overall. I revisited the full dataset to check that candidate themes made sense in relation to the coded extracts, the data set as a whole, and the research questions. Candidate themes that were not supported by the data were collapsed or merged into other themes where possible. In some cases, candidate themes were abandoned if they were not relevant to the research questions. At this stage, relationships between the themes, and how they related to the literature review (Chapters 2 and 3) and the wider context of the research were considered. Some codes are developed into “subthemes” which are concepts nested within an overarching theme.

6.4.7.5 Stage 5: Refining, defining and naming themes

Refining, defining, and naming themes involves writing a brief analytical description for each theme to ensure that it was built around an appropriate, and research-significant, core concept. Once the themes and subthemes were developed, I wrote a brief synopsis to define the meaning of each theme. This was done to interrogate how they related to the research questions and ensure that there was so significant overlap between themes. Then, an appropriate and descriptive name was given to each theme.

6.4.7.6 Stage 6: Writing up

Writing the research report is an integral part of the analysis process by helping to further collate the themes, situate them within the context of the data and the wider context of the project, and directly address the research question and objectives. The descriptions of the themes that were generated in step five became the basis for writing up the analysis. Below, I present a narrative to illustrate how each theme was relevant to the research question. Illustrative quotes from the data were chosen to provide the context and evidence to support the arguments made from the themes. The age, ethnicity, and location (i.e., region of England) of the participants was including with each quote, in the following format: (age, ethnicity, region). For participants who are living with HIV, their HIV status was included with each quote (age, ethnicity, region, living with HIV) to compare and contrast their data with other participants in the sample.

6.4.8 Reflexivity

As discussed above, undertaking reflexive thematic analysis involves interrogating and questioning one's position, choices, values, and practices within the research process, and identifying how these aspects can influence the generation of knowledge. In this way, the results of the analysis are not value-neutral or objective, rather this research and my engagement with the data has been shaped by my positioning. This is not to say that the analysis was not rigorous or backed in evidence from both the data, and the literature, but acknowledges that the research was shaped by my perceptions and positionality; i.e., my role as a researcher is not

removed from my identities, experiences, values, and biases. In this section, I discuss how these aspects may have influenced this study, from my approach to conducting the research, through to my interpretation of the findings, and how I was perceived by the study participants.

6.4.8.1 My position as a researcher

I have experience in health and sexual health research through my MSc and PhD studies, and through past my employment positions. For my MSc in Infection and Immunity, my dissertation focused on the prevalence of using the internet to find sexual partners, and prior to embarking on my PhD I was an HIV/STI scientist at Public Health England. This experience, alongside training as an outreach and testing volunteer with a local HIV charity, has made me comfortable discussing sensitive topics such as sex, sexual behaviour, HIV risk factors, and HIV prevention.

Despite my experience working as a researcher, at the beginning of each interview, I introduced myself as a PhD student studying at UCL. I chose to present myself as a PhD student as I felt that it was a more recognisable position and easier to explain than “researcher”. I also felt that the role of a “PhD student” may be perceived as having less social status than “researcher”, which is a professional role⁴⁴¹, and so presenting myself as a student could help minimise any perception of power differentials, while still being a clearly defined role with the legitimacy of a university affiliation. In this way, I hoped that participant’s perception of me as a “PhD student” helped put them at ease and made them feel able to express themselves naturally during interviews. I also endeavoured to mirror participant’s language during the conversations^{xx} and minimise the use of formal language when introducing or discussing concepts that were new to participants. However, I acknowledge that some power dynamics may still have existed through the hierarchy of the interviewer-interviewee relationship.

In this project, I was interested in women’s knowledge and awareness of HIV prevention and PrEP, and so I would ask the participants to tell me what they knew about these subjects. During interviews, some respondents would get flustered or

^{xx} Except in the case that stigmatising language was used. I aimed to use person-first language during all of the conversations.

apologise for not knowing “more” information. It is possible that I was perceived as knowing more about this subject, and participants were worried about not having the “right” or “correct” information. To combat this, I would reiterate to participants that there were no “right” answers, I was just interested in what they knew, and that they were not being tested.

6.4.8.2 My position as a woman

As a woman living in England, I share some of the experiences of my interview participants, particularly around accessing NHS-provided healthcare services generally, and sexual and reproductive healthcare more specifically. It is possible that my position as a woman made participants more at ease, or more willing to discuss their sexual and reproductive healthcare experiences. As was the case for the study participants, I also hold multiple identities and social positions as a woman. I did not grow up in England, and so my experiences of using and navigating the healthcare system may be different from people who were born and raised in England. I did not discuss my identities, social positions or characteristics with the participants, but some of these may have been apparent; e.g., my status as a graduate student indicated my education level, and participants may have been able to tell from my accent that I did not grow up in England, and during interviews where webcams were used, that I am of mixed ethnicity.

In their 2009 paper discussing group membership in qualitative research, Dwyer and Buckle state that being part of a group (in this study, identifying as a woman), does not “denote complete sameness within that group”, just as not being part of a group “does not denote complete difference”⁴⁴². There were commonalities and differences between myself and each of the participants, some of which may have been apparent, and others which may not. Although it is not possible to know how I was perceived during the interviews, many of the participants expressed that they enjoyed the experience of the interviews and felt able to express their thoughts and opinions easily.

6.4.8.3 The position of my values regarding health access, health promotion, and health literacy

My interest in this project was not purely academic—I firmly believe that every person deserves access to the knowledge, tools, and services that will help them achieve a state of health and wellbeing. My interest in sexual health and HIV prevention also stems from a desire to remove the barriers of stigma and taboo that persist for these subjects.

Although the aim of this project was to address the research questions outlined above, it also presented an opportunity to discuss HIV prevention, and provide additional information when requested. If, during the discussion, a participant brought up an incorrect piece of information about sexual health or HIV/HIV prevention, I would discuss this matter further, and give the correct information. The 5 HIV facts leaflet used as a discussion aid was useful in this way, as I could refer back to the information that was discussed earlier. I would not interrupt participants, and in some cases (where appropriate) I waited until the end of the interview to provide additional information so as not to break up the flow of conversation.

Although I believe that the analyses that I present are supported by the data and the wider literature, I am aware that they were influenced by the values and beliefs that I hold, and my desire to dismantle HIV-related stigma. In general, the interviews were led by me, and the participants did not ask many questions about my values or motivations, apart from one participant who asked if my research was sponsored by the drug company that sold PrEP.

6.5 Results

6.5.1 Sample Description

A total of 18 participants were recruited and interviewed. The data collected from the 18 interviews was felt to be sufficient to address the project's research question (i.e., information power had been reached). This section provides a description of the sample demographics.

6.5.2 Demographics

Participants' ages ranged from 23 – 61, with a median age of 29.5 (Table 5).

Although the study was advertised as open to anyone identifying as a woman (including both cis gender and transgender women), female, or gender diverse and assigned female at birth, only cisgender women took part. Most participants identified as heterosexual or straight (n=15), had some level of university education (n=14), were married or in a long-term relationship (n=11), and were in part-time or full-time employment (n=10). Nine of the 18 participants described their ethnicity as “white”, and eight resided in London. Sixteen participants reported their HIV status as negative or unknown, and the remaining two participants were living with HIV.

Table 5: Demographics characteristics of study participants (N=18)

Demographic characteristic	n	%
Age		
18 – 25	7	38.9
26 – 35	3	16.7
36 – 45	5	27.8
46 – 55+	3	11.1
Gender identity		
Cisgender	18	100.0
Sexual identity		
Heterosexual/straight	15	83.3
Bisexual	3	16.7
Ethnicity		
Asian*	4	22.2
Black**	4	22.2
Mixed	1	5.6
White	9	50.0
Education level		
Degree level or higher	14	77.8
Less than degree level	4	22.2
Location		
London	8	44.4
West Midlands	2	11.1
Yorkshire and the Humber	1	5.6
South West	3	16.7
South East	1	5.6
North West	1	5.6
East of England	2	11.1
Rurality		
Urban	16	88.9
Rural	2	11.1
HIV status		
Negative/Unsure/Unknown	16	88.9
Positive	2	11.1
Employment status		
Full time or part time work	10	55.6
Student	5	27.8
Retired	1	5.6
Carer	1	5.6
Not in employment, education, or training	1	5.6
Relationship status		
Single	11	61.1
Married/in a committed relationship	7	38.9

*Includes participants who identify as South Asian and East Asian

**Includes participants who identify as black African, black Caribbean, and black British

6.5.3 Themes

Inductive analysis led to the development of three overarching themes: information gaps in HIV, HIV prevention and PrEP; information flow; and meeting people where they are. Themes and subthemes are summarised in Figure 5 and discussed in detail below. A full table of themes, subthemes, and supporting quotes is included in Appendix 16, Table 20.

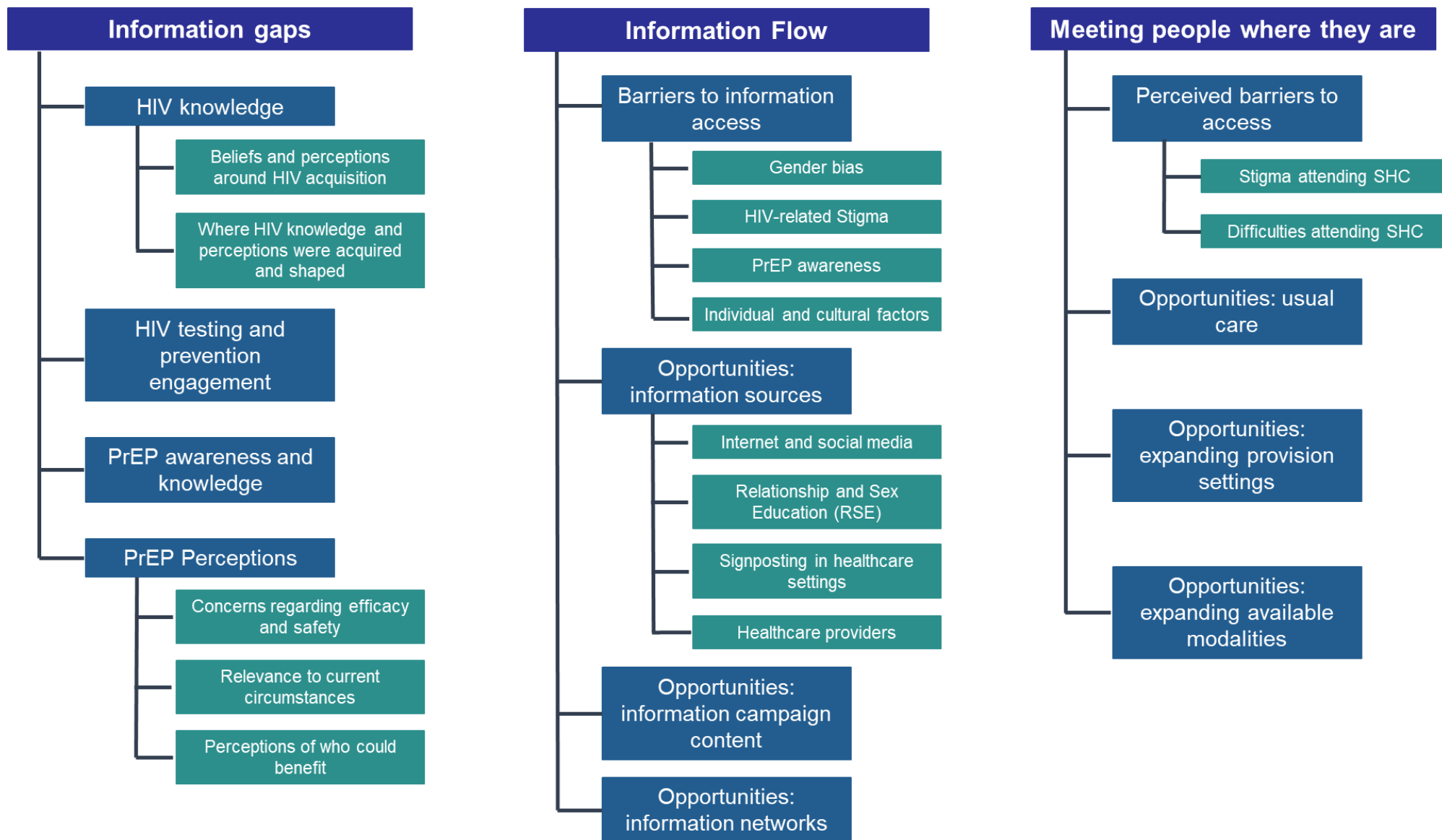


Figure 5: Thematic Map of women's awareness and perceptions of PrEP and PrEP provision

6.5.3.1 Theme 1: Information gaps: HIV, HIV prevention, and PrEP

During the interviews, it became apparent that it was necessary to begin with a more general conversation about HIV before introducing PrEP. Information gaps around HIV could make it difficult for participants to conceptualise what PrEP is, who could take it, and why they might want to take it. This indicated that improving HIV knowledge more generally was important for improving PrEP knowledge specifically. This also meant that misinformation, HIV-related stigma, or biases and preconceptions concerning HIV and HIV risk influenced how PrEP awareness and knowledge was (or was not) obtained. This theme describes the variations in HIV and PrEP awareness and knowledge within this sample of women.

6.5.3.1.1 HIV Knowledge

Participants were generally aware that HIV is a virus that affects the immune system and could describe modes of HIV acquisition, however, HIV knowledge varied greatly across the sample. Most participants were aware that condoms could be used to prevent HIV, and that HIV tests were available, but not all participants knew where or how an HIV test could be obtained, and some were unsure whether there was treatment available for people living with HIV.

In some cases, biomedical prevention tools, such as PEP and PrEP were new concepts, and most participants were surprised to learn that people living with HIV who are on treatment and have an undetectable viral load cannot transmit HIV to their sexual partners (Undetectable = Untransmittable, U = U)^{xxi}.

P09 (24, white, South West): Yeah. So I didn't know that if you're on effective treatment then you can't pass it on. I thought that you would still be able to pass it on, so that surprised me.

The two participants who were living with HIV were diagnosed prior to the announcement and subsequent campaigns for U = U (i.e., diagnosed before 2016), but both participants have since been made aware of U = U.

^{xxi} The abbreviation U = U is often used in HIV awareness and prevention campaigns in the United Kingdom

*P07 (23, black British, Yorkshire and the Humber, living with HIV):
OK yeah after I was diagnosed sorry. I learned something new, that I
still can be sexually active with an HIV negative person and still not
infect them. That was new to me.*

Some participants were aware of terms or phrases related to HIV, but conflated or confused concepts, or were unable to provide any details. For example, the distinction between HIV and AIDS was not always clear for participants, and two participants confused the human papillomavirus (HPV) with HIV. A few participants also mistook cervical screenings for HIV tests. A number of participants were familiar with the concept of using antiretroviral medication to treat and prevent HIV but were not able to clarify the difference between ARVs for treatment, PrEP, and PEP.

6.5.3.1.1 Beliefs and perceptions around HIV acquisition

In general, participants understood that anyone could acquire HIV, but felt that there were certain behaviours or communities that were associated with a higher risk of acquisition. GBMSM were often the first population that participants mentioned when discussing who they thought was at risk of acquiring HIV. Some participants also described HIV as often affecting people living on the African continent.

*P08 (29, Chinese, West Midlands): And also I think it got stigmatised
quite a bit over the past few decades because of how people feel
like it's a disease that is really popular in some kind of people from a
sort of sexual orientation. Like it got portrayed in media that it is very
popular around homosexual people which made it a burden to them.
Also it was a disease that was very popular in those of the African
countries, so it got a very bad stigmatisation over there.*

On several occasions, participants would describe characteristics that they felt were associated with a risk of HIV acquisition, then reflect on their initial responses, often acknowledging or interrogating their own thoughts or biases.

*P013 (52, white, East of England): Well, I suppose it could affect
anybody, but I suppose there's groups of people that may be more –
what's the word? Not susceptible. I don't know. I suppose it is a very
stereotyped disease, there's a very stereotyped view, gay or*

bisexual men, men who have sex with men, drug users, whatever. But I know it's more complicated than that, so yeah. I suppose it's just the stereotypes spring to mind, but it could be – in theory, it could be anybody, really.

P01 (41, white, London): And you know, I'm embarrassed to say, I still have the stereotype that it is maybe, you know, promiscuous, gay men that are still the main target for it, even though rationally I know that it's not anymore.

Participants often acknowledged that their perceptions around HIV risk were often stereotyped or “outdated”, but that nevertheless these associations could prevent engagement with HIV prevention, even when these perceptions were acknowledged to be incorrect.

P04 (37, black British, London): I think for a long time, I think people always associate AIDS and HIV with, you know, homosexuality which that was the old school way of thinking. But I still think people still – they know it's not that anymore, but they're not really, you know, like someone goes now, they go in sexual health, they would go sort of, you know, so they're not doing the prick or taking a blood swab.

6.5.3.1.1.2 Where HIV knowledge and perceptions were acquired and shaped

Where, when, and how participants learned about HIV influenced, and in some cases reinforced, their perceptions and biases around HIV and risk acquisition. Participants learned about HIV from a variety of sources, including the media, relationships and sex education (RSE) in school, and through conversations with friends and family members. Participants who grew up in the UK during the 1980s recalled public awareness campaigns, in particular the “AIDS: Don't of Ignorance” public health campaign that began in 1986⁴⁴³. Participants recalled feeling a sense of “fear” and “panic” when these adverts originally aired. One participant described how the narrative in the media shifted from one where HIV could affect anyone, to one where HIV was only relevant to GBMSM.

P15 (61, white, East of England): Because of my age, I can remember the very first public awareness information things that were put out on the television, so there was a really strong programme of information and warnings that were put on the television, and they were quite frightening, really. They were very powerful. And at that time, it kind of gave you the idea that every second person on your street was going to have it, and you would almost certainly know somebody who died of it, and there was, at that point, there was no antivirals, as such, developed, it was a death sentence at that point.

So that had made me think about it then, and had been very aware of it, but then that kind of faded down over the years, and then it became known as the gay disease, and you kind of thought, “Oh, OK, that’s not me. I’m straight.”

Participants recalled the impact that these campaigns had in creating a sense of fear and panic around HIV, which in turn created and perpetuated HIV-related stigma, particularly for populations who were most affected by HIV. In some cases, this stigma prevented participants from recognising their own risk.

P14 (50, white, London): I think I took some stupid risks when I was young, and yeah, I think – and I think that there was, particularly as this was in the ‘80s and there was very much an attitude that HIV kind of was only happening to gay men, so like it’s not going to happen to a nice, young, straight girl like you, kind of thing, which is obviously not true.

Several participants referred to how HIV “used to be”, discussing the sense of fear, stigmatisation of HIV and people living with HIV, and the initial lack of treatment options. However, participants who encountered HIV related media more recently described how these portrayals had improved their understanding and knowledge of HIV. For example, one participant described learning about U=U from Ru Pauls’ Drag Race, a popular reality show on which several contestants have described their experiences as people living with HIV. Other participants described how social media was becoming a more common way to encounter HIV information.

P09 (24, white, South West): And also, I don't know – like, with access to social media and to Instagram now, you have access to so many people talking about so many different topics, and I feel like you just pick up just through social media, you just pick up different viewpoints and stuff.

6.5.3.1.2 HIV testing and prevention engagement

Among the sixteen participants who reported their HIV status as negative or unknown, four could not recall ever having had an HIV test. Three participants described experiences attending SHS or receiving postal self-testing/self-sampling tests during periods when they were sexually active with new partners. Three participants recalled having an HIV test as part of a routine appointment to test for STIs (not at a SHS) or as part of antenatal testing. Four participants were unsure as to whether they had ever had an HIV test but felt they may have as part of another routine appointment. Two participants sought out an HIV test after learning that their partners had engaged in paid sex with sex workers during their relationship, without their prior knowledge or agreement.

Participants discussed their reasons for not testing regularly. These included: low self-perceived risk, being in a monogamous relationship, discussing sexual histories with new potential partners, and using condoms with all sexual partners. One participant explained that she had never tested for HIV because she never felt that she was at risk of acquisition.

P08 (29, Chinese, West Midlands): I was quite, or I'm still quite confident about my health issues and then in terms of sexual health because I have regular partners and, not at the moment, but like previously. So I was quite confident that I would not get HIV in any times, like in different channels in my life so I've never thought that I should get one.

Although low self-perceived risk was a common reason for not testing, several participants discussed how their risk perception during a particular time period could change in hindsight, i.e., only realising or acknowledging behaviour that increased

their risk of HIV acquisition after the fact. In some cases, this happened several years later.

P03 (37, white, London): No. I was probably quite careless should I say from when I started to having sex to maybe mid 20s. It was mainly boyfriends but there was just a period in time when I went to Australia for a year and I just did not care, clearly.

Interviewer: When you say careless, can you tell me a little bit more about that?

P03 (37, white, London): Well I rarely used a condom. That sounds awful, yeah I just kind of risked it and thought I'd deal with after.

____P13 (52, white, East of England): I think, yes, I mean, thinking about it in terms of my sexual behaviour in late teens, 20s, yes. I probably should've been more concerned.

6.5.3.1.3 PrEP Awareness and Knowledge

Ten of the 18 participants were aware of PrEP prior to taking part in the study. However, just as with HIV knowledge, PrEP knowledge (e.g., what PrEP is, who would benefit from using PrEP, how PrEP is accessed), varied across the sample. Two participants (both HIV-negative) had in depth knowledge about PrEP; one participant was a researcher who studied HIV in sub-Saharan Africa; the other had used PrEP for a period of time, prior to taking part in the study. Both of the participants who were living with HIV became aware of PrEP after their diagnosis, although for one participant the distinction between PrEP and PEP was not clear.

Of the remaining six participants with prior PrEP awareness, most had “heard the term PrEP” or were aware that there was medication available to prevent HIV but did not possess any detailed PrEP knowledge.

P14 (50, white, London): So I did hear a bit about the prophylaxis type thing that you could go out and take, because I think I maybe

read a news story or something about a research project which was looking at clubbers in London or something like that

6.5.3.1.4 PrEP Perceptions

Although knowledge of PrEP was low across most of the sample, participants felt that PrEP was a beneficial tool for HIV prevention after learning more about it.

P05 (40, black Caribbean, London): So for me knowing about this HIV thing now, it's like, and knowing it's available and, you know, in a pill format, and it's out there to protect you and it's 90 percent effective, that's very good information to know

Several participants were surprised not only to learn that PrEP existed as a prevention tool, but that they had never heard of it prior to taking part.

P08 (29, Chinese, West Midlands): I was surprised of not knowing it earlier because I feel like it is quite effective and I assume it is very popular because it's been a while in the UK. So I was surprised that I didn't know about it and I was wondering if it is a very well known information for everyone here?

Participants were at times unclear about the “social norms” around PrEP; i.e., their beliefs about what other women knew about PrEP, and the extent to which other women were approving or disapproving of PrEP⁴⁴⁴, and questioned whether their lack of awareness was common among other women.

P09 (24, white, South West): No. Yeah, I don't know if I should have done. I don't know if most people do or not, but no.

Many participants were also surprised to learn that PrEP could be taken by anyone, of any gender or sexuality. In some cases, when participants had heard about PrEP prior to taking part, they assumed it was only something that was for, or could be taken by, GBMSM. In the case of the participant who had previously used PrEP, she initiated PrEP after a discussion with a nurse at a SHS. Prior to that encounter, she did not feel that she was a candidate for PrEP, in part because of her gender.

P010 (30, black African, London): I think for the most part, again, I had seen it for like MSM type drug.

6.5.3.1.4.1 Concerns regarding efficacy, side effects, and safety

Questions concerning the efficacy, side effects, and safety of PrEP were common. One participant felt unable to share her perceptions of PrEP as a prevention option until she had more information.

P02 (25, Asian, London): I'd need to know how effective it is. I mean, people who consume it, like, if it's something like seventy percent protection, I think yeah, people might not...

Although the PrEP information leaflet (Appendix 9), briefly covered these topics, participants wanted specific information in terms of PrEP's efficacy, the common side effects, and how safe it was to take PrEP over a prolonged period.

Despite most participants feeling that PrEP was beneficial, three participants voiced concerns about PrEP use and risk compensation. Risk compensation is a theory which suggests that an individual recognises a level of risk that they are comfortable with, and may adjust their behaviour in response to changes in their perceived level of risk⁴⁴⁵. This means that a person may become less careful when they feel more protected, for example riding less carefully when wearing a bicycle helmet. Concerns were expressed that people using PrEP would take less precautions and engage in sexual behaviours that increased their risk of STIs or unwanted pregnancy. One participant compared it to risk compensation that she observed during the COVID-19 pandemic.

P04 (37, black British, London): But I think it might make people, I don't know, it's Catch 22, some people might just – because it's preventing them, they might just take it and then be like, "Oh we can have sex whenever, you know, because we're not going to get HIV," so it is a Catch 22. People do, you know, say the vaccine, "Oh well, I've got the vaccine I don't need to cover up." It's that, you know, I think people will do what they're going to do.

6.5.3.1.4.2 Relevance to current circumstances

None of the participants felt that PrEP was relevant to their current personal circumstances; reasons for this were similar to participant's reasons for not testing regularly for HIV, including: low self-perceived risk, not being sexually active, and being in a monogamous relationship or sexual partnership. The participant who had previously used PrEP discussed her reasons for discontinuation.

P10 (30, black African, London): The most, I guess, important reason was, I just wasn't at risk anymore. I wasn't at university, I went into a much more stable relationship, and yeah, I think that was, yeah, the crux of it. And then obviously, the relationship was still open, but we definitely, definitely forced for every single person to use a condom and to get tested.

6.5.3.1.4.3 Perceptions of who could benefit from PrEP

Although no participants were interested in using PrEP at the time of the interviews, once they learned PrEP could be taken by anyone who is HIV negative and at risk of acquisition (e.g., not just by GBMSM) they described scenarios where they felt an individual might want to take or could benefit from taking PrEP. For example, participants felt that a person with multiple sexual partners might be interested in taking PrEP.

P09 (24, white, South West): Like, I only have one partner, so I guess, like, some people who have more than one person that they're having sex with are going to maybe – maybe want to take it more.

Some participants pointed out that people who experienced difficulties around their sexual health autonomy (including people experiencing coercive or violent power dynamics in a relationship), engaged in transactional sex, or had other circumstances or dependencies that would impact their ability to use condoms consistently or employ other HIV prevention methods may benefit from using PrEP.

P14 (50, white, London): I guess anyone who is leading or wants to lead a promisc – that's the wrong word, I don't mean – but just wants

to have sex and – you know what I mean? Maybe sort of lives a lifestyle where they may be using drugs and alcohol, so that they may not be able to take all the precautions that they might want to or need to.

6.5.3.1.4.4 Perceptions of who should have information about PrEP

During the interviews, participants made the distinction between who they perceived could benefit from taking PrEP, and who they felt should be aware of and have access to information about PrEP; the former was specific to individuals whose behaviour or circumstances were perceived to put them at higher risk of HIV acquisition, whereas the latter was deemed to be anyone who is or may become sexually active. It was emphasised that information about PrEP should be made widely available.

P07 (23, black British, Yorkshire and the Humber, living with HIV): Everyone should know about PrEP because I want to believe everyone wants to have safe sex, so if everyone, so if the information is available to everyone that can be good. That information should be available to everyone without discrimination of any type.

PrEP awareness and knowledge were viewed as a pre-requisite for PrEP uptake, but several participants indicated that HIV, HIV prevention, and factors that would put someone at risk of HIV acquisition were not well understood by the general population. One participant described how a lack of information could have a detrimental impact on a person's wellbeing.

P15 (61, white, East of England): Oh, because I've read articles about how many women now are being infected, and how it's impacting on their lives, and that a lot more women now are being tested positive probably than ever before. It seems to be particularly certain groups of women who are, for whatever reason, are not protecting themselves, or don't have enough information to keep themselves safe.

While there was an increase in the number of women testing positive for HIV in 2022 compared to 2020 and 2021²⁶⁹, there is no evidence from surveillance data to indicate that new diagnoses of HIV among women are at an all-time high.

6.5.3.2 Theme 2: Information Flow

The previous theme explored how information gaps in women's HIV and PrEP awareness and knowledge, and how an individual's perceptions of HIV can influence their perceptions of PrEP. Participants agreed that HIV prevention and PrEP information should be more widely available. The "Information Flow" theme explores some of the barriers that might prevent individuals from accessing information about HIV and PrEP, and opportunities for improving access and engagement.

6.5.3.2.1 Barriers to information access

6.5.3.2.1.1 Gender bias

Participants discussed how gender bias has led to a paucity of information on women, HIV, and HIV prevention.

P11 (27, white, South West): I think women are quite overlooked, at least in my experience in the UK HIV response.

For some participants, excluding women from conversations and messaging impacted how they viewed the relevance of HIV and HIV prevention to them, personally.

P16 (25, white, North West): I didn't realise that it'd be something – like, obviously I'm aware everyone has sexual health and that sort of thing, but as a woman, I've never thought of it as something that particularly would affect me, so that's my own kind of naiveté, I suppose, to what HIV is and things. So I think upon the presumption that it's very likely other women are in the same naiveté as I am, I think that would be a big barrier.

As discussed above, when participants learned about PrEP they were generally favourable towards it as a prevention option, but many participants wondered why

they had not learned more about it before taking part. One participant felt this was, in part, due to a lack of importance that is given to women's health in general.

P01 (41, white, London): Yeah, I think it's really important. I wonder if I'm not – again, this is the stereotype, do I not know about it because I'm not the target group for it? Or is that – or is this just another symptom of poor women's health?

6.5.3.2.1.2 HIV-related stigma

HIV-related stigma was identified as a barrier to engaging with HIV prevention and PrEP information. One participant described how the stigma around HIV could prevent someone from seeking out advice or information about HIV and HIV prevention.

P17 (25, Bangladeshi, London): I think it's because of a lack of knowledge, and maybe the taboo regarding it, we just don't want to talk about these things, and just asking for help and stuff, it's really – I don't know, sometimes it's quite difficult.

HIV-related stigma was also seen as a barrier to women's willingness to engage with HIV information and prevention, which could in turn limit an individual's ability to internalise or recognise the relevance of information when they do encounter it.

P05 (40, black Caribbean, London): You know what, I think sometimes people have this, when they hear the word 'HIV' it rings alarm bells. It's like a connotation to it, it's like when AIDS first come out, people – or HIV, they look at you with scorn. So it can have that negative look to it by thinking, "You know what, I don't want to have nothing to do with that and I don't," you know what I mean.

By preventing engagement with HIV, HIV-related stigma cannot be effectively challenged and can therefore be self-perpetuating. Participants recognised the need to reduce HIV-related stigma as a way of increasing access and engagement with PrEP information. One participant, who was living with HIV, described how increasing knowledge around PrEP could itself help to dismantle some of the stigma around HIV.

P06 (24, Mixed, West Midlands, living with HIV): I think generally it will help everyone, from judging, and stigmatisation. It will reduce stigmatisation and I know the PrEP knowledge will really help. Because people treat you the way they do because of lack of knowledge.

6.5.3.2.1.3 PrEP awareness as a pre-requisite to seeking out information

As discussed above, during discussions about PrEP, participants periodically asked questions about PrEP or were interested in learning more about it. Participants identified that a lack of PrEP awareness was a barrier to improving PrEP knowledge.

P09 (24, white, South West): So... I don't really know, because to find the information you kind of just have to be looking for it, but if you're not even aware it exists, then you can't really search for it.

It is worth noting that awareness of PrEP was seen as being important whether or not a person's self-perceived risk of acquiring HIV was high. None of the participants in the sample felt that PrEP was currently relevant to their personal circumstances or behaviour, however, several participants did recognise the value of knowing about PrEP in case it did become relevant to them at some time in the future.

P17 (25, Bangladeshi, London): Yeah, because, like now I know about it, these situations could happen in my life, then I definitely might talk about it, saying like, you know I remember this method, and ask for more information of how to get access to it, rather than not having the information, then I just wouldn't know what it is. I wouldn't even think about it, basically. Yeah, so I think having the information, firstly, is very important.

6.5.3.2.1.4 Individual and cultural factors

Participants identified individual and cultural factors or circumstances that could restrict women's access to information about their health more generally and about PrEP specifically. While some participants described upbringings where sex and relationships were openly talked about, others grew up in environments where it was not the norm to discuss these matters. One participant described the impact of

growing up in a culture and religion where sexual health and HIV were not openly discussed.

P10 (30, black African, London): I reckon a lot of these things, people just tell you to wait until marriage, don't warn you. I think that would've happened to my aunties quite a lot, growing up in a catholic household. They were just assumed to sort of give to the will of their husbands, and yeah, I don't know, that's just a bit stupid and doesn't give you a lot of negotiating for HIV, yeah, and your own health and safety.

Participants described the need for PrEP information that was available in a variety of languages and culturally sensitive formats, to ensure that it was accessible to as many women as possible.

In a few instances, participants discussed how experiencing intimate partner violence, or being in a controlling or coercive relationship could limit a woman's access to PrEP information.

P13 (52, white, East of England): Someone might be in an abusive relationship because someone might restrict – someone might be in a controlling relationship, they might control what they do, so they don't have access to information.

6.5.3.3 Information sources

Most participants felt that there needed to be more opportunities for women to encounter PrEP information, however, across the sample, the preferred information source(s) varied.

6.5.3.3.1 Internet and social media

For some, the internet was seen as the first “port of call” to seek out PrEP information. For these participants, healthcare professionals would only be consulted if they had further questions and/or wanted to access PrEP. Participants expressed that they would rather seek out information from websites that they deemed to be accurate and trustworthy. The NHS website in particular was seen as a trusted source of information.

P01 (41, white, London): I'd say I'd look online, if it was me, I'd probably just look online. I suppose I'd just be presuming it would be on the NHS website or sexual health websites. What else? Yeah, or yeah, health websites, I suppose. I suppose that's what I'd be pointing people towards.

However, as discussed above, participants acknowledged that an individual would only access websites if they had prior awareness of PrEP and that strategies were needed to increase awareness of PrEP more generally, and for women specifically. Campaigns run on social media (e.g., advertisements on social media platforms, “boosted” or paid-for posts^{xxii}), were viewed as an appropriate and acceptable way to increase PrEP awareness.

P12 (37, white, South East): Maybe the internet like forums, Facebook groups, maybe that sort of thing, or advertise – because obviously I know that with Facebook algorithms and things, you can set adverts to target certain audiences on Facebook – I think that'd be a good idea, something like that.

6.5.3.3.2 Relationship and Sex Education (RSE) in schools

Secondary schools were identified as acceptable venues in which concepts around HIV prevention and PrEP could be introduced. Since 2020, RSE has been compulsory for all pupils receiving secondary education⁴⁴⁶ in England, however, individual schools develop their own programmes of teaching, and there is great variability between them. One participant emphasised the importance of standardised RSE to ensure that there were no discrepancies in RSE content.

P16 (25, white, North West): I think at school at the earliest standpoint, but I think it needs to be something that's routine because for example, my understanding of the sexual education I was given is different from people even in my year group at school who went to the same school.

While the RSE guidance states that pupils should know how HIV is transmitted and how risk can be reduced through safer sex practices⁴⁴⁷, this does not necessarily mean that information on PrEP will be a standard part of RSE.

^{xxii} These are posts wherein the account holder can pay to have their post reach a wider audience.

Participants felt that it was important for women to learn about HIV, HIV prevention, and PrEP just before, or around the time when they become sexually active, as this would equip pupils with the information to better recognise if and when their risk of HIV acquisition changed, and by extension if and when PrEP might become relevant to them

P18 (24, Asian, London): I guess, again, it's probably education, to have it – have some sexual health lessons at school, and advertise it, to put the correct information to people, to the students and children – well, not young, young children, but teenager, maybe, so they're aware of it from when they're young.

Introducing information about HIV, HIV prevention and PrEP into schools routinely was also seen as a way to standardise and normalise conversations around HIV. Equipping people with the necessary knowledge to challenge stereotypes around HIV, was seen as a way to help dismantle HIV-related stigma. In turn, this could make it easier for someone to seek out or engage with HIV and HIV prevention information.

P17 (25, Bangladeshi, London): I think start it off at school, when teenagers, I think it's very important that they should have access to this information from the beginning, and so that it's more talked about, it's not like – because if you talk about it, if you're aware of it from the beginning, maybe it's not going to be as daunting or embarrassing or something you just don't want to talk about might be the point that you might actually be positive, it's too late. So having that openness, and the information and awareness at the beginning, I think is important.

6.5.3.3.3 Signposting and conversations in healthcare settings

Healthcare settings were seen as appropriate venues to signpost PrEP information and services. Participants stressed that signposting should not just occur within settings where people can currently access PrEP but should be displayed at other healthcare services to increase awareness amongst people who do not attend specialist SHS.

P16 (25, white, North West): It's not enough even in the sense of awareness, because I've never been to a sexual health clinic for myself, I've always been the GP, so that's probably one of the reasons why I've never heard of it. I've never had a reason to know that was a thing.

GP surgeries were highlighted as good places to make PrEP information available; participants commonly observed that most people will attend a GP surgery at one time or another.

P02 (25, Asian, London): If it's only sexual health clinics, then probably yes, because some people might not be as educated about sexual health. But almost everybody will have to go to their GP at one point in their lives, so it would be a good way for people to be exposed to this preventative method.

Participants noted that GP surgeries and pharmacies often had health promotion posters and/or leaflets advertising other health services, and therefore HIV prevention and PrEP information would not be seen as out of place. Furthermore, making this information available could initiate or facilitate HIV prevention and PrEP conversations with healthcare professionals.

P04 (37, black British, London): I mean also you have like little leaflets and it's placing these like, yeah, having like these leaflets because people look around. I mean when you go to the GP, when you go to a Health Centre, these things are like, whether it's digitally displayed or whether it's on a rack with information there, people I'm sure, but have it in peoples' view because like when you go to your GP or you go to – chemist is another place you can actually, people go to the chemist to pick a prescription up. Have a display board, however, you know, whether they – however, it's getting it across. (...) Some people won't ask but if it's there they might be prone to ask you a question and that could lead the conversation. Sometimes, never know, from not knowing to wanting to find out more.

6.5.3.3.4 The role of healthcare providers

In addition to being a source of information for people who were interested in accessing PrEP, healthcare professionals were seen as having a role to play in identifying opportunities to provide HIV prevention and PrEP advice and/or recognising when a patient might benefit from taking PrEP. Participants felt that it would be acceptable to discuss HIV prevention and/or PrEP during routine sexual and reproductive health appointments at GP surgeries, e.g., at cervical screenings or contraception appointments. However, participants did express concern that biases held by healthcare professionals, whether conscious or unconscious, could result in missed opportunities to discuss sexual health and HIV prevention options based on a patient's characteristics, such as their age.

P11 (27, white, South West): ... if you want to look at who GPs will ask sexual health questions to, it is younger people, people that look like me. If they're going to ask anyone, it'll be younger people. But actually, as well as the aging people who got HIV when they were younger, well, you've still got people who are sexually active who are older, who are still getting HIV, right? So we need to not only be able to say, "Yes, ask the young people these questions," but also ask the older people these questions, and I think in a way, that's almost a bit – that's even a bit more of a taboo, talking to old people about sexual health, is very much, like, I think, people don't do it.

For people who have a mental or physical disability, biases and assumptions held by healthcare providers were seen as a potential barrier to receiving relevant information.

P16 (25, white, North West): So if you don't fall into that sexually active bracket which is deemed as, you know, normal in society, then yeah, I think ... The mental and physical disability, yeah. a lot of people think people with a mental or physical disability can't have sex, so therefore why would they need to access, which again, isn't the case. They can have sex, and they do have sex.

Participants were clear that PrEP awareness and knowledge should be shared with anyone who is or may become, sexually active. Participants saw a need to incorporate routine conversations around sexual health anywhere that reproductive and sexual healthcare could be accessed, in part to ensure that individuals do not feel targeted or stigmatised, and in part to ensure that individuals had information should it become relevant to them later. This was illustrated by one participant, who was advised to take an HIV test after discovering her partner had been visiting sex workers.

P15 (61, white, East of England): But I guess, as you get older, that kind of passes you by because you don't need those services anymore. But that could put you in a difficult position, as it did me, because when I had my AIDS test, I was in my 50s, so definitely wasn't so tuned into the services then and had to take obviously other people's advice what to do.

6.5.3.3.5 Information campaign contents

The content of awareness and information campaigns, materials, and conversations around HIV prevention and PrEP were just as important as the information source, in the “information gaps” theme, I discussed the information that women wanted to know in relation to taking PrEP (e.g., efficacy, side effects, regimen etc.), but participants also identified the need to detail who could take PrEP and why they might want to take it for women to recognise themselves as PrEP candidates. One participant emphasised the need to provide information about PrEP but expressed concern as to how to get the messaging across appropriately.

P15 (61, white, East of England): Everybody. If you're going to offer people health style choices, then obviously they need to know everything that's available to them. I'm not sure how you'd get that message over though. That would be very difficult, without scaring everybody into thinking they all needed to take it regardless, but ...

Participants in the sample did not perceive themselves to be at risk of HIV acquisition, but not all were confident in their assessments and expressed the need for more guidance on assessing their own risk. Clear, accessible guidelines detailing

when a person would be eligible to take PrEP and/or may have a need for PrEP were considered a good way to ensure that people had the right information to make decisions around their PrEP need, without creating demand among people for whom the risk of acquisition is low.

P08 (29, Chinese, West Midlands): I guess might be get a checklist or anything on the website so that when people they are reading those kind of information they can also fill in the checklist by themselves to assess the risk of getting HIV and then make them aware that they're probably more high risk than others, I guess it might make them more likely to get PrEP.

Participants emphasised the need for materials to be both inclusive and specific; the former to prevent reinforcing stigma or making certain communities or populations feel “targeted”, and the latter so that individuals, could see themselves and their identities reflected. Participants felt that the language in the information leaflet that was used as a conversation aid during interviews (Appendix 9), struck this balance. For example, one participant appreciated the inclusive language that was used to describe who could take PrEP:

P13 (52, white, East of England): And yeah, it can be taken by anyone of any gender, women, men, non-binary, so yeah, it is quite – the language is quite inclusive as well, it's not something you'd look at that and think, oh, well this isn't for me because ... It sounds like it is for anybody who is sexually active, but just it's not stigmatising certain groups of people, I think that's what I'm trying to say.

Whereas another participant commented on how using specific language addressed HIV-related gender and sexuality stereotypes:

P16 (25, white, North West): Particularly, what I like as well is how it says anyone of any gender, and it lists women first, that to me is like ... Because typically, if you're seeing that, it'd say men. Typically people associate HIV and AIDS with gay men, so the fact 'women' is

first is, I think, really good at preventing that stigmatisation towards a certain population.

This is notable, particularly as the participant who had previously used PrEP indicated a lack of women-specific, or women-generated information on PrEP that she encountered before and during the time she was taking PrEP.

P10 (30, black African, London): Yeah, and I actually feel like most of the information I read was from a – and I obviously went out and did my own research after leaving the clinic – most of the information I got was from men who were taking it, especially around the side effects because she didn't really describe many side effects. She mentioned something around my kidney and needing to come back every six months to get a blood test, but yeah, apart from that, there wasn't much mention of anything woman specific to my body.

6.5.3.4 Information networks

Participants acknowledged that improving an individual's awareness and knowledge of HIV prevention could have additional benefits for the wider community. For example, women might engage with members of their social circle to share knowledge and discuss HIV prevention and/or PrEP. Community and third sector organisations have a history of using peer educators and mentors to increase awareness and engagement with HIV prevention in general. One participant described how she was able to encourage people in her social networks to engage with HIV testing by introducing them to postal self-sampling tests.

P04 (37, black British, London): ...my sister and my friend, they wasn't really interested in the whole testing thing and then I'm the one who started getting them into the kits, and I was like, "Oh we can get the kits sent to the house," and it's like, now it's like, "Oh you got your pack?" "Oh yeah, I got my pack."

Despite not showing an interest in using PrEP, or seeing themselves as PrEP candidates, participants were enthusiastic about having conversations about PrEP with people that they knew, and in some cases, this included their extended family.

P03 (37, white, London): I feel its good information to have, it may not ever be relevant to me but I have four nieces and nephews that are all in their 20s, well one just hit 30 yesterday. So it's information I can pass on if I ever feel that, you know they talk to me about things and what they're up to. (...) Also I'm quite keen now to tell my gay friend, because he's never heard of this either, and how that is possible I don't know.

As discussed above, PrEP knowledge was low among most of the participants. However, after learning more about PrEP through the interviews, many participants identified people in their lives who they felt would benefit from knowing about PrEP.

P13 (52, white, East of England): Yeah, I would talk about it with my – I would definitely talk about it with my daughter. I would talk about it with people I know that have just started dating again, or having sex with a new person. Yeah, I mean, if I had that kind of relationship with them, though, we'd talk about it, but yeah, I would mention it to people.

6.5.3.5 Theme 3: Meeting people where they are

The previous two themes discussed the knowledge gaps around HIV prevention and PrEP and how they might be addressed. However, once these information gaps are addressed, that acquired knowledge must then be applied for effective engagement with HIV prevention. The “meeting people where they are” theme explores barriers to using and applying HIV information, and opportunities to embed HIV prevention and PrEP in settings that women routinely attend for their general and sexual and reproductive healthcare. It also discusses how expanding PrEP provision in terms of service settings and available modalities may make PrEP more accessible for women, i.e., meeting people where they are in terms of their PrEP preferences. The theme also describes the importance of embedding PrEP information and services into HIV prevention more generally.

6.5.3.5.1 Perceived barriers to PrEP access with current PrEP implementation in England

As discussed in the “information flow” theme, many participants felt that only being able to access PrEP from sexual health clinics was a limiting factor for PrEP awareness and knowledge, and this was also seen as a barrier to PrEP access.

P12 (white, East of England): Not everyone, or not everywhere has access to a sexual health clinic. Where I am now, it's quite a long way, like make 30 miles to the nearest sexual health clinic.

6.5.3.5.1.1 Stigma of attending SHS

Some participants felt that there was a stigma, or sense of shame, associated with attending sexual health services. This could be amplified for participants who lived in small, or close-knit communities. This was the case for one participant, who was directed to her local SHS by her GP after she developed a rash near her genitals.

P14 (50, white, London): The actual place I live is quite small and I was thinking – and again, there isn't any shame and there isn't any stigma, and people should be going there to make sure that everything's OK, but I was a bit like, “Oh, I hope no one actually gets to see me.”

Later, the same participant described how that feeling might prevent someone from attending services.

P14 (50, white, London): I think again, as much as we try not to, it's still a bit of a stigma, and again, if you live in a place like mine that's really small, then you might be thinking about who else might see you going in there, and why they think you're going in there, and all that kind of thing. I think that can really have an impact, yeah, on people wanting to do it, I think.

It was not uncommon for participants to use similar language when describing the HIV-related stigma and stereotypes and the stigma associated with attending sexual health services; i.e. they “knew” there should not be stigma attached to attending a

SHS, but still “felt” it. Participants often expressed associations of judgement or shame with attending SHS, but then interrogated these associations after expressing them. For example, one participant described the sense of shame that would accompany a hypothetical visit to a sexual health service.

P09 (24, white, South West): Like, for me, you would go to a sexual health clinic if you had unprotected sex and then you needed, like, the morning after pill or something. To me it's, like, a bit shameful, which I know it's not, but that's just how I – like, my immediate reaction. I can reason my – I can, like, with logic know it's not that, but that's my automatic response to one.

By presenting a barrier to SHS attendance, stigma, feelings of shame, and worries about being judged are in turn a barrier to accessing PrEP from SHS.

6.5.3.5.1.2 Difficulties attending SHS

Participants described circumstances and scenarios that would make it difficult to attend a sexual health clinic, and the impact that this would have on someone trying to access PrEP. SHS provision varies greatly across England^{76,111,145}, in part due to the fragmentation of services and differences in the services commissioned by local authorities. This can create a “postcode lottery”, wherein a person’s access to health services is dependent on the area in which they live. One participant described her experiences accessing sexual and reproductive health services within a rural location.

P11 (27, white, South West): So this is where the rural area thing comes in a little bit. So obviously, for my – very different bits of my education, I've been in city locations, but the majority of my experience of accessing sexual health has been through GP services, basically, or like out-of-hours equivalents. And I think that's quite interesting because I imagine that I'm not alone in that, and what that means is that the things that aren't offered through your GP, you just don't get. And I think that includes PrEP, at least at the moment.

Even when the services are available in an area, there may not be appropriate structures or services (e.g., transportation) in place to ensure that they are accessible.

P13 (52, white, East of England): Yeah yeah, like if they lived in a village somewhere and the only sexual health clinic is miles away in town and they haven't really got the money to get the bus there or they don't drive, or something like that.

Difficulties navigating physical access to settings where PrEP is available reduces the accessibility and presents a barrier to use.

6.5.3.6 Opportunities to embed HIV prevention and PrEP into usual care

Participants discussed how HIV prevention and PrEP could be better integrated into services that women are already accessing for their reproductive and sexual health care. Improving access to HIV prevention and PrEP information in healthcare settings was discussed in the “information flow” theme, and participants felt it would be appropriate to expand HIV testing and PrEP provision in a similar manner; integrating these services into venues and appointments that women were already attending.

P03 (37, white, London): Yes absolutely. So they could bring it up at smear tests, at blood tests all those kinds of things.

Embedding services into usual care was seen as an effective way of normalising HIV prevention and reducing HIV-related stigma. For example, one participant described her experience of having an HIV test as part of her routine antenatal care.

P13 (52, white, East of England): You know, when you're pregnant, you have a lot of tests for a lot of things so it just became another test. It wasn't a big thing in its own right, it was just like, they have to do this. So yeah, OK, that's yeah, another test, that's fine, yeah.

Interviewer: So it felt like it was part of –

P13 (52, white, East of England): It just felt like it was part of the antenatal care, yeah.

Convenience was also seen as an important factor in getting women to engage with HIV prevention. One participant said that she would not seek out an HIV test on her own, however, she would be receptive to having a test if she were having blood drawn for another reason.

P09 (24, white, South West): So, like, for example, if I was already having my blood taken and tested for something and if they offered that then I might as well, because it's, like, no extra effort on my part. I've already had the blood taken, so yeah, they might as well. Yeah (...) because I'm already there for a reason, so it's just added on. It's nothing extra to do.

This preference for “convenient” services that required little additional effort on the part of patients was also mentioned in the context of PrEP. Some participants mentioned avoiding pregnancy as their main sexual and reproductive health concern, and contraception appointments were considered a good opportunity to increase women’s engagement and embed PrEP into routine care.

P10 (30, black African, London): I think if you want to get women on board with it, then potentially coupling it with contraceptives would be great because then it kind of gives someone already something that they're doing that they're already thinking about, and yeah, then just putting this extra, 'and PrEP' alongside it

In a similar vein, one participant felt that PrEP information and provision could be integrated into conversations about STI testing, for example when being offered a chlamydia test as part of the National Chlamydia Screening Program^{xxiii}.

P16 (25, white, North West): Yeah, and just like, doctors speak about as well at the GP, they do often ask you, “Are you sleeping with multiple people? Have you got multiple sexual partners?” that sort of thing, but they speak about it more so from like Chlamydia type of a perspective. I think if they were to include that and say, “Well, we've actually got this as well that can be a preventative.

^{xxiii}The National Chlamydia Screening Program (NCSP) recommends that all sexually active women under the age of 25 accessing a sexual and reproductive health service, termination of pregnancy service, GP, or pharmacy be offered a chlamydia test.

Would you like the prescription for it, if you are sleeping with multiple partners,” or yeah.

6.5.3.7 Expanding PrEP provision settings

As discussed in above, participants felt that only providing PrEP in sexual health clinics limits access to both PrEP information and PrEP itself. Participants overwhelmingly felt that expanding the settings where PrEP was available was necessary to increase engagement and access to PrEP.

GP services were seen as an appropriate place to access PrEP, just as they were seen as an appropriate venue to access PrEP information. GP services were seen to be more accessible and available than SHS.

P12 (37, white, South East): So it should realistically be made to be able to access it with your GP as well, at least, at the bare minimum. (...) When I lived in London, there was – I had probably on my doorstep six or seven sexual health clinics. They was everywhere in London, but here where I am now, they’re unheard of.

One participant expressed the view that GPs may have more insight into non-sexual behaviour related factors associated with HIV risk (such as experiencing housing instability, or intimate partner violence) than, for example, a sexual health clinician.

P10 (30, black African, London): I reckon GPs probably have much closer access to know if someone is in a domestic violence relationship, yeah. Hm, like not – people still feel a sense of stigma going into a sexual health clinic, so even if pharmacies have it, like morning after pill type thing, that would probably be quite good. But if it’s still every six months you need the kidney test, then yeah, I think GPs might be the best bet, that they can still order blood tests.

Pharmacies were also frequently as acceptable and accessible settings for PrEP provisions. Some participants noted that emergency contraception was available from pharmacies, and therefore pharmacists may be used to having conversations about sexual health with women. Furthermore, pharmacists routinely explain medication regimens, contraindications, and side effects, making them well-placed to

discuss this PrEP information. Participants did not necessarily feel that PrEP required a prescription but did feel that a potential user should have to ask for it specifically to ensure that these conversations took place.

P01 (41, white, London): Yeah, I would say chemists, like the normal chemist but behind the counter where you have to talk to the pharmacist about it. That's where they keep the sleeping pills, the sleeping pills are behind the counter, you have to ask for a sleeping pill that you can buy over the counter everywhere else. Yeah, I think that's probably a good place for it.

However, for some participants, SHSs were still seen as the most appropriate place to initiate PrEP. SHS staff were thought to be experts in sexual health and better able to assess PrEP eligibility and monitor patients taking PrEP.

P18 (24, Asian, London): In a way, I guess it's important to have those specialists to assess it before you can get it, but maybe it's – is it the one-time thing, and then the second – like, afterwards you can get repeated prescriptions at a pharmacy rather than (...) it's less convenient, but still, if it requires the correct monitoring, etc, it's probably best to just keep it at the sexual health clinics.

Despite some differences of opinion on where PrEP should be available, participants agreed that anyone providing PrEP information and access should be well informed and able to discuss PrEP confidently and sensitively in a non-judgemental and confidential setting. The actual occupation or position of the person providing PrEP was seen as less important than the ease with which they could be accessed, and their ability to provide accurate information and considerate care.

P15 (61, white, East of England): GPs, yeah. Not necessarily the GP, maybe the nurse practitioner or somebody who would perhaps have more time to explain it to you. I don't think – yeah, I don't think it has to be an actual 'doctor' doctor, but just to make it more widely available and easily accessible, because some of these clinics which are attached to hospitals, as I say, our hospital in this city is quite a way out of the city.

Similarly, rather than participants identifying the best or ideal place for PrEP provision, participants emphasised the importance of providing a choice of setting when accessing PrEP, noting that preferences for venue would differ from person to person.

P14 (50, white, London): I think it should be available from everywhere, so from the sexual health clinic, from the GP, and from the pharmacy, actually, because again, you can get things in the pharmacy like – you can get, as I said, you can get your script if you need to have – methadone script, you can get the morning after pill, and I think it kind of sits within all those things, really, doesn't it? Yeah. But I just think that the more you can broaden it out, the more people are going to uptake [it]. Even just things as simple as that the sexual health clinic might be quite far away for some people to go, whereas if they've only got to go down to Boots, then they're obviously going to get it from there, aren't they?

6.5.3.8 Preferences for PrEP modalities

Overall, participants felt positive towards alternative PrEP modalities, and described scenarios in which one modality might be preferable over another. Long-acting modalities, such as injectables were seen as a good alternative for women who have trouble taking daily pills.

P04 (37, black British, London): Because some people are very crap on the Pill and that causes people a lot of pregnancies, unwanted pregnancies and things like that because people were like not equipped if they miss the pill for 12 hours, are you supposed to go on to the next one, miss one? So I think that the injection will make it so much easier.

Long-acting PrEP modalities were also seen as more convenient and less burdensome for some participants.

P14 (50, white, London): I think that's even better because if you're – the least action you've got to take, the better, so if you can just pop

a ring in and you're done for a month, or the injection for a month, that's great, isn't it? You haven't even got to think about it, yeah.

One participant, who was living with HIV, described the impact that the perceived convenience of long-acting PrEP could have on people in or entering serodifferent relationships.

P07 (23, black British, Yorkshire and the Humber, living with HIV): I think the different ways of taking PrEP are very beneficial and will encourage more people to at least embrace having intimacy with sexually, sorry with an HIV person. Because having to do it once a month it's not tiresome, it's something somebody can live with.

Modalities that could be taken infrequently and discreetly were thought to minimise the HIV-related stigma that PrEP users might experience. Additionally, for one participant, such modalities would improve access to people who might be experiencing health autonomy issues or were experiencing intimate partner violence.

P10 (30, black African, London): So I reckon the injectable one, where you don't forget, where it's just there, you go to a clinic once or you have a home visitor, I think that's going to be a huge game-changer. And also, again, sorry to keep talking about people in domestic abuse situations, but I think they can even keep it a secret from their partner, because having a pill that's to do with sex may be a trigger for some partners, like "Are you having sex outside this relationship? Do you not trust me?"

Event-based PrEP was discussed during the interviews, however, participants were made aware that it was not currently an available option for women. Participants were generally disappointed to learn that this option was not available more widely.

P03 (37, white, London): I think that's great don't get me wrong, I think that's great. It's just a bit of a shame it's not the same for the women I suppose. I'd probably be more likely to take it if there wasn't so much pre-planning involved.

On many occasions, participants drew comparisons between daily PrEP and the contraceptive pill; the concept of taking a daily pill for prevention was familiar and not

novel. However, participants were quick to point out that neither the contraceptive pill nor daily PrEP were a one-size-fits-all solution for preventing unwanted pregnancies and HIV respectively and emphasized the importance of choice to cater for individuals preferences and needs.

P16 (25, white, North West): Oh, I think it's vital because it's the same with things like contraception. Some contraceptives work for some people, some don't work for others. So for me, for example, I would absolutely never get the IUD or a coil because – and I've been told the coil in particular for things like periods, as opposed to taking a normal pill, but for my preference, I don't want to put anything into my body. I don't like the kind of thought of internal. But on the flipside, I know plenty of people who don't like taking tablets. They can't take tablets. So by having multiple ways for this to be delivered as a prevention, it just makes healthcare accessible.

Interestingly, this same participant felt that the modalities themselves provided information on who could not only be impacted by HIV, but who could take PrEP.

P16 (25, white, North West): But the fact that there's a vaginal ring, I find that really interesting. It's really emphasising to me the fact that it is something that can impact any gender, any sex.

6.6 Discussion

I conducted 18 semi-structured interviews with women residing in England to discuss their awareness, knowledge, and perceptions of PrEP. I used thematic analysis to develop themes to improve our understanding of women's awareness and knowledge of PrEP, discuss whether current PrEP provision services in England meet the needs and preferences of women, and apply an equity lens to identify barriers and facilitators to PrEP awareness and access for women in England. I also discussed women's perceptions and preferences for current PrEP delivery services in England.

6.6.1 Summary of findings

These interviews suggest that improving PrEP awareness and knowledge among women requires an improvement of HIV awareness and knowledge more generally. At a certain level of HIV knowledge was needed for discussions on PrEP, many of the barriers to developing women's HIV knowledge also impeded the development of PrEP awareness and knowledge. Therefore, situating PrEP within wider conversations around HIV may improve uptake and engagement with both PrEP specifically and HIV prevention more generally.

Participants' beliefs about and perceptions of HIV were influenced by when, where, and how they learned about it. Their engagement with HIV prevention methods, such as testing, depended on each individual's perceived risk of HIV, and their risk perception was influenced, in part, by their perceptions of who could be affected by HIV. This meant that a participant's perceived risk did not always match up with their sexual behaviour.

Once they learned about PrEP, participants were in favour of it as a prevention option, although none of the interviewees felt that PrEP was currently relevant to their lives. PrEP was thought to be beneficial for people at increased risk of HIV acquisition, but participants emphasised the need for greater PrEP knowledge and awareness among women, regardless of their current risk of HIV acquisition. Gender bias and a lack of focus on women's health needs, in regard to both the UK's HIV response and women's health in general, was thought to be a barrier preventing women from learning about PrEP, and subsequently accessing PrEP. Stigma was also identified as a barrier to learning about and accessing PrEP. Both HIV-related stigma and stigma associated with attending SHS were also identified as barriers. Possible solutions to these barriers included women-specific and women-generated PrEP content, increasing opportunities for women to encounter HIV and PrEP information, and integrating information and awareness campaigns into trusted sources and services that were routinely used by women such as schools, GP surgeries, and pharmacies. Improving an individual's HIV prevention and PrEP knowledge could in turn provide opportunities for women to engage with their social networks about HIV and PrEP, as participants were keen to engage with others about new information that they learned in the interviews.

However, participants acknowledged that in order for HIV and PrEP information to be accessible, it must be available in a variety of formats and languages, to prevent reinforcing or creating new disparities in HIV and PrEP knowledge among women. This means that awareness or education campaigns need to include the right kind of information (e.g., efficacy, eligibility criteria, etc.), while presenting the information in a way that is culturally sensitive for the intended audience. Healthcare providers that women interacted with commonly, such as GPs, nurses, and pharmacists, were seen as being well-placed to initiate HIV prevention and PrEP conversations, however, participants noted that a provider's biases or assumptions around who might be sexually active could prevent some of these conversations from occurring.

The strategies identified to improve women's access to PrEP information were similar and in some cases the same as, to those identified for improving access to PrEP itself, such as embedding HIV prevention and PrEP into services that women routinely use and are comfortable attending, such as GP surgeries and pharmacies. Choice was seen to be important for PrEP provision, both in terms of where to access PrEP and what PrEP modalities were available. Having more options was preferable to finding a single best option for provision setting and modality, in order to accommodate for a range of individual needs and preferences. Furthermore, increasing the availability of PrEP provision settings and modalities was seen as a solution to several of the barriers to PrEP access that participants identified. Expanding provision settings could help avoid the stigma associated with attending SHS, while making PrEP more accessible to people who do not live near a SHS, or experience structural barriers that make it difficult to attend SHS, such as a lack of public transportation infrastructure. Expanding the availability of PrEP modalities could provide more options for women who struggle to take daily pills, or who experience sexual health autonomy issues and would benefit from options that afford more privacy and discretion.

6.6.2 Discussion of the findings in the context of health literacy

This research aimed to explore PrEP awareness and knowledge among a sample of women in England, and in doing so identify ways to improve engagement with PrEP information and services in this population. However, in many cases, it was necessary to situate discussions around PrEP into HIV prevention more widely.

In order to improve HIV prevention and PrEP engagement for women, awareness and knowledge of both HIV and PrEP must be improved in a way that allows women to both understand information and apply it to their own decision making around HIV prevention and PrEP, i.e., in a way that develops women's HIV and PrEP related health literacy. The concept of health literacy encompasses the skills that allow an individual to learn, understand, and use health information to make health-related decisions and take actions that will have an impact on their health⁴⁴⁸. To facilitate framing the findings within the wider context of HIV literacy, I used the Developing HIV Literacy Framework⁴⁴⁹.

6.6.2.1 The Developing HIV Literacy Framework

The Developing HIV Literacy Framework⁴⁴⁹ was created in a project led by Dr Ingrid Young at the University of Edinburgh, in collaboration with clinical, third sector, and community organisations and members, as a tool to support understanding and engagement with HIV literacy, to ultimately ensure that combination HIV prevention methods are impactful and effective.

The framework defines HIV literacy as a specific type of critical health literacy. Critical health literacy takes the concept of health literacy beyond an individual's skills and abilities, and frames it as a complex "social practice"⁴⁵⁰, which involves networks of people working together to make sense of health information and achieve health goals⁴⁵¹. In this way, critical health literacy requires people to actively engage with each other, their communities, and healthcare providers to effectively learn about and use health-related information. HIV literacy considers these critical health literacy skills within the context of HIV and is defined as:

*"the ability and skills of individuals and communities that means they are equipped and willing to engage with HIV, have access to and understand HIV information, able to apply learned HIV information within their sexual practice and able to engage with others about this HIV knowledge and related sexual practices."*⁴⁴⁹

This means that HIV literacy encompasses more than just having the right information; it relies on the support of peers, partners, communities, and healthcare services to engage with, make sense of, and apply this information to make

decisions related to HIV prevention and care. This also means that HIV literacy can be impacted by social and structural barriers, such as HIV-related stigma or a lack of access to prevention care and health services. By recognising that HIV literacy is a social practice, the framework asserts that simply repeating HIV messages is not enough to improve HIV literacy.

The framework consists of five domains that support and create the environment necessary to improve and achieve good HIV literacy. The five domains are willingness to engage with HIV, access to HIV information, understanding HIV information, using & applying HIV information, and engaging with others about HIV. Although the domains are presented separately, they may be interconnected and overlapping (Figure 6).

Developing HIV Literacy Framework Domains

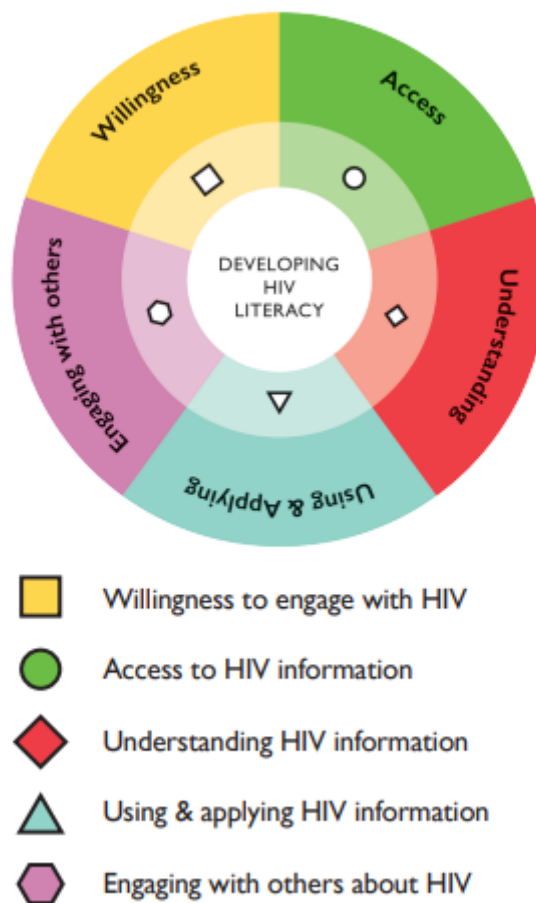


Figure 6: The domains of the Developing HIV Literacy Framework⁴⁴⁹

Importantly, these domains are not just relevant at the individual level. The framework identifies five different levels, or categories, where the domains can apply: individual, sexual partners, communities (e.g., peers), organisations (e.g., third sector, health, or education), and social/structural (e.g., policy, stigma, regulation) (Figure 7). In this way, the framework considers how developing HIV literacy is impacted by the complex interplay between individuals, their relationships, their communities, and societal factors.

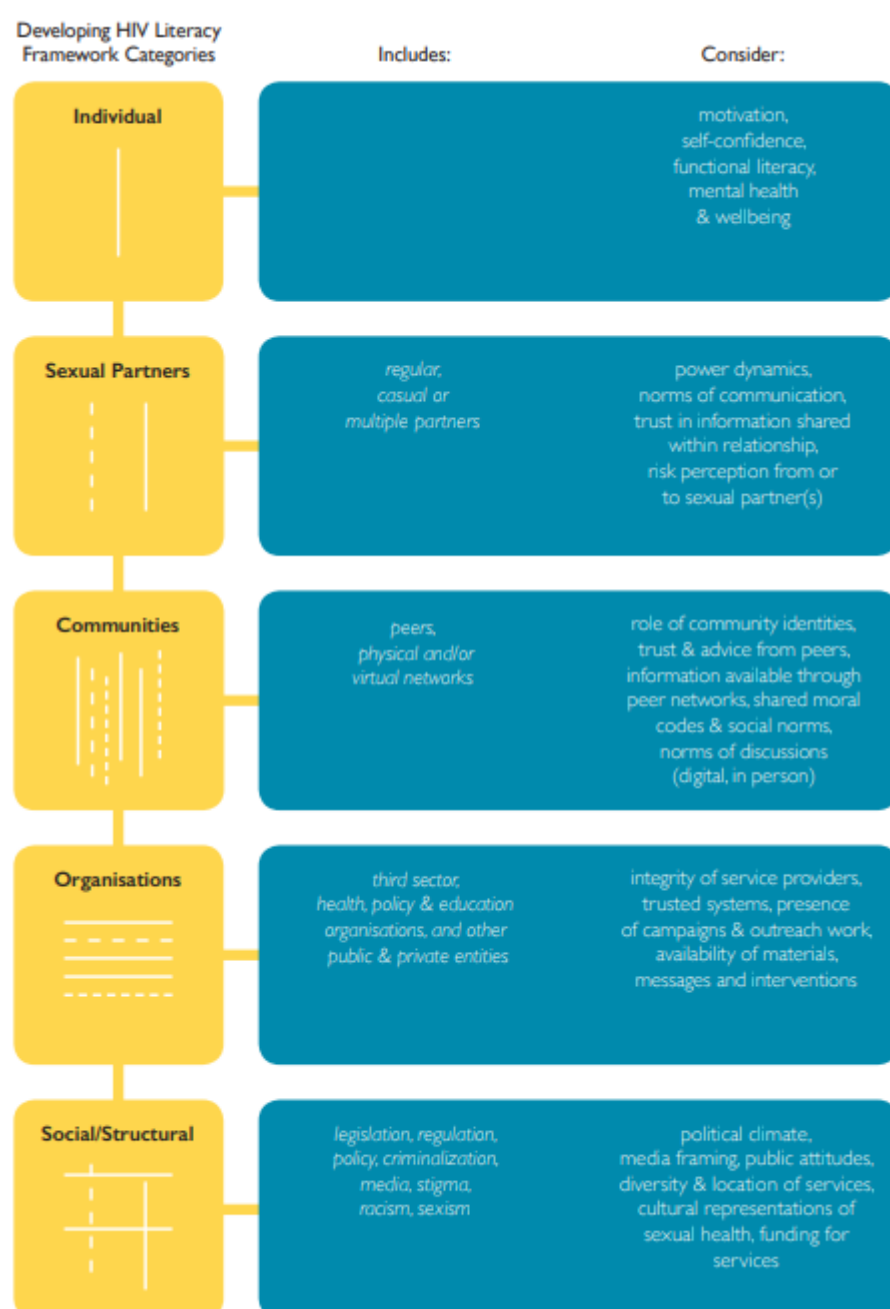


Figure 7: The categories of the Developing HIV Literacy Framework⁴⁴⁹

The Developing HIV Literacy Framework has previously been used to create a PrEP community tool to support the roll-out of PrEP in Scotland⁴⁵². In this research I have mapped the domains of the framework onto the themes and subthemes presented above to illustrate how the results of this study relate to the development of HIV and PrEP literacy (Figure 8).

6.6.2.2 Mapping the Developing Literacy Framework to themes and subthemes

The first theme, information gaps, related to four of the five domains of the Developing HIV Literacy Framework: willingness to engage with HIV, access to HIV information, understanding HIV information, and using and applying HIV information. As discussed above, conversations around PrEP often required an initial discussion around HIV and HIV prevention where participants' knowledge of HIV was low. To cultivate this knowledge, women must not only have access to and encounter HIV and PrEP information, but they must be willing to notice and engage with the information and recognise if and when it is relevant for them. In the case of PrEP, a level of knowledge of PrEP (including its efficacy in different populations, eligibility criteria, and how to access it) is required for women to recognise themselves as PrEP candidates (using and applying).

The second theme, information flow, builds on this concept by identifying and addressing barriers to information access. Creating more opportunities for women to encounter HIV information (access), and tailoring information and educational campaigns in which women see themselves reflected (willingness and understanding). In this theme, the importance of the "engaging with others" domain is apparent. Engaging with healthcare providers and other educators about HIV prevention and PrEP provides an opportunity for women to access and understand information, and participate in conversations about how HIV prevention, including PrEP, might be relevant to their own lives. Additionally, developing an individual's HIV and PrEP literacy may lead to further engagement within their social networks and/or sexual partners, which in turn may help normalise conversations around HIV prevention.

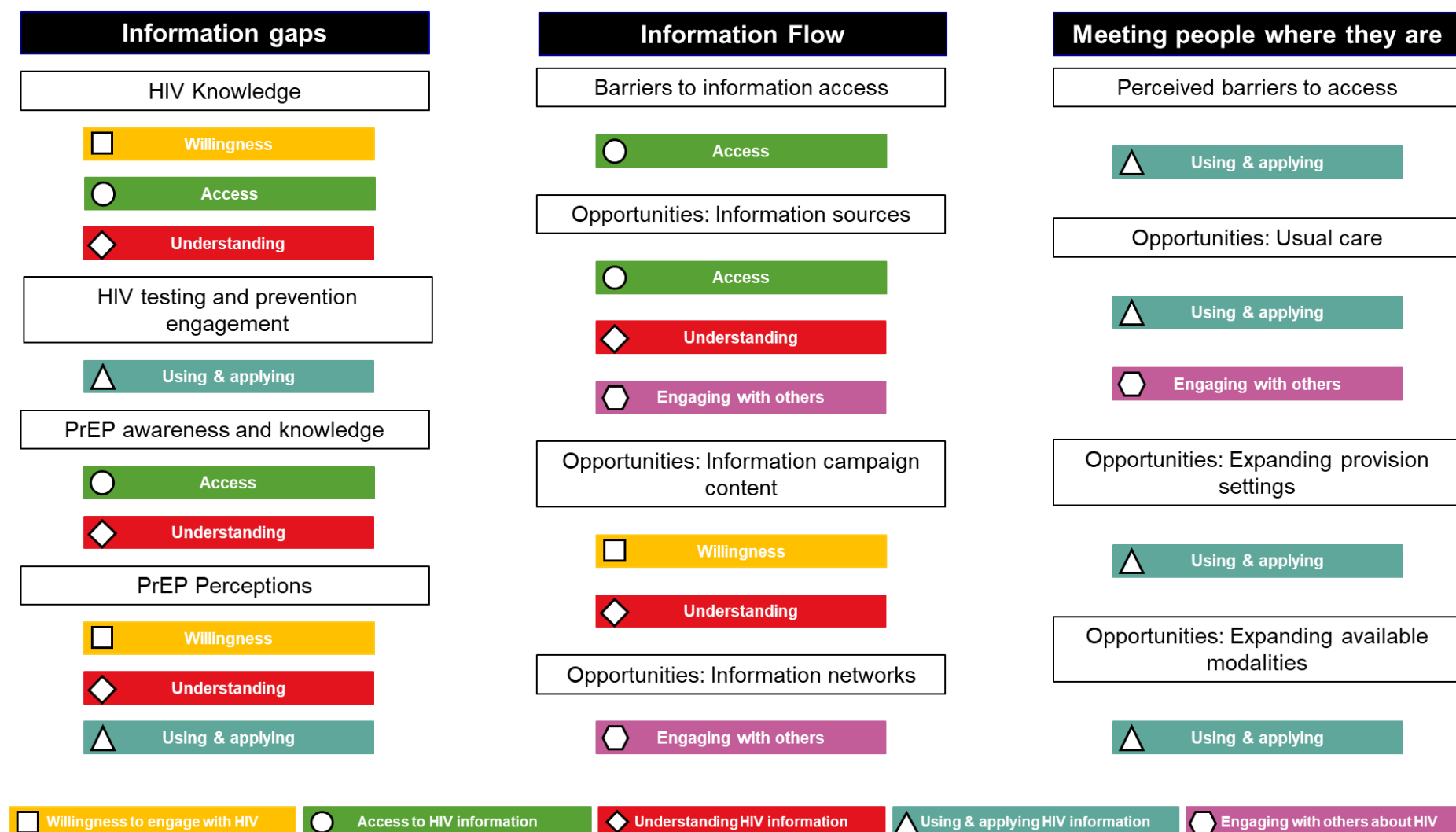


Figure 8: Domains of the Developing HIV Literature Framework mapped to the themes and subthemes

The final theme, meeting people where they are, identifies ways to improve access to HIV prevention and PrEP (using and applying). Embedding HIV prevention and PrEP into services that women already attend for their sexual and reproductive healthcare, may make it easier for women to engage with combination HIV prevention methods, particularly if they can see their preferred service providers (engaging with others). Similarly, increasing available options for PrEP modality may make PrEP more accessible for women (using and applying).

6.6.3 Discussion of the findings in the context of the current literature

Where barriers or opportunities to develop HIV and PrEP literacy were identified, these are discussed in relation to the framework categories (Figure 7) to illustrate at which levels interventions may be needed.

6.6.3.1 Individual factors

6.6.3.1.1 Awareness and knowledge

Low PrEP awareness, HIV- and PrEP-related stigma, low self-perceived HIV risk, and limited access to PrEP have previously been identified as reasons for low PrEP uptake among women^{190–193,200,318,453}, and the results of this study suggest that they impact how women encounter and engage with HIV and PrEP information, and how they apply this information to their own lives and circumstances. PrEP awareness alone is not sufficient to support and encourage PrEP uptake among women; low PrEP knowledge has been reported as a barrier to PrEP use among women, even when they are aware of PrEP⁴⁵⁴.

Developing women's PrEP literacy may need to happen alongside developing women's HIV literacy more generally, and this in turn should be addressed more holistically as part of a conversation on women's sexual and reproductive health²¹³. This may be especially important, as not all women in this study were confident or accurate in assessing their own HIV risk, and similar findings have been reported among populations of women in the USA⁴⁵⁵, and the UK²⁰⁰.

Despite low awareness and knowledge, the women in this sample were generally positive towards PrEP as a prevention method for HIV, and other studies focusing on women have reported similar results^{14,200–202,213}. Where participants did have

concerns, they had mainly to do with PrEP's efficacy, safety, and side effects. Information on all three of these items is readily available and should therefore be included in any educational materials on PrEP. Risk compensation was another concern that was voiced by a few participants. Risk compensation and PrEP have been explored in several studies focused on GBMSM, and there has been some evidence of risk compensation with PrEP in this population⁴⁵⁶. In a study of women who inject drugs in the USA, there was little evidence of risk compensation with PrEP use⁴⁵⁷, but less is known about women more generally and whether PrEP is used as a complementary or alternative HIV prevention strategy when taken by women.

6.6.3.2 Community factors

6.6.3.2.1 Social networks and social norms

Social networks are an important way in which women learn and discuss information on safer sex practices²⁰⁰, and it has been suggested that leveraging informal communication networks among women could improve how women engage with PrEP^{458,459}. Although none of the women in this study saw themselves as PrEP candidates, they identified people in their lives with whom they would want to discuss PrEP. Social networks have been shown to be important for PrEP engagement, and PrEP awareness has been shown to be associated with having social network members who were aware of or used PrEP previously³⁶⁹.

Improving social norms around PrEP may be a key facet to improving engagement, and women may be more likely to use PrEP if they believe their friends would use it²⁰⁶. However, this study demonstrates that for women who have low PrEP awareness and knowledge, the social norms around PrEP can be unclear. Therefore, there is an opportunity to positively influence social norms alongside building awareness and knowledge. This could be achieved in part by using peer navigators for PrEP education and outreach^{213,460}.

6.6.3.3 *Social/Structural factors*

6.6.3.3.1 Stigma

Stigma is a well-recognised barrier to accessing HIV prevention and care generally^{461,462}, and a barrier to PrEP use specifically^{13,420,463}. It is unsurprising, therefore, that HIV-related stigma also impacts how women encounter and engage with HIV prevention and PrEP-related information. HIV-related stigma is still a major problem in the UK; in a recent research programme conducted on the public attitudes and knowledge towards HIV, four-fifths of people felt that people living with HIV frequently faced negative judgement from others, and only one-third of respondents fully agreed that they would have sympathy for all people living with HIV⁴⁶⁴. The same report described three main factors that contribute to HIV-related stigma: associating HIV with ‘irresponsible’ behaviour (e.g., promiscuity or condomless sex), low knowledge of HIV treatment and prevention, and negative attitudes towards LGBT people, who the sample closely associated with HIV⁴⁶⁴. The association between “irresponsible” behaviours and HIV extends to PrEP, wherein users are often stereotyped as irresponsible, immoral, or promiscuous, which discourages engagement with PrEP generally⁴⁶⁵, and for women specifically^{200,318}.

Participants in this study described the impact that early public health campaigns and messaging around HIV created a sense of fear around HIV, while at the same time marginalising groups such as GBMSM. Tackling HIV-related stigma, and the attitudes that contribute it is an essential part of improving and strengthening combination HIV prevention programmes, including PrEP provision. More inclusive messaging around HIV and PrEP is needed to combat stigma, engagement with HIV prevention and PrEP^{466,467}.

6.6.3.3.2 Gender bias

Gender bias and sexism are established barriers to healthcare for women in general, so it is unsurprising that they were recognised as barriers to developing good HIV and PrEP literacy. In the Government’s 2022 Women’s Health Strategy for England, it is acknowledged that the healthcare system is historically “male as default”, i.e., designed “by men for men”, where women are an afterthought regarding research and clinical trials, education and training for healthcare professionals, and the design

of healthcare policies and services⁴⁶⁸. This is true for HIV, where a lack of focus on women in England has been noted by advocacy groups¹⁶² and the All-Party Parliamentary Group on HIV & AIDS⁴⁶⁹. As discussed above, there is a paucity of research on women and PrEP in Europe¹³ and the UK¹⁶, and a lack of women-specific messaging around PrEP. Third-sector and advocacy organizations have recognised and created campaigns to address this oversight^{213,470,471}, and while these can be effective at raising awareness, they are often limited by short-term funding and a lack of capacity^{16,213}.

Multi-level interventions are needed to address the gender bias in PrEP information and access. As noted above, third-sector organisations can play an important role in raising PrEP awareness, and there have been calls for more community-level PrEP education and outreach programmes for women⁴⁷², however additional strategies to increase engagement among both women and healthcare providers should also be employed. For example, participants in this study called for clear, specific eligibility criteria so that women could better recognise when they might benefit from taking PrEP. There have been calls for better decision aids to help HCP identify potential PrEP candidates among women^{473,474}, as practitioners are not always confident in operationalising PrEP eligibility criteria²⁰⁷. For example, in a SHS in England, a questionnaire has been used to help identify PrEP candidates among women so that HCP can initiate PrEP conversations⁴⁷⁵, and similar strategies may help identify opportunities to discuss PrEP.

6.6.3.4 Moving away from a one-size fits all approach

The “one-size fits all” approach to PrEP provision has been identified as a barrier to PrEP for women in the UK¹⁶, and the results of this study suggest that limited settings for accessing PrEP and limited modalities may prevent women from encountering and engaging with PrEP information in the first place. For women, providing choices that reflect individual preferences and needs is more important than finding the “best” setting to access PrEP.

Providing PrEP in a diversity of settings has been recommended to increase access²⁰⁷, and ideal settings for PrEP provision may be those that potential users find convenient and familiar⁴⁷⁶. For example, in Thailand, PrEP engagement among trans women has been improved by providing combination HIV prevention, including

PrEP, alongside gender-affirming treatment and care⁴⁷⁷. Integrating HIV prevention and PrEP services into settings that women routinely use for their reproductive and sexual healthcare needs, may help increase women's engagement. In Britain, most women use general practice to obtain contraception⁴⁷⁸, and recently a contraceptive pill has been made available to purchase from pharmacies without a prescription⁴⁷⁹, meaning there may be opportunities to integrate HIV prevention and PrEP into these settings. It is worth noting that any expansion of PrEP services needs to happen alongside training and capacity building to ensure that HCPs can discuss PrEP confidently, competently, and in a culturally sensitive manner²⁰⁷. Most of the research exploring the feasibility, acceptability, and recommendations for providing PrEP in these settings have been from the USA^{480–486}, and therefore more work is needed to investigate how best to expand PrEP implementation in England.

Expanding the available modalities of PrEP may also increase engagement among women, particularly as the once-daily pill is the only modality available in England. Ease, convenience, and comfort using a particular modality has been shown to be important to women when choosing a preferred PrEP modality, and preferences often align with women's contraceptive practices⁴⁸⁷; e.g., women who prefer long-acting reversible contraception may also prefer long-acting reversible PrEP. Choice has been demonstrated to be an important factor in contraception uptake as the use of modern contraception overall increases as more methods become available⁴⁸⁸, and the same could be true for PrEP. Furthermore, the different PrEP modalities themselves could help raise awareness of who can take PrEP. The communication theorist Marshall McLuhan coined the phrase "the medium is the message"⁴⁸⁹ to describe how the medium in which a message is delivered influences how the message is perceived, and this can be applied to PrEP modalities. The dapivirine vaginal ring (DPV-VR), is a female-initiated option that is worn within the vagina for a period of 28 days. The DPV-VR can be used by anyone with a vagina, which highlights that PrEP can be taken by women. Therefore, offering the DPV-VR may influence women's perceptions of who can take PrEP.

6.6.3.5 Addressing inequities and barriers to PrEP engagement

This study highlighted several barriers to women accessing both PrEP information and PrEP, many of which could be addressed at the structural and policy level. For

example, difficulties attending sexual health services, whether due to social barriers such as stigma, or physical barriers such as distance to clinic, may be mitigated by offering PrEP at more common or accessible locations, such as GP surgeries and pharmacies. This may also increase opportunities for women to encounter and engage with PrEP information.

While expanding PrEP to other healthcare settings addresses some of the barriers that were discussed, there is the potential to introduce additional barriers. For example, provider bias may dictate who the subject of HIV prevention and PrEP is broached with. For example, providers may not talk to people with disabilities about sex due to discomfort or lack of competence or confidence in approaching the subject⁴⁹⁰, or they may not discuss sexual health with older people, due to biases around who is sexually active²⁰⁸.

Although it was not discussed by any of the participants in this study, it is important to note that ethnicity has been commonly reported as a barrier to PrEP, both from women experiencing institutional racism^{200,212} and as provider biases influencing their willingness to prescribe PrEP based on a patient's ethnicity⁴⁹¹. There are several potential reasons why ethnicity was not discussed as barriers in these interviews. For example, none of the women in the sample were currently interested in using PrEP, therefore, conversations centred around hypothetical, rather than actual or intended PrEP users. Although the study sample was diverse, and a range of ethnicities were represented, participants may not have felt that their experiences or observations of racism and/or how their ethnicity impacted their access to healthcare were relevant in these hypothetical situations. Furthermore, this study asked about participant's experiences or thoughts regarding a range of factors that impact health equity, and in this sample, it may be that ethnicity and racism played a small role in their experiences of healthcare access. It is also possible that I did not probe participants enough regarding their experiences or perceptions of healthcare access in relation to their ethnic identity and experiences of racism, but this was in part because ethnicity was not a specific focus of this study. Regardless, disparities in health and healthcare between people of different ethnicities in the UK are well established^{492–494}, and it is likely that addressing these disparities at the policy and structural level will have a positive impact on all areas of healthcare access, including HIV prevention and PrEP.

Routinization of HIV prevention and PrEP in primary care and reproductive health settings is a key factor in improving access and equity. In a 2017 paper, Calabrese *et. al.* made four arguments for integrating PrEP into routine preventative healthcare as a way to mitigate existing HIV disparities⁴²⁴. The first argument is that taking a routinized approach and broaching PrEP with all patients seeking reproductive or sexual health care ensures that PrEP information is provided to all who could benefit from it. Secondly, a routinized approach helps destigmatise PrEP by normalising PrEP conversations for providers, patients, and the public. Thirdly, a routinised approach helps transmit knowledge to the broader community, as patients may share information that they have learned with members of their social networks. Lastly, a routinized approach empowers patients to decide whether PrEP is right for them, thereby facilitating patient-centred care.

Routinization of other HIV prevention methods has shown success in England, such as the high uptake of HIV tests in antenatal care¹⁶⁶, and opt out HIV testing⁵⁴. Routinization of PrEP in England may be more about ensuring women have access to PrEP information, rather than about dramatically increasing offers of PrEP prescriptions. It also may be important to consider where these conversations can take place outside of healthcare settings, for example in RSE as discussed above. Consideration will need to be given as to the best way to embed PrEP conversations into routine care, improve social norms around HIV prevention and PrEP, and how best to bolster and support conversations around HIV prevention more generally.

6.6.4 Strengths and limitations

A strength of this study is that, to my knowledge, it is one of the first to qualitatively explore PrEP awareness, knowledge, and preferences among a diverse sample of women in England since PrEP was routinely offered on the NHS. The use of maximum variation sampling meant that the developed themes were significant among a sample with a range of ages, ethnicities, geographic locations, HIV statuses and experiences. Application of the Developing HIV Literacy Framework helped situate PrEP more widely within HIV prevention, and the study discussion reflects this.

A limitation of the study is that it only included women living in England, and this may limit the transferability of the findings to other contexts. Additionally, only people who

Speak English were able to take part, which means that the experiences and preferences of people who are not proficient in English have not been captured. This may be important when improving equity of access to PrEP, as people who do not speak English may face additional difficulties navigating the healthcare system in England.

Participants who took part were comfortable discussing sexual health and HIV to some degree, and therefore their views may be different to women who do not have this level of comfort. Furthermore, none of the HIV-negative participants were interested in using PrEP at the time of interview, so their preferences for PrEP provision should be interpreted with caution. All of the participants who took part were cisgender women, therefore this study cannot comment on trans people's knowledge and preferences around PrEP.

6.7 Conclusions

In this chapter, I have used qualitative interviews to describe PrEP awareness, knowledge, and perceptions among women in England. I have illustrated that improving PrEP literacy among women relies on improving HIV literacy more generally. Although this study identified several multi-level, interdependent barriers to developing HIV literacy and PrEP knowledge among women, improving equity of PrEP information and access can be achieved, in part, by embedding HIV prevention and PrEP into routine conversations and care. However, this was a qualitative study, and little is still known about the level of PrEP awareness among women in England more generally.

6.8 Implications for the rest of the thesis

In the next chapter, I present the results from my quantitative survey investigating PrEP awareness, interest, and preferences among a sample of women in England. Using logistic regression, I identify associations between participant's sociodemographic, behavioural, and other equity characteristics and PrEP awareness and interest to explore possible drivers of inequity in PrEP awareness.

Chapter 7 Exploration of women's PrEP awareness and interest: a cross sectional survey

7.1 Chapter overview

In this chapter, I present the methods and findings from a quantitative study investigating awareness, interest, and preferences for PrEP provision among women in England. The data were collected from an online, self-completed, cross-sectional survey of a convenience sample of women. I developed, designed, and distributed the survey, then managed and analysed the data collected. Data from the survey were used to investigate associations between PrEP awareness and interest and socio-demographic and other factors known to influence health equity.

7.2 Background

In Chapter 6, I used semi-structured interviews to explore PrEP awareness and knowledge among a sample of 18 women living in England. Approximately half of the sample of women were aware of PrEP before taking part in the study, however, levels of HIV literacy and PrEP awareness varied widely between participants. As this was a qualitative sample, this does not indicate what PrEP awareness levels are like more generally for women living in England. As highlighted in Chapter 3 and the systematic review in Chapter 5, there is a lack of quantitative research exploring women's PrEP awareness and interest in high-income countries, and the majority of existing research has been conducted in the USA.

Of the few quantitative studies that have focused on PrEP awareness among women in England, levels of reported awareness and interest have varied. In 2018, the "Women and HIV Invisible No Longer" report, 74% of 151 women surveyed had heard of PrEP, however, this survey was conducted among women who had experienced concerns about HIV¹⁶². Conversely, in a conference presentation at the 2019 British HIV Association (BHIVA) conference, results from a 2018 survey of people in England reported that 22% of women in the sample had heard about PrEP⁴⁹⁵.

Quantitative research on PrEP interest among women outside of the USA is scarce, and little is known about PrEP interest among women in England. To my knowledge, there is only one published survey reporting PrEP interest among women in the UK, The Flash! PrEP in Europe survey. The survey results reported that 18% of respondents were interested in using PrEP, however, only 28 of the 678 participants lived in the UK, and it was not known how many were in England²⁰¹.

Gaining an understanding of women's awareness and interest in PrEP through quantitative methods may provide a useful benchmark against which subsequent research can be compared. Research from the USA has demonstrated that PrEP awareness and interest can differ between and among women, based on characteristics such as ethnicity^{198,295} and socioeconomic status¹⁹⁸. By identifying inequities in the demand stages of HIV prevention and PrEP, it may be possible to better develop and carry out interventions and educational and awareness campaigns that aim to address and improve these inequities.

Little is known about women's preferences for PrEP, and whether the current PrEP provision programme meets the HIV prevention needs of women in England. Improving our understanding of women's PrEP preferences is particularly important given the emergence of new PrEP formulations and modalities that are becoming available or are in development. In order to optimise PrEP provision and ensure that everyone who wants and needs to use PrEP can access it, it will be important to explore women's preferences for formulations, modalities, and service models.

Studies in the UK and England looking at PrEP awareness and interest among women have mostly been qualitative explorations¹⁶, and there have been very few quantitative studies. Unlike qualitative research, quantitative research can allow us to explore the level of PrEP awareness and interest in a sample, identify characteristics that are associated with awareness and interest, and provide findings that may be generalisable to the wider population. It has been suggested that more community-based surveys and quantitative research would complement existing research and surveillance data¹⁵⁰. In recent years, there has been an increase in online, non-probability surveys being used in sexual and reproductive health research^{19,224,496–}

498.

To my knowledge, there are no studies investigating PrEP awareness, interest, and preferences among women in England that have been conducted since PrEP was routinely commissioned in 2020.

7.3 Research aims and objectives

The quantitative survey was carried out to address the third, fourth, and fifth thesis objectives described in Chapter 4 (i.e., quantitatively explore levels of PrEP awareness, knowledge, and interest, and preferences for PrEP provision among a sample of women in England; identify potential barriers and enablers to women's PrEP engagement (i.e., PrEP awareness, interest, knowledge, and use); and employ an equity lens to consider the implications of these findings for public health policy and practice). Specifically, this research aims to investigate awareness of, interest in, and preferences for PrEP among a sample of women in England. The specific objectives are to:

1. Assess the levels of PrEP awareness and interest among a sample of women living in England.
2. Identify associations between sociodemographic and other factors that influence health equity and PrEP awareness and interest.
3. Investigate women's preferences for PrEP delivery.

7.4 Method

To achieve the study aims I designed, conducted, and analysed data from an online, non-probability, self-completion, cross-sectional survey. The survey was designed to be anonymous and voluntary, and the sample was self-selected and opportunistic.

7.4.1 Ethics approval and data governance

This study received ethical approval from the UCL Research Ethics Committee (Project ID: 20443/002). This research was also found to be compliant with General Data Protection Regulation 2018 and received approval from the UCL Data Protection Officer. The Data Protection Registration number is: *Z6364106/2022/08/76 health research*.

7.4.2 Sampling method

The two sampling methods for cross-sectional studies are probability sample and non-probability sampling. In probability sampling, a sample is selected from the target population in such a way that each individual has an equal chance of being chosen, meaning the sample is representative of target population. Conversely, in non-probability sampling, each member of the target population does not have an equal chance of being selected^{499,500}. A common method of non-probability sampling is convenience sampling, where the recruited sample is “conveniently” accessible and available to the researcher⁵⁰⁰. Although non-probability convenience samples lack the generalisability that is achieved with probability surveys, they are often cheaper, more efficient, and easier to implement^{501,502}.

An online, non-probability, convenience survey design was chosen for this study. There are several reasons for this decision. Pragmatically, this approach was considered to be achievable within the bounds of an individual PhD project. Additionally, online surveys are advantageous in that participant anonymity can be guaranteed, this is particularly relevant when collecting data on sensitive subjects, such as sexual health. Online surveys can also facilitate the recruitment of a diverse sample of participants from a wide geographic area. However, it is important to recognise that non-probability samples can introduce sources of bias into the research, for example sampling bias wherein some individuals are more likely to be included than others, and this can impact the interpretation of the study results.

7.4.3 Participants

Eligible participants for the survey were women (i.e., anyone who identified as a woman, and this included anyone who identifies as female, including cis and transgender women, and those identifying within the gender diverse umbrella who felt the study was applicable to them), residing in England, aged 18 years or over. Participants also needed to be able to understand English sufficiently to provide informed consent and complete the survey. Cisgender and transgender men or people who identified as male were not eligible to participate.

7.4.4 Recruitment

Participants were recruited through social media platforms, in a strategy that was adapted from McCarthy et.al¹⁹. The survey was advertised via paid-for advertisements and paid-for promotions of posts on Meta social media platforms (e.g., Facebook and Instagram), and through Google advertising platforms. All ads and boosted posts were set to be shown to women, aged 18 or over, resident in England.

The study was also advertised via the study's X (formerly Twitter) page (Women and HIV prevention research projects, www.twitter.com/whivpr). Friends and colleagues were asked to retweet the study advertisements and to circulate them within their own networks. I did not actively seek out HIV and sexual health organisations to promote the survey, as I did not want the sample to over-represent women who had previously engaged with these services and may therefore have greater knowledge about HIV and HIV prevention methods. An advertisement was also taken out on the study recruitment site "Call for participants".

A series of six graphic images were used as the basis for all advertising material. The images were chosen for their representation of different ethnicities, body types, and gender expressions. Images and text were reviewed by PPI representatives for their acceptability and accessibility. More details on the PPI feedback are included below. Example advertisements for all recruitment platforms are included in Appendix 17 (Figure 17 and Figure 18).

No a priori sample size was calculated, and the sample was self-selected and opportunistic. Initially, the advertising budget was set at £4000, and data collection was set to run for a period of 4 weeks, until the advertising budget was depleted, or until 5,000 participants had completed the survey, whichever was first. However, after three weeks, the spending budget was increased to £5300 in an effort to boost the number of survey completions.

There was no financial or other incentive for taking part in the survey.

7.4.5 Survey development

The survey consisted of 77 questions and collected data on participant's demographics, PrEP awareness and interest, sexual behaviour, and perceived HIV risk. Data was also collected on PROGRESS-Plus categories and additional characteristics that were identified as being important for HIV risk and/or PrEP engagement from my literature review (Chapters 2 and 3). The survey took approximately ten minutes to complete. To decrease the time burden on participants, many questions included routing or branching based on what response was given, so that participants were only asked questions that were relevant to their experiences.

To develop the survey, I first compiled a list of data items to collect, informed by my literature review and systematic review. Then, existing PrEP and sexual or reproductive health surveys that were conducted in England or the UK were reviewed. Where possible, questions were taken from, or based on questions from existing surveys or sources, and the final questionnaire was reviewed by PPI advisors and my supervisory panel, which included clinical staff from primary care and sexual health, researchers in sexual and reproductive health, and experienced quantitative researchers and survey designers. Key survey items are described in more detail below. The full survey, including data items and branching, is included in Appendix 18.

7.4.5.1 Sociodemographic and PROGRESS-Plus categories

The survey collected data on participant's age, ethnicity, gender identity, sexual identity, educational attainment, socio-economic status, and social capital. Many of the categories in the PROGRESS-Plus framework overlap with typical sociodemographic categories. Table 6 describes how PROGRESS-Plus categories were captured in the survey.

Table 6: PROGRESS-Plus data collected in the survey

PROGRESS-Plus category	Data collected
Place of residence	Region of England, urban/rural classification
Race/ethnicity/culture	Ethnicity, country of birth
Gender/sexual identity	Gender identity, sex assigned at birth, sexual identity
Religion	Whether participant considers themselves to be religious, what religion they belonged to, whether they considered themselves to be actively practising their religion
Education	Level of educational attainment
Socioeconomic status	Index of multiple deprivation, whether they had enough money to meet their needs
Social Capital	Relationship status, Oslo social support scale ⁵⁰³
Plus- Age	Age
Plus- Disability	Whether they considered themselves to have a disability
Plus- Intimate Partner violence	Current and past experience of intimate partner violence
Plus- Housing instability	Experience of housing instability in the past year
Plus- Experience of transactional sex	Experience of transactional sex, ever

Questions on participant's place of residence, ethnicity, country of birth, gender identity, sexual identity and religion were taken from the 2021 census questionnaire for England¹³.

7.4.5.1.1 Place of residence

Participants were asked to supply their postcode in the survey, and postcode data was used to derive additional information using Office for National Statistics (ONS) look up tables, which link postcode data to higher-level geographic areas and area-level deprivation data. I anticipated that participants might be reluctant to include their postcode in the survey, and so this question was accompanied by additional text that reminded participants that the survey was anonymous and confidential and that no attempts would be made to identify participants from the information they provided.

Participant postcode was used to derive the region of England in which participants lived⁵⁰⁶, and the urban/rural classification of their place of residence⁵⁰⁷.

7.4.5.1.2 Socio-economic status

Postcode data was also used to derive Index of Multiple Deprivation (IMD) quintiles for the participant's area of residence as a measure of socio-economic status. IMD was derived using the participant's postcode⁵⁰⁸. As IMD is an area-level measurement that may be subject to ecological fallacy^{xxiv}, an additional individual measure of socio-economic status was included; participants were asked "Do you have enough money to cover your basic needs (e.g., food, rent, gas, electricity, water, etc.)", and could choose from the following answers: Yes, always; Yes, most of the time; Yes, some of the time; No.

7.4.5.1.3 Social capital

Social capital is a complex concept, which the ONS defines as "a term used to describe the extent and nature of our connections with others and the collective attitudes and behaviours between people that support a well-functioning, close-knit society"²³². The systematic review presented in Chapter 5 found that relationship status was the most commonly included measure of social capital in studies investigating PrEP awareness and interest, and other definitions tended to be specific for gender and sexual minorities (e.g., the number of people a participant was out to; a participant's involvement in their local gay community; participation in ballroom or pride events).

Social network support is one aspect of social capital that has been shown to have an impact on both general health⁵¹⁰ and HIV prevention and HIV-related risk behaviours⁵¹¹. Even as a component of social capital, social network support is complex and multi-faceted, and there are various ways in which it can be measured. For example, the ONS social capital headline indicators include nine indicators for social support⁵¹². In order to minimise the survey's time burden on participants, I searched relevant literature to find measures for social network support that were

^{xxiv} An ecological fallacy arises when an inference about an individual is made based on aggregate data for a group⁵⁰⁹.

both validated^{xxv} and brief. Based on the literature review, I settled on the Oslo 3 Social Support Scale (OSSS-3), a brief measure that assesses three types of social support^{514,515}: the number of close confidants, sense of concern felt from others, and relationships with neighbours. The OSSS-3 was thought to be suitable as it was brief; the feasibility, reliability, and validity of the scale have been demonstrated^{516,517}; and it has been used previously in large-scale population based surveys^{515,518}.

The scale consists of three items (Table 7), and respondents are given a sum-score ranging from three to fourteen⁵⁰³, where higher scores indicate a higher level of social support. In the original scale, the third item asks respondents how easy it is to get practical help “from neighbours”, however, for this study it was changed to “from people around you”, after feedback from survey piloting and PPI advisors.

Table 7: The adapted Oslo Social Support Scale (OSSS-3) instrument

Measure	Responses
How many people are so close to you that you can count on them if you have great personal problems?	1. None 2. 1-2 3. 3-5 4. 5+
How much interest and concern do people show in what you do?	1. None 2. Little 3. Uncertain 4. Some 5. A lot
How easy is it to get practical help from people around you if you need it?	1. Very difficult 2. Difficult 3. Possible 4. Easy 5. Very easy

For this study, the OSSS-3 was operationalised into three broad categories of social support, as has been previously reported by Bøen *et al.*⁵¹⁶:

3-8 poor social support

9-11 moderate social support

12-14 strong social support

^{xxv} Validity is concerned with how accurately an instrument (e.g., scale) is measuring what it is intended to measure⁵¹³

7.4.5.2 Plus categories

In addition to the sociodemographic and PROGRESS categories, four additional “plus” categories were collected in the survey (Table 6): experience of housing instability, experience of intimate partner violence, disability status, and experience of transactional sex. These categories were chosen as they have previously been shown to be associated with a risk of HIV acquisition^{152,519–523}.

7.4.5.2.1 Housing instability

The question on housing instability was modelled on the ONS definition of housing difficulties (i.e., any periods of time when the respondent had no home of their own, either rented or owned)⁵²⁴. To assess whether participants had experienced housing difficulties within the past year, the following question was asked:

In the past year, have you experienced any sort of housing difficulties? Housing difficulties could include staying with family or friends temporarily, sleeping rough or sleeping in public places, staying in a place not intended as a permanent home, or staying in emergency or other temporary accommodation.

Participants could respond with the options “Yes”, “No”, “Unsure”, or “Prefer not to say”.

7.4.5.2.2 Transactional sex

The question on transactional sex was guided by the London School of Hygiene and Tropical Medicine STRIVE research consortium resources⁵²⁵. To assess whether participants had participated in exchange or transactional sex, the following question was asked:

In the past year, have you ever received money, drugs, or goods in exchange for sex?

Participants could respond with the options “Yes”, “No”, or “Prefer not to say”

7.4.5.2.3 Intimate partner violence

Questions on participants' experience of IPV were from the PROUD study annual questionnaire⁵²⁶. The instrument includes questions on psychological, physical, and sexual intimate partner violence. The PROUD study included ten questions on IPV; five on perpetration and five on victimization. In this survey, only the questions on victimization were included. The reasoning behind this was threefold: firstly, there is more evidence around IPV victimization and HIV acquisition risk and PrEP⁵¹⁹; secondly, IPV victimization, but not perpetration, was discussed by participants in the qualitative interviews; and lastly, in order to minimise the time burden on participants.

Participants were asked whether they were frightened of their partners, whether they experienced coercive control from their partners, whether they had experienced a physical, whether they had experienced a sexual assault, and whether they had been coerced into having condomless sex when they didn't want to. For each IPV topic, participants were asked a question, e.g.:

Have you ever needed to ask a partner's permission to work, go shopping, visit relatives, or visit friends (i.e., beyond the usual of being considerate to and checking with a partner).

For each IPV question, participants could choose from the following responses: "Never", "Yes, more than 1 year ago", "Yes, within the last year with former partner", or "Yes, within last year with current partner". Participants could choose more than one answer for the IPV questions.

7.4.5.2.4 Disability

The question on disability was modelled on the 2021 census question⁵⁰⁵. To assess whether participants considered themselves to have a disability, the following question was asked:

Do you consider yourself to have a disability? A disability is defined as a physical or mental impairment that has a "substantial" and "long-term" negative effect on your ability to do normal daily activities.

Participants could respond with the options “Yes”, “No”, “Don’t know/Unsure”, or “Prefer not to say”.

7.4.5.3 Sexual health and behaviour questions

Sexual health, sexual behaviour, and perceived HIV risk questions were from or based on questions from existing sexual and reproductive health and PrEP surveys, the “Reducing inequalities in Sexual Health (RiiSH)-COVID” surveys^{224,527}, the “Women’s Reproductive Health Tracker Survey”¹⁹, the Attitudes and Understanding Risk of Acquisition of HIV (AURAH) study⁵²⁸ women’s questionnaire, and the third British National Survey of Sexual Attitudes and Lifestyles (Natsal-3) questionnaire⁵²⁹.

Participants who reported having had sex in the previous six months were asked additional questions about their sexual behaviour (e.g., condom use) and the characteristics of their recent sexual partners (e.g., “How many sexual partners have you had in the last six months”).

7.4.5.4 PrEP questions

Data was collected on participants’ PrEP awareness, interest, and use. Participants were also asked about their preferred PrEP modality and service setting.

7.4.5.4.1 PrEP awareness

As discussed in the systematic review in Chapter 5, questions concerning PrEP awareness often include a brief description of PrEP, before asking about an individual’s awareness. I felt that it was particularly important to include a description of PrEP before asking about participants’ awareness in the survey, given the variation in PrEP knowledge that was demonstrated by participants in the qualitative interviews, and the confusion that some participants expressed between PrEP and PEP (Chapter 6). The PrEP awareness question was modelled from the RiiSH-COVID survey⁵²⁷, with additional details added to the description of PrEP after input from the PPI representatives. The following text was used to assess PrEP awareness:

“PrEP is a medication that can be taken by HIV-negative people that reduces the risk of getting HIV. It involves taking a pill daily, on an

ongoing basis (starting before a person is exposed to HIV and continuing for as long as the person is at risk). It is one of the many safer sex tools that can be used for HIV prevention. Before taking part in this study, had you ever heard of PrEP?”

Participants could respond with the options “Yes”, “No”, or “Unsure”. For analysis, participants answering “Unsure” were grouped with participants answering “No”. Questions investigating where participants had learned about PrEP were modelled after the “Women & Other Groups PrEP survey” from UKHSA (in development, unpublished), e.g.:

To the best of your memory, where did you first learn about PrEP?

7.4.5.4.2 PrEP Interest

As discussed in the systematic review (Chapter 5), several previously published studies report both interest in using PrEP and interest in learning more about PrEP. While the former may give an indication on PrEP demand, the latter may highlight knowledge gaps and opportunities to design educational and awareness campaigns. Both measures were included in this survey.

The systematic review found that these measures were frequently presented to participants, as Likert scales with answers dichotomised for analysis, and the same approach was taken in this study. To assess participants’ interest in PrEP, participants the following text was used:

“Please read each statement carefully and choose the answer that is closest to your viewpoint.

I would be interested in learning more about PrEP.

I would be interested in using PrEP.”

Response options were in the form of a five-point Likert scale, with responses ranging from “1. Strongly agree” to “5. Strongly disagree” for each statement. For analysis, responses were dichotomised into two groups: Strongly agree/agree indicated an interest in PrEP, and Neutral/Uncertain/Disagree/Strongly disagree indicated a lack of interest in using or learning about PrEP. Questions on PrEP

interest were only asked to participants who reported their HIV status as negative or unknown.

7.4.5.4.3 PrEP preferences

The questions on PrEP modality preference were adapted from Chan *et al.*'s questionnaire exploring preferences for current and future PrEP modalities among GBMSM in Australia⁵³⁰. Participants were presented a range of options from the currently available modality (i.e., daily oral PrEP), to other modalities that are in development or not yet available in England. The following text was used:

“New forms of PrEP are currently under development. If all of these options were available and equally effective in preventing HIV, which of these would you want to use? (Please tick all that apply)”

The response options were “1. daily pill”, “2. event-based or “on-demand” pill”, “3. long-acting injectable”, “4. removable implant”, “5. Other (please describe)”, and “6. I would not want to use any of these”. Participants who selected “Other” could type an additional answer into a free text box. Responses 2-4 included additional text with a brief description of how the modality is taken or administered.

The question on preferred setting to receive a PrEP prescription was adapted from the “Women & Other Groups PrEP survey” (in development, unpublished). The following text was used to assess preferring for location:

“New ways of delivering PrEP are currently under discussion. Some of the options below are already available. If all of these options were available, which of these would you want to use to get PrEP? (Please tick all that apply)”

The response options were “1. Sexual health clinic”, “2. GP surgery”, “3. Pharmacy/Pharmacist”, “4. The internet”, “5. A private clinic”, “6. Other (please describe)” and “7. I would not want to use any of these”. Participants who selected “other” could type an additional answer into a free text box.

Participants were able to choose more than one preference for both modality and setting.

7.4.5.5 *Quality assurance questions*

Surveys and research conducted through the internet, although often convenient and less costly to administer, can be beset by a number of sources of information and selection bias. These include: 1) eligible individuals who take the survey twice (likely without malice or ill intent), 2) eligible individuals who participate in a study multiple times in order to receive additional incentives or compensation, and 3) ineligible individuals who take the study (either once or repeatedly) to profit from incentives or compensation⁵³¹. Based on the experience recruiting participants for the qualitative study, I included additional measures to prevent bots, or “fraudulent” participants from taking part. As there was no compensation or incentive for participating, I was less worried about type two or three problems, however, I did want to discourage people from taking the survey “mindlessly”, i.e., filling in random, rather than their own personal, answers.

Due to the sensitive nature of the survey subject, and to ensure anonymity and confidentiality of the survey responses, no IP tracking or cookies were used. The survey was programmed and hosted using Research Electronic Data Capture (REDCap)^{532,533} research data collection service (more details below). Two versions of REDCap are available for researchers at UCL to use: the standard version and the DSH version. Due to the sensitive nature of the survey material, the DSH version of REDCap was used. The standard version of REDCap has an integrated Google reCAPTCHA⁵³⁴ feature^{xxvi}, however, it is not available on the DSH version as feature requires unrestricted access to servers outside the security of the DSH and this is considered too high a risk for exposing the sensitive data of the DSH. However, I was able to integrate methods for detecting and preventing study duplication and fraud within the questionnaire. Firstly, approximately halfway through the questionnaire, participants were presented with a scale that had five possible responses ranging from “1- Not applicable” to “6- All of the time”. Participants were instructed to select “6- All of the time” as their response. This was in part to ensure respondents were paying attention while filling in the survey, rather than filling in random answers, and to exclude any bots that would choose a random selection.

^{xxvi} A CAPTCHA is a challenge-response test that is used in computing to identify whether a user is human. It is used frequently to discourage and prevent bot attacks and prevent spam. reCAPTCHA is a free service provided by Google that helps protect websites from spam and abuse.

The final question was a free text box with the instructions “Please leave this question blank”, to identify any bots what would fill in something regardless. Answers to these questions were reviewed in the data management stage below.

7.4.6 Survey hosting and data collection

As discussed above, the survey was programmed and hosted, and data were collected and managed using the REDCap research data collection service on the UCL DSH. REDCap is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources.

Participants followed a URL from the study advertisements (or in the case of the Twitter, now X, posts, a QR code) to access and complete the survey. The survey ran for a four-week period from 21 November – 19 December 2022.

7.4.7 Survey piloting

The survey questions were piloted by a panel of ten colleagues, friends, and PPI advisors. During the pilot phase, the survey was checked for comprehension, length, spelling errors and typos, and to test question branching. The survey was updated considering the pilot feedback before the final version went live on 21 November 2022.

7.4.8 Patient and public involvement

All study materials, including the survey questions, participant information leaflet and consent text, and study advertisements were reviewed by the panel of PPI advisors. The same advisors previously reviewed materials for the qualitative study (Chapter 6). Study documents were checked for accessibility, appropriateness, and acceptability. For the survey questions, PPI advisors were asked to check whether question wording was comprehensible and to identify and highlight any language that may be seen as stigmatising, and to comment on the ordering of questions

within the survey. Questions were reworded or altered, or the question order was changed in light feedback from the PPI advisors, and once the survey was programmed into REDCap, advisors were provided with a pilot link to test and review the changes.

Given that no financial or material incentives were used to attract participants to the study, PPI advisors felt that it was important to highlight the study motivations and potential impact, e.g., improvements in women's sexual and reproductive health, and the wider implications for HIV prevention policy and practice. After receiving this feedback, the study motivations and potential impacts were more clearly highlighted in both the advertising materials and the participant information sections of the survey.

Initially, the study advertisements contained stock images of real women. Although efforts were made to ensure that women of diverse ages, gender expressions, body types, and ethnicities were included in the advertisements, the PPI advisors felt that using stock photos made the adverts feel "tokenistic" and disingenuous, as it was not possible to capture enough breadth of diversity in a few advertisements. Advisors instead preferred advertisements that featured illustrations of diverse women from the stock photo website Shutterstock (<https://www.shutterstock.com/>), as it was felt that more women would self-identify with the illustrations over realistic stock photos.

7.4.9 Data management

Survey data was downloaded from REDCap and the data was cleaned and managed using R/R studio version 4.1.2⁵³⁵ (hosted on the UCL DSH). The survey data was completely anonymous, and participant postcode information was used to derive place of residence and IMD variables before being removed from the dataset.

For some questions, a free textbox was available for participants to input responses or provide additional information. These responses were reviewed in R studio and, categorized during data cleaning and analysis. For example, if a participant described their relationship status as "seeing multiple people", this would be recategorized as "in more than one type of relationship" for the analysis. Free text responses were then removed from the dataset.

Question responses were checked for consistency, and participants whose answers failed quality assurance checks were removed from the dataset.

The cleaned, data was transferred to a secure, restricted access directory on the UCL server.

7.4.10 Analysis

Descriptive statistics were produced for the sample demographics, PrEP variables, sexual behaviour, sexual health use, and HIV testing behaviour. Where possible, demographics of the sample were compared to the relevant figures from the 2021 census or other official population estimates.

The percentage of missing data was calculated for each survey item, taking question branching into account (i.e., whether the data item was non-response vs not asked to the participant).

7.4.10.1 Item non-response

If the non-response rate was >10% for an item, the age and ethnicity were compared for participants who provided a response and participants who did not provide a response.

The median age of participants was compared for the item response and item non-response groups using the unpaired two-samples Wilcoxon test^{xxvii}, and the distribution of ethnicity between the groups was compared using the chi squared (χ^2) test.

7.4.10.2 Logistics regression models

Univariable and multivariable binary logistic regression models were used to identify associations between the explanatory variables and outcome variables. Logistic regression was deemed appropriate as the outcomes of interest (i.e., PrEP awareness and PrEP interest), were dichotomous variables and the explanatory or predictor variables were categorical^{536(p16)}.

^{xxvii} The unpaired two-sample Wilcoxon, or Mann-Whitney test is used to compare the median when the data is not normally distributed.

7.4.10.2.1 Outcome variables of interest: awareness and interest

There were two outcomes of interest that were investigated using logistic regression models: PrEP awareness and PrEP interest. The logistic regression models for each outcome were built independently. The section below details the steps that were taken to build the logistic regression models, and details pertaining to the specific models for awareness and interest are discussed later.

7.4.10.2.2 Explanatory variables of interest

Sociodemographic and PROGRESS-Plus characteristics were included as explanatory variables of interest, in order to identify associations between factors that influence health equity and PrEP awareness and interest. Sexual health seeking behaviour (i.e., ever attending a sexual health clinic and ever having an HIV test) was also included, to explore whether and how these behaviours were associated with PrEP awareness and interest.

Additional sexual behaviour variables were included in models where the sample was restricted to participants who had sex within the preceding six months. Only participants who reported having sex in this time frame were asked these questions in the survey.

A history of transactional sex, although an important factor for HIV prevention was reported by only a low number of participants (<10), and perfectly predicated PrEP awareness (i.e., all participants who reported transactional sex reported PrEP awareness). For these reasons, this variable was not included in either the univariable or final logistic regression models.

7.4.10.2.3 Multivariable models

Listwise deletion, wherein observations with missing data for any of the outcome or explanatory variables were dropped, leaving only complete cases for the logistic regression models. Then, binary logistic regression was used to identify associations between each of the outcomes and exposures, producing crude odd ratios (OR). Then, a stepwise approach was used to produce the final models. In stepwise regression, the procedure for selecting variables for the multivariable model is performed by the statistical package, based on a set of criteria⁵³⁷. Stepwise

selection, as opposed to purposeful selection, identifies variables as candidates for the multivariable model based on statistical criteria. Stepwise selection was deemed appropriate, as this was an exploratory study, i.e., predictors of PrEP awareness in women are not well characterised. Stepwise selection begins with the full model (i.e., all of the explanatory variables), and variables are selected sequentially^{538(pp89-151)}. For this study, the Akaike information criterion (AIC)⁵³⁹ was used to determine whether variables would remain in the final model. Further details on the statistical commands are included below.

In the final models, the threshold for identifying statistically significant associations between the explanatory and outcome variables was set at $p < 0.05$ for all models. The p-value measures the probability that the observed results from the model occurred due to chance; a p-value of 0.05 indicates a 5% (or 1/20) chance that the observed results are purely due to chance. Therefore, p-values that are greater than 0.05 are not considered to be statistically significant and show no evidence of difference between the outcome groups.

7.4.10.2.4 Logistic regression model for the outcome of PrEP awareness

For the model in which awareness was the outcome of interest, all participants with complete data were included in the model (i.e., all participants who completed all relevant questions pertaining to the outcome and explanatory variables). This group included people living with HIV since, as discussed in Chapter 6, even though they would not take PrEP themselves, awareness of PrEP may be relevant to their romantic or interpersonal relationships.

7.4.10.2.4.1 Sensitivity analysis: awareness

A further sensitivity analysis was carried out for the sample who reported having sex in the previous six months, as awareness of PrEP may be more relevant to these participants at the time of taking the survey. These participants were asked additional questions about their sexual behaviour (e.g., number of sexual partners, HIV status of sexual partners), and these additional sexual behaviour variables were included in both the univariable and multivariable analyses.

7.4.10.2.5 Logistic regression model for the outcome of PrEP interest

Although two assessments of PrEP interest were collected in the survey (interest in using PrEP and interest in learning more about PrEP), only interest in using PrEP was investigated in the logistic regression models. This analysis included only participants who reported having sex in the previous six months, and whose HIV status was negative or unknown, as these are the participants for whom PrEP may be most relevant at the time of taking the survey.

7.4.10.3 Statistical software and commands used

All data management and analyses were conducted in R⁵⁴⁰ and R studio v4.1.2⁵³⁵.

To compare the median age between the response and non-response groups, the “*wilcox.test*” command from the *stats* package⁵⁴⁰ was used. To compare ethnicities between the response and non-response groups, the command “*chisq.test*” from the *janitor* package⁵⁴¹ was used.

The “*complete.cases*”⁵⁴⁰ command from the *base* package was used to carry out listwise deletion for the logistic regression models. The “*glm*” command from the *glm2* package⁵⁴² was used to produce the univariable logistic regression model, and the “*stepAIC*” command from the *MASS* package⁵⁴³ was used to produce the final models. The models were run with the direction set to “backward”.

7.5 Results

7.5.1 Survey recruitment and final sample

The survey ran for a four-week period between November 21st and December 20th, 2022. In this time there were 1404 survey initiations. Only data from participants who clicked the “submit” button at the end of the survey were saved; 988 participants submitted their survey, reflecting a 70.4% completion rate. Figure 9 shows the number of surveys completed on each day of the recruitment period.

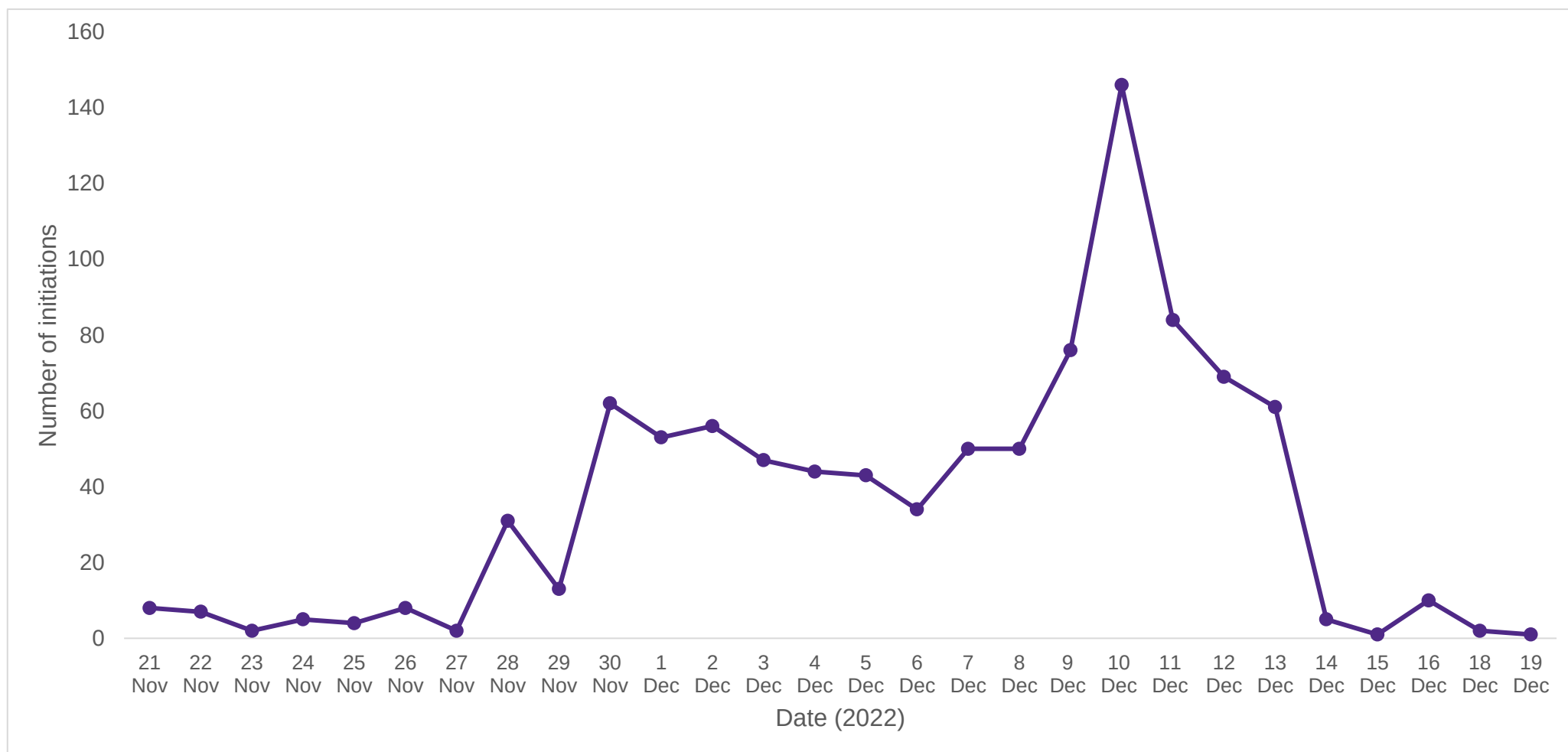


Figure 9: Number of survey initiations by date

7.5.2 Recruitment drive

At the start of the recruitment campaign, paid for advertisements and boosted posts were only taken out on Meta social media platforms as per McCarthy *et. al.*¹⁹. However, due to the Meta advertising service advertisement regulations, the total campaign was initially limited to a spending cap of £42.53 per day while the advertisements underwent review by Meta. During this first week of the recruitment period, there were fewer than 10 survey completions per day. Once the meta spending cap was removed, additional boosted Instagram and Facebook posts were made (i.e., posts made on these platforms that were paid to be promoted in user's feeds, rather than as side-bar advertisements), the survey reached an average of 43 completions per day. In the second week of the recruitment drive, a Google advertising campaign was started to boost survey numbers. At the peak of the campaign, there were 146 survey completions in a single day.

On 16 December, four days before the recruitment drive was scheduled to end, the Meta recruitment drive was suspended due to a suspected violation of Meta's ad policy. Throughout the campaign, I received a small number of comments on the Facebook study page from "gender-critical"^{xxviii} users who felt that a study focused on women's health should only include cisgender women. Although there were no details on what policy the advertisements had violated, I suspect that the ads were flagged or reported by one of the small number of people who were opposed to the inclusive nature of the project. I appealed the decision and was able to restart the advertising campaign on 18 December. Advertisements ran until the recruitment budget of £5300 was spent.

7.5.3 Final survey sample

At the end of the recruitment drive, there were 988 survey completions. This represents a cost of £5.36 per completed survey. Of these, one participant did not provide consent for their responses to be used and was excluded from the final sample. The survey responses were downloaded and reviewed for completeness and to identify any suspect or inconsistent responses. All responses to the quality assurance questions were reviewed to ensure the respondents should be excluded.

^{xxviii} The term "gender-critical" refers to those who are critical of or opposed to the belief that gender identity is more important or significant than biological sex.

In some cases, respondents used the final text box quality assurance questions to provide feedback on the survey. For example, one respondent wrote that the survey was not optimised for use on mobile. In these cases, the survey responses remained included in the final sample. Three respondents were excluded for providing incorrect responses to the two quality assurance questions.

Ten participants were excluded because they did not meet the study eligibility criteria; four participants did not provide a gender identity, and six participants identified as male. This left a total of 974 participants for the data analysis.

7.5.4 Item response

Overall, item non-response rate was low: less than 2% for all but six items: whether participants considered themselves to be actively practising a religion (2.2% missing), perceived risk of STIs (2.2% missing), perceived risk of HIV (3% missing), number of sexual partners in the past six months (7% missing), whether participants considered themselves to have a disability (7.8% missing) and participant postcode (20% missing). The postcode question had the lowest response rate, with 196 participants not providing a full postcode. As participant region, IMD, and rural/urban classification were derived using the participant's postcode, these items were also missing in 20% of the survey responses.

7.5.4.1 Comparison of respondents with and without a provided postcode

The median age of participants who provided a postcode was compared to participants who did not provide a postcode. Figure 10 shows the distribution of ages in both groups. Performing the two-sample Wilcoxon test resulted in a p-value of 0.92, therefore the median age does not differ significantly between the group that provided a postcode and the group that did not. This means that there is no statistically significant difference in the ages of participants who provided their postcode and participants who did not.

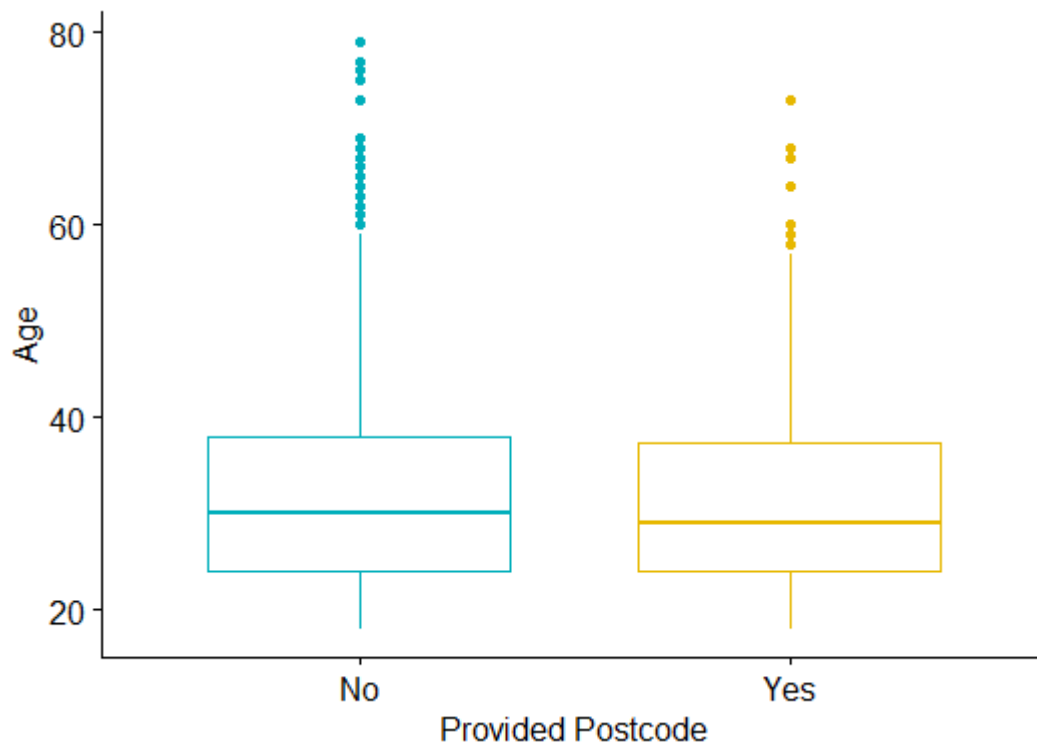


Figure 10: Ages of participants in the postcode item response and non-response groups

The distribution of ethnicity of participants for these two groups was also compared. Table 8 shows the chi square table for ethnicity. Performing the χ^2 test resulted in a p-value of <0.001 , therefore there is an association between the participant's ethnicity and whether a postcode was provided. There was a higher proportion of participants whose ethnicity was reported as Asian or black in the group that did not provide a postcode.

Table 8: Comparison of respondent's ethnicities in postcode item response and non-response groups

Ethnicity	Postcode not provided		Postcode provided		χ^2 (df*)	p
	n	%	n	%		
Asian	26	13.5	46	5.9	22.58 (3)	<0.001
Black	19	9.9	40	5.2		
Mixed or other	8	4.2	65	8.4		
White	139	72.4	625	80.5		
Total	192	100	776	100		

*degrees of freedom

7.5.5 Participant characteristics

7.5.5.1 Comparison to national estimates

The following characteristics were compared to national estimates from the 2021 census for England and Wales⁵⁴⁴: age, ethnicity, sexual identity, gender identity, region of residence, and religion. Participant's rural/urban classification was compared to the mid-year population estimate for England, 2020⁵⁴⁵. Table 9 shows the survey results compared to the national estimates.

Table 9: Demographic characteristics of respondents (N=974) compared to Census 2021 estimates

Demographic characteristic	n	%	Census 2021
Age group (N=974)			
18-24	259	26.5	10.9%
25-29	223	22.8	8.9%
30-34	163	16.7	9.5%
35-39	119	12.2	9.1%
40-44	89	9.1	8.5%
45-49	29	3.0	8.5%
50-54	24	2.5	9.3%
55-59	20	2.0	9.0%
60-64	20	2.0	7.7%
65+	31	3.2	18.6%
Ethnicity (N=968)			
Asian	72	7.4	9.6%
Black	59	6.0	4.4%
Mixed or other	73	7.5	5.1%
White	764	78.2	81.0%
Sexual identity (N=968)			
Heterosexual/Straight	508	52.0	89.11%
Gay/Lesbian	53	5.4	1.14%
Bisexual	316	32.3	1.76%
All other identities	74	7.6	0.41%
Gender identity (N=974)			
Cisgender	908	92.9	99.5%
Nonbinary	51	5.2	0.1%
Transgender and all other gender identities	15	1.5	0.4%
Region (N=778)			
North East	22	2.8	4.69%
North West	73	9.4	13.10%
Yorkshire and The Humber	60	7.7	9.68%
East Midlands	48	6.2	8.59%
West Midlands	46	5.9	10.48%
East of England	69	8.9	11.20%
London	262	33.7	15.72%
South East	134	17.2	16.44%
South West	64	8.2	10.10%
Rurality (N=778)			
Urban	701	90.1	17.1%*
Rural	77	9.9	82.9%*
Religion (N=968)			
No religion	761	78.4	39.0%
Christian	139	14.3	49.3%
Hindu	10	1.0	1.9%
Jewish	13	1.3	0.5%
Muslim	19	2.0	7.1%
Any other religion	29	3.0	2.1%

*Population rurality estimates from the mid-year population estimates for England 2021⁵⁴⁵

7.5.5.1.1 Age

Compared to the census estimates, participants age 18 – 44 were overrepresented, while participants age 45 or over were underrepresented. The median age of participants in the survey samples was 30 (IQR 26 – 34).

7.5.5.1.2 Ethnicity

Participants reporting their ethnicity as white were marginally underrepresented, compared to the national estimates (78.2% vs 81.0%), as were participants who reported their ethnicity as Asian (7.4% vs 9.6%). Whereas participants reporting their ethnicity as black, or mixed/other were marginally overrepresented (6.0% vs 4.4% and 7.5% vs 5.1% respectively).

7.5.5.1.3 Sexual identity

The proportion of participants who identified as LGB+^{xxix} was much higher in the sample compared to national estimates. Thirty-three per cent of the survey sample identified as bisexual (compared to census estimate of 1.8%), 5.6% as Gay/Lesbian (vs 1.1%), and 7.8% identified in another way (e.g., as queer, pansexual, asexual), vs 0.41% of the national population estimate. Only 53.0% of the population identified as heterosexual or straight (vs 89.1% of the national average).

7.5.5.1.4 Gender identity

Fewer participants identified as cisgender in the survey compared to the national estimates (93.2% vs 99.5%). Participants identifying as non-binary or transgender/all other gender identities (e.g., gender diverse, bigender and genderqueer) were overrepresented (5.2% vs 0.09% and 1.5% vs 0.4%, respectively).

7.5.5.1.5 Region of residence

Of the 778 participants who provided location data, there was an overrepresentation of participants who lived in London (33.7% vs 15.7%). All other regions were

^{xxix} The notation the ONS uses to denote anyone who identifies as gay, lesbian, or another sexual orientation.

underrepresented, except for participants residing in the Southeast of England (17.2% vs 16.4%). Participants who lived in a rural conurbation were underrepresented compared to the mid-year population estimate for England (9.9% vs 17%)⁵⁴⁵.

7.5.5.1.6 Religion

Participants who did not regard themselves as religious were overrepresented in the survey sample, compared to national estimates (78.6% vs 39.0%). Participants of all religions were underrepresented; with the exception of participants whose religion was Jewish (1.3% vs 0.5% of the national estimates). Although 21.4% of the sample regarded themselves as religious, only 11.4% considered themselves to be actively practising their religion (no national estimates available).

7.5.5.2 Other demographics

The distribution of the sample by participants' demographics is in Table 10. Note that national estimates from the 2021 census data were not available or were not available disaggregated by gender at the time of writing for the demographics presented in this section. Therefore, no comparisons to the population of women in England have been made.

The majority of the sample was educated to degree level or higher (73%, n=714). Although census education data was not available disaggregated by gender, this proportion is higher than in the general population across England and Wales, where the proportion of adults educated to degree level or higher is 33.8%⁵⁴⁶. Fifty-three per cent of the sample were married or in a steady relationship, while 30% were single and under ten per cent were in a new/casual relationship or in more than one type of relationship (7.3% and 9.5% respectively).

Forty-one per cent of the sample had a "moderate" level of social support, according to the OSSS-3, while similar proportions had a poor or strong level of support (29% and 30%, respectively).

Index of multiple deprivation quintile data was available for participants who provided a full postcode. A similar proportion of participants resided in the least deprived quintile, as the most deprived quintile (15% each). The majority of participants

resided in the second least deprived quintile (27.6%). Most participants had enough money to meet their needs always (59%) or most of the time (30%), with much smaller proportions reporting having enough money to meet their needs some of the time (6.9%) or not at all (4.2%). Just under a third of the sample considered themselves to have a disability (32%, n=309), while 6.85% (n =66) were unsure.

Table 10: Additional respondent demographics (N=974)

Demographic characteristic	n	%
Education level (N=972)		
No formal education qualifications	7	0.7
GCSEs or equivalent	55	5.7
A-levels or equivalent	127	13.1
Higher education below degree level	69	7.1
Degree level or higher	714	73.5
Employment status (N=971)		
Employed full or part time	630	64.9
Full or part time student	219	22.6
Full or part time carer	13	1.3
Not in employment or education	109	11.2
Index of multiple deprivation (quintile) (N =778)		
1: Least deprived	119	15.3
2	215	27.6
3	173	22.2
4	151	19.4
5: Most deprived	120	15.4
Enough money to cover basic needs (N=960)		
Yes, always	567	59.1
Yes, most of the time	287	29.9
Some of the time	66	6.9
No	40	4.2
Relationship status (N=972)		
Single	289	29.7
Married/in a steady relationship	519	53.4
In a new/casual relationship	74	7.6
In >1 type of relationship	90	9.3
Level of social support (N=970)		
Poor	281	29.0
Moderate	401	41.3
Strong	288	29.7
Has a mental or physical disability (N=964)		
Yes	309	32.1
No	589	61.1
Unsure	66	6.8
Actively practising a religion (N= 953)		
Yes	109	11.4
No	844	88.6

7.5.6 Plus category characteristics

Table 11 shows the proportion of participants who reported “Plus” category characteristics. A minority of the sample reported experiencing housing instability in the past year (11%, n=103). Eight per cent experienced intimate partner violence in the past year (n=78) with a former or current partner, and 1.3% (n=13) reported a history of transactional sex in the past year.

Table 11: Respondent “Plus” characteristics (N=974)

Plus characteristic	n	%
Intimate partner violence, past year (N=974)		
Yes	78	8.0
No	896	92.0
Housing instability, past year (N=964)		
Yes	103	10.7
No	861	89.3
Transactional sex, past year (N=968)		
Yes	13	1.3
No	955	98.7

7.5.7 SHS attendance, STI testing and risk perception

Table 12 shows the SHS attendance, STI testing behaviour, HIV status, and STI risk perception for the sample. The majority of participants had visited a sexual health clinic at least once ever (65.7%, n=636), and 71.6% (n=697) had ever had an STI test. Of these, most participants tested either at a SHC (29.1%, n=283) or via an online self-sampling service (26.9%, n=262).

Table 12: STI testing and risk perception among respondents (N=974)

Category	n	%
Ever visited a sexual health clinic (N=968)		
Yes	636	65.7
No	332	34.3
Ever had an STI test (N=974)		
Yes	697	71.6
No	227	23.3
Location of most recent STI test (N=973)		
Sexual health clinic	283	29.1
GP surgery/clinic	122	12.5
Self-sampling service*	262	26.9
Other	29	3.0
Not applicable	277	28.4
Diagnosed with an STI, past year (N=974)		
Yes	17	1.7
No/Prefer not to say	957	98.3
"I worry about getting an STI" (N=973)		
Strongly/tend to agree	313	32.2
Uncertain or tend to/strongly disagree	660	67.8
"I am confident that I know where I can get an STI test" (N=969)		
Strongly/tend to agree	790	81.5
Uncertain or tend to/strongly disagree	179	18.5
Perceived risk of an STI (N=953)		
Greatly/quite a lot	104	10.9
Not very much/not at all	849	89.1

STI = Sexually transmitted infection

*In self-sampling services, individuals collect their own sample before sending it to a lab or health facility for testing

7.5.8 HIV status, testing, and risk perception

Over half of the sample had ever had an HIV test (57%, n=542), and 2.1% (n=20) of the sample population reported living with HIV. Of the 542 participants who had ever taken an HIV test, for 41% (n= 225), the most recent test took place at a sexual health clinic (Table 13).

Among participants whose HIV status was negative or unknown (n= 954), 74% (n=708) agreed or strongly agreed with the phrase “I am confident that I know where I can get an HIV test”. Seventeen percent (n=166) strongly or tended to agree that they worried about getting HIV, but only 5.7% (n=53) perceived themselves as “greatly” or “quite a lot” at risk of acquiring HIV.

Table 13: HIV testing and risk perception (N=974)

Category	n	%
HIV status		
Negative/Unknown	954	97.9
Positive	20	2.1
Ever had an HIV test (N=951)*		
Yes	542	57.0
No	409	43.0
Location of most recent HIV test (N=950)*		
Sexual health clinic	225	23.7
GP surgery/clinic	54	5.7
Self-sampling service^	185	19.5
Self-test°	12	1.3
Screening during pregnancy	34	3.6
Other	31	3.3
Not applicable	409	43.1
“I am confident that I know where I can get an HIV test” (N=952)*		
Yes	708	74.4
No/Prefer not to say	244	25.6
“I worry about getting HIV” (N=954)*		
Strongly/tend to agree	166	17.4
Uncertain or tend to/strongly disagree	787	82.5
Perceived risk of HIV (N=925)*		
Greatly/quite a lot	53	5.7
Uncertain/Not very much/not at all	872	94.3

*Only asked to respondents who reported their HIV status as negative or unknown, N=954

^ In self-sampling, individuals collect their own sample before sending it to a lab or health facility for testing

° In self-testing, individuals collect their own sample and perform the test themselves, receiving and interpreting their own result

7.5.9 Sexual Behaviour

Data on sexual behaviour was collected for participants who had had sex in the previous six months (n=732) (Table 14). Of these, the majority (74%, n=501) had one partner, 19% (n=128) had 2-3 partners, and 7% (n=50) had four or more sexual partners. For 80% (n =584) of the sample, their partners were exclusively male, and a smaller proportion had exclusively female (5.75%, n=42) or exclusively transgender/non-binary/gender diverse partners (2.33%, n=17). Twelve per cent had more than one type of sexual partner.

Three-quarters of the sample (n=552) had condomless anal or vaginal sex, and just under one-quarter had condomless sex with ≥ 1 partner(s) of unknown HIV status. Approximately 10% of the sample had condomless sex due to difficulties negotiating condom use (n=71).

Table 14: Sexual behaviour in the previous six months (N=732)

Category	n	%
Number of sexual partners (N=679)		
1	501	73.8
2-3	128	18.9
4+	50	7.4
Gender of sexual partners (N=730)		
Exclusively male	584	80.0
Exclusively female	42	5.8
Exclusively transgender/non-binary/gender diverse	17	2.3
>1 type of partner	87	11.9
Condomless anal or vaginal sex (N=728)		
Yes	552	75.8
No	176	24.2
Condomless sex with partners of unknown HIV status (N=721)		
Yes	173	24.0
No	548	76.0
Difficulties negotiating condom use (N=728)		
Yes	71	9.8
No	657	90.2

7.5.10 PrEP items

7.5.10.1 *PrEP awareness and use*

Seventy-one per cent of the sample (n=688) were aware of PrEP before participating in the study (Table 15). The majority of participants heard of PrEP in the news or on the internet (56%, n=385), followed by friends or family (17%, n=117) and work or training (13.23%, n=91). Less than one per cent of the sample had ever used PrEP (n <10).

7.5.10.2 *PrEP interest*

Among participants whose HIV status was negative or unknown (n=948), 43% agreed or strongly agreed that they would be interested in learning more about PrEP, and 11% (n=106) that they would be interested in using PrEP.

7.5.10.3 *Preferences for PrEP modality and location*

Participants who indicated they were interested in learning more about PrEP and/or were interested in taking PrEP (44.6%, n=434) were asked about their preferred locations to get PrEP and preferred modality (Table 15). As more than one selection was allowed for each question, therefore the per cent add up to greater than 100.

The most preferred modality was long-acting injectable PrEP (53%, n=228), followed by event-based PrEP (51%, n=223). Daily PrEP (at the time of writing, the only PrEP available in the UK recommended for cisgender women) was a preference for only 38% of the sample (n=164). Less than ten per cent (7.1%, n=31) would not want to use any of the response options.

Regarding setting preference for getting a PrEP prescription, a similar proportion would prefer to get PrEP from a Pharmacy or Pharmacist (74%, n=321) and from the sexual health clinic (74%, n=320), closely followed by a GP surgery (70%, n=303). Only 2.3% (n=10) of respondents did not find any of these venues acceptable.

Table 15: PrEP awareness, interest, and preferences (N=974)

Category	n	%
Aware of PrEP (N=974)		
Yes	688	70.6
No	286	29.4
First learned about PrEP from (N=688)*		
Sexual health clinic	41	6.0
Sexual partner	5	0.7
Friend or family member	117	17.0
In the news or on the internet	385	56.0
Through work or training	91	13.2
TV or other media	30	4.4
Other	19	2.8
Ever used PrEP (N=973)		
Yes	6	0.6
No	967	99.4
Interested in learning more about PrEP (N=942)**		
Strongly/tend to agree	413	43.8
Uncertain or tend to/strongly disagree	533	56.6
Interested in using PrEP (N=942)**		
Strongly/tend to agree	106	11.3
Uncertain or tend to/strongly disagree	840	89.2
Preferred PrEP modality (N=434)***^		
Daily Pill	164	37.8
Event based PrEP	223	51.4
Long-acting injectable	228	52.5
Removeable implant	149	34.3
Another method	11	2.5
None of these methods	31	7.1
Preferred location to access PrEP (N=434)***^		
Sexual health clinic	320	73.7
GP surgery	303	69.8
Pharmacy	321	74.0
The internet	198	45.6
A private clinic	70	16.1
Another location	4	0.9
None of these locations	10	2.3

*Only asked to respondents who were aware of PrEP

**Only asked to respondents who reported their HIV status as negative or unknown and who had never used PrEP

***Only asked to respondents who were interested in learning more about PrEP

^Respondents could choose >1 response.

7.5.11 Logistic regression analyses

7.5.11.1 *PrEP awareness*

As discussed in the methods, only participants with a complete set of responses for the explanatory and outcome variables were included in the logistic regression analyses. For the survey sample included in the logistic regression model (N=686), the level of awareness was similar to that of the total survey population (72.5% vs 70.6%, respectively). Sample composition, and the results of the univariable and multivariable analyses are included in Table 16.

7.5.11.1.1 Univariable analysis

In the univariable analysis, more women age 26-35 had heard of PrEP, compared to women age 18-25 (80.6% vs 68.3%), whereas fewer women age 45+ were aware of PrEP (44.8%), and this association was significant in the univariable regression (unadjusted odds ratio (OR) = 1.93, Confidence interval (CI) 1.27 – 2.94) for women 26 – 35 vs. 0.38 (0.21-0.67). Women who identified as LGB+, lived in London, lived in an urban environment, were educated to degree level or higher, were in full or part/time employment, also had a higher level of PrEP awareness compared to their counterparts (Table 16).

Levels of awareness were similar across ethnicities, with the exception of participants who reported their ethnicity as Asian. Forty-seven per cent of Asian participants (OR = 0.32, CI 0.17-0.61) had previously heard of PrEP, compared to 75% of both black and mixed/other ethnicity and 74% of white participants.

Participants who were actively practicing a religion had lower levels of PrEP awareness compared to participants who were not (60.9% vs 73%, OR = 0.55, CI 0.33-0.94). There was a small difference in PrEP awareness between participants who were single/in more than one kind of relationship^{xxx} and participants who were married or in a committed relationship (69.2% vs 76.2%, OR = 1.41 (CI 1.01 – 2.00)). Awareness also increased slightly as participants' level of social support increased

^{xxx} This category includes all participants who did not report being in a monogamous relationship, e.g. single participants, participants in a casual relationship and participants who were “dating”, in a polyamorous relationship, or reported being in >1 type of relationship.

(65.2% vs 73.4% vs 76.7% for a poor, moderate, and strong level of social support, respectively), and was higher among participants who had enough money to meet expenses and needs vs those who did not (73.7% vs 60.9%, OR = 1.81, CI 1.07-3.01)).

There was no significant association between PrEP awareness and reporting a mental or physical disability, experiencing IPV in the past year, or experiencing housing instability in the past year.

Perceived risk of HIV was not significantly associated with awareness of PrEP, however, engaging in health seeking behaviour was. More participants who had ever visited a SHC reported awareness of PrEP than those who had not (78.6% vs 69.9%, OR = 2.46, CI 1.74-3.49), and awareness was even higher among participants who had ever had an HIV test compared to those who had not (82.5% vs 58.9%, OR = 3.29, CI 2.32-4.68).

Table 16: Associations with PrEP awareness among the general survey sample (unadjusted and adjusted odds ratios) (N=686)

Characteristic	Sample composition (col%, n)	Aware of PrEP (row %, n)	OR	95% CI	P-value	AOR	95% CI	p-value
Total (686)	100% (686)	72.45% (497)						
Age								
18-25	27.55 % (189)	68.25% (129)	1		<0.001	1		<0.001
26-35	43.49% (299)	80.60% (241)	1.93	1.27-2.94		0.86	0.50-1.47	
36-45	19.10% (131)	74.05% (97)	1.33	0.81-2.19		0.7	0.36-1.33	
45 +	9.77% (67)	44.78% (30)	0.38	0.21-0.67		0.22	0.11-0.44	
Gender identity								
Cisgender	92.57% (635)	71.81% (456)	1		0.2	1		0.2
Transgender, Nonbinary, or identifies in another way	7.43% (51)	80.39% (41)	1.61	0.82-3.46		1.75	0.79-4.18	
Sexual identity								
Straight/heterosexual	49.85 (342)	66.37% (227)	1		<0.001	1		<0.001
Gay, Lesbian, Bisexual, or identifies in another way	50.15% (342)	78.49% (270)	1.85	1.32-2.61		2.2	1.44-3.40	
Ethnicity								
White	81.20% (557)	73.79% (411)	1		0.006	1		0.002
Asian	6.12% (42)	47.62% (20)	0.32	0.17-0.61		0.24	0.12-0.51	
Black	4.23% (29)	75.86% (22)	1.12	0.49-2.87		0.97	0.39-2.73	
Mixed or other	8.45% (58)	75.86% (44)	1.12	0.61-2.17		0.68	0.35-1.41	
Region of England								
London	34.26% (235)	79.75% (187)	1		0.002	1		0.6
Outside London	65.74% (451)	68.74% (310)	0.56	0.39-0.82	0.78	0.89	0.56-1.38	
Urban/Rural classification								
Urban	89.94% (617)	74.07% (457)	1		0.006	1		0.053
Rural	10.06% (69)	57.97% (40)	0.48	0.29-0.81		0.55	0.31-1.01	
Education level								
Degree or higher	73.62% (505)	78.81% (398)	1		<0.001	1		<0.001
Less than degree level	26.38% (181)	54.70% (99)	0.32	0.23-0.47		0.3	0.19-0.46	
Employment Status								
Full/Part time employed	64.72% (444)	76.58% (340)	1		0.001	1		0.4
Not in employment	35.28% (242)	64.88% (157)	0.56	0.40-0.80		1.22	0.78-1.93	

OR = odds ratio, CI = Confidence Interval, AOR = adjusted odds ratio

Characteristic	Sample composition (col%, n)	Aware of PrEP (row %, n)	OR	95% CI	P-value	AOR	95% CI	p-value
Total (686)	100% (686)	72.45% (497)						
Religion								
Not religious or actively practising a religion	89.94% (617)	73.74% (455)	1		0.028	1		0.6
Actively practising a religion	10.06% (69)	60.87% (42)	0.55	0.33-0.94		0.83	0.45-1.55	
Relationship status								
Married/in a committed relationship	55.25% (379)	69.39% (263)	1		0.046	1		0.014
Single or other type of relationship	44.75% (307)	76.22% (234)	1.41	1.01-2.00		1.64	1.10-2.46	
Level of social support								
Poor	26.82% (184)	65.22% (120)	1		0.031	1		0.5
Moderate	41.25% (283)	73.85% (209)	1.51	1.01-2.25		1.29	0.80-2.07	
Strong	31.92% (219)	76.71% (168)	1.76	1.14-2.73		1.27	0.75-2.14	
Enough money to meet expense and needs								
Some of the time/No	10.06% (69)	60.87% (42)	1		0.028	1		0.039
Always/Most of the time	89.94% (617)	73.74% (455)	1.81	1.07-3.01		1.9	1.03-3.46	
Experienced Housing instability, past year								
No	90.23% (619)	72.05% (446)	1		0.5	1		0.6
Yes	9.77% (67)	76.12% (51)	1.24	0.70-2.29		1.2	0.62-2.42	
Disability								
No/Unsure	67.78% (465)	72.47% (337)	1		>0.9	1		>0.9
Yes	32.22% (221)	72.40% (160)	1	0.70-1.43		1.01	0.66-1.57	
Experienced IPV, past year								
No	91.55% (628)	72.45% (455)	1		>0.9	1		0.8
Yes	8.45% (58)	72.41% (42)	1	0.56-1.87		0.93	0.47-1.88	
Ever visited a SHC								
No	33.09% (227)	59.91% (136)	1		<0.001	1		0.012
Yes	66.91% (459)	78.65% (361)	2.46	1.74-3.49		1.79	1.14-2.81	
Ever had an HIV test								
No	42.57% (292)	58.90% (172)	1		<0.001	1		<0.001
Yes	57.43% (394)	82.49% (325)	3.29	2.32-4.68		2.46	1.59-3.84	
Perceived risk of HIV								
Not very/Not at all at risk	93.88% (644)	72.20% (465)	1		0.6	1		>0.9
Greatly/Quite a lot at risk	6.12% (42)	76.19% (32)	1.23	0.61-2.69		0.99	0.45-2.35	

OR = odds ratio, CI = confidence interval, AOR = adjusted odds ratio, IPV = Intimate partner violence, SHC = sexual health clinic

7.5.11.1.2 Multivariable logistic regression

The final multivariable model was adjusted for the effect of age, sexual identity, ethnicity, urban/rural classification, education level, relationship status, having enough money to meet expenses and needs, ever visiting a sexual health clinic and ever having an HIV test.

In the multivariable model, the association between age group and PrEP awareness persisted for participants who were age 45 or older, compared to participants who were age 18 – 25 (adjusted odds ratio (aOR) = 0.22, CI 0.11 – 0.44), however, unlike in the univariable models, there was no significant association for the other age groups. The association between sexual identity and awareness also persisted (aOR = 2.20, CI 1.44-3.40), as did the association with having enough money to meet expenses and needs (aOR = 1.9, CI 1.03 – 3.46), and being single or in >1 type of relationship (aOR = 1.64, CI 1.10 – 2.46).

As in the univariable models, Participants who were educated to less than degree level had lower odds of PrEP awareness compared to those educated to degree level or higher (aOR = 0.3, CI 0.19-0.46). For Asian participants, the odds of being aware of PrEP compared to white participants decreased slightly in the multivariable model (aOR = 0.24, CI 0.12 – 0.51 vs OR = 0.32, CI 0.17-0.61).

Although in the univariable model, PrEP awareness was significantly associated with living in London, living in an urban environment, being in employment, actively practicing a religion, and higher levels of social support, these associations did not persist in the multivariable model.

Engaging in health seeking behaviour remained significantly associated with awareness in the multivariable model for both ever having visited a SHC (aOR = 1.79, CI 1.14 – 2.81), and ever having had an HIV test (aOR = 2.46, CI 1.59 – 3.84).

7.5.11.1.3 PrEP awareness among the sexually active sample (sensitivity analysis)

For the sample who were sexually active in the preceding six months, the level of PrEP awareness was slightly higher compared to the general survey sample (i.e.,

the population included in the univariable analysis above) and the total survey population (75.10% vs 72.5% vs 70.6%, respectively). Additional explanatory variables were included for this population: number of sexual partners, having condomless sex with a partner of unknown HIV status, and difficulties negotiating condom use within the preceding six months. Sample composition and the results of the univariable and multivariable analyses are presented in Table 17.

7.5.11.1.3.1 Univariable analysis

Unlike in the general survey sample, PrEP awareness was not significantly associated with age, ethnicity, region of England, urban/rural classification, actively practicing a religion, having enough money to meet expenses and needs, level of social support or employment status in the univariable analysis for the population who was sexually active in the preceding six months.

However, as was the case for the general survey sample, participants who had an LGB+ sexual identity reported higher PrEP awareness (81.8% for LGB+ vs 68.4%, OR = 2.07, CI 1.36 – 3.19), as did participants who were single or in >1 type of relationship (82.3% vs 71.4%, OR = 1.86, CI 1.18 – 3.01). Similarly, participants whose education level was less than degree level reported lower PrEP awareness (57.8% vs 80.5% for participants educated to degree level or higher, OR = 0.33, CI 0.21 – 0.52).

Engaging in health seeking behaviour was similarly associated with awareness in this sample. Participants who had ever visited a SHC reported higher awareness of PrEP than those who had not (80.5% vs 61.6%, OR = 2.61, CI 1.69-4.03), as did participants who had ever had an HIV test compared to those who had not (84.6% vs 59.1%, OR = 3.8, CI 2.48-5.86).

For the sexual behaviour variables, only number of sexual partners was significantly associated with PrEP awareness. Participants who reported four or more sexual partners in the preceding six months had the highest PrEP awareness (91.7%), compared to participants reporting two to three partners (79.8%) and those reporting one partner (72.2%). There was no significant association between condomless sex or difficulties negotiating condom use.

Table 17: Associations with PrEP awareness among sexually active sample (unadjusted and adjusted odds ratios) (N=486)

Characteristic	Sample composition (col%)(n)	Aware of PrEP %(n)	OR	95% CI	P-value	AOR	95% CI	p-value
Total	100% (486)	75.10% (365)						
Age								
18-25	26.75% (130)	73.08% (95)	1		0.052	1		0.3
26-35	49.97% (238)	78.99% (188)	1.39	0.84-2.27		0.75	0.38-1.45	
36-45	18.31% (89)	74.16% (66)	1.06	0.58-1.97		0.72	0.32-1.60	
45 +	5.97% (29)	55.17% (16)	0.45	0.20-1.05		0.35	0.13-0.97	
Gender identity								
Cisgender	94.03% (457)	74.62% (341)	1		0.3	1		0.4
Transgender, nonbinary, or identifies in another way	5.97% (29)	82.76% (24)	1.63	0.66-4.94		1.55	0.55-5.15	
Sexual identity								
Straight/heterosexual	50.21% (244)	68.44% (167)	1		<0.001	1		<0.001
Gay, Lesbian, Bisexual, or identifies in another way	49.79% (242)	81.82% (198)	2.07	1.36-3.19		3.01	1.84-5.01	
Ethnicity								
White	82.51% (401)	75.81% (304)	1		0.2	1		0.3
Asian	5.14% (25)	56.00 % (14)	0.41	0.18-0.94		0.46	0.18-1.18	
Black	3.50% (17)	82.35% (14)	1.49	0.47-6.56		1.29	0.36-6.18	
Mixed or other	8.85% (43)	71.76% (33)	1.05	0.52-2.32		0.69	0.31-1.66	
Region of England								
London	34.57% (168)	77.89% (131)	1		0.3	1		0.7
Outside London	65.43% (318)	73.58% (234)	0.79	0.50-1.22		1.12	0.67-1.84	
Urban/rural classification								
Urban	90.53% (440)	76.14% (335)	1		0.11	1		0.2
Rural	9.47% (46)	65.22% (30)	0.59	0.31-1.14		0.59	0.29-1.26	
Education level								
Degree or higher	76.13% (370)	80.54% (298)	1		<0.001	1		<0.001
Less than degree level	23.87% (116)	57.76% (67)	0.33	0.21-0.52		0.27	0.15-0.47	
Employment status								
Full/Part time employed	67.28% (327)	76.76% (251)	1		0.2	1		0.2
Not in employment	32.72% (159)	71.70% (141)	0.77	0.50-1.18		1.47	0.87-2.54	

OR = odds ratio, CI = Confidence Interval, AOR = adjusted odds ratio

Characteristic	Sample composition (col%)(n)	Aware of PrEP %(n)	OR	95% CI	P-value	AOR	95% CI	p-value
Total	100% (486)	75.10% (365)						
Religion								
Not religious or actively practising a religion	91.77% (446)	75.78% (338)	1		0.3	1		0.6
Actively practising a religion	8.23% (40)	67.50% (27)	0.66	0.34-1.37		0.81	0.38-1.81	
Relationship status								
Married/in a committed relationship	66.26% (322)	71.43% (230)	1		0.007	1		0.5
Single/In >1 type of relationship	33.74% (164)	82.32% (135)	1.86	1.18-3.01		1.21	0.66-2.27	
Level of social support								
Poor	23.25% (113)	72.57% (82)	1		0.7	1		0.9
Moderate	41.77% (203)	74.88% (152)	1.13	0.66-1.89		0.95	0.52-1.71	
Strong	34.89% (170)	77.06% (131)	1.27	0.73-2.19		1.1	0.59-2.06	
Enough money to meet expense and needs								
Some of the time/No	9.05% (44)	65.91% (29)	1		0.2	1		0.084
Always/Most of the time	90.95% (442)	76.02% (336)	1.64	0.83-3.13		1.98	0.91-4.20	
Experienced housing instability, past year								
No	89.71% (436)	74.77% (326)	1		0.6	1		0.6
Yes	10.29% (50)	78.00% (39)	1.2	0.61-2.53		1.22	0.57-2.78	
Disability								
No/Unsure	69.55% (338)	73.96% (250)	1		0.4	1		>0.9
Yes	30.45% (148)	77.70% (115)	1.23	0.78-1.96		1.01	0.6-1.71	
Experienced IPV, past year								
No	90.53% (440)	75.00% (330)	1		0.9	1		0.8
Yes	9.47% (46)	76.09% (35)	1.06	0.54-2.25		0.89	0.41-2.05	
Ever visited a SHC								
No	28.19% (137)	61.63% (84)	1		<0.001	1		0.027
Yes	71.81% (349)	80.52% (281)	2.61	1.69-4.03		1.79	1.07-3.00	
Ever had an HIV test								
No	37.42% (181)	59.12% (107)	1		<0.001	1		<0.001
Yes	62.76% (305)	84.59% (258)	3.8	2.48-5.86		3.18	1.93-5.32	

OR = odds ratio, CI = confidence interval, AOR = adjusted odds ratio, IPV = Intimate partner violence, SHC = sexual health clinic

Characteristic	Sample composition (col% (n)	Aware of PrEP %(n)	OR	95% CI	P-value	AOR	95% CI	p-value
Total	100% (486)	75.10% (365)						
Perceived risk of HIV								
Not very/Not at all at risk	93.42% (454)	74.89% (340)	1		0.7	1		0.5
Greatly/Quite a lot at risk	6.58% (32)	78.12% (25)	1.2	0.53-3.07		0.67	0.24-2.02	
Number of sexual partners								
1	73.25% (356)	72.19% (257)	1		<0.001	1		0.07
2 to 3	19.34% (94)	79.79% (75)	1.52	0.89-2.71		1.25	0.69-2.35	
4+	7.41% (36)	91.67% (33)	4.24	1.48-17.9		3.78	1.18-17.2	
Condomless sex with partners of unknown HIV status								
No	76.95% (374)	76.47% (286)	1		0.2	1		0.4
Yes	23.05% (112)	70.54% (79)	0.74	0.46-1.19		0.79	0.45-1.38	
Difficulties negotiating condom use								
No	92.18% (448)	75.00% (336)	1		0.9	1		0.7
Yes	7.82% (38)	76.32% (29)	1.07	0.51-2.47		0.84	0.34-2.19	

OR = odds ratio, CI = confidence interval, AOR = adjusted odds ratio

7.5.11.1.3.2 Multivariable analysis

The final multivariable analysis was adjusted for sexual identity, education level, employment status, having enough money to meet expenses and needs, ever visiting a sexual health clinic, ever having an HIV test, and partner number.

In the multivariable analysis, higher odds of PrEP awareness were only significantly associated with reporting an LGB+ sexual identity (aOR = 3.01, CI 1.84-5.01), ever visiting a sexual health clinic (aOR = 1.79, CI 1.07 – 3.00), and ever having an HIV test (aOR = 3.18, CI 1.93 – 5.32). Lower odds of PrEP awareness was associated with an education level that was less than degree level (aOR = 0.27, CI 0.15 – 0.47).

7.5.11.2 *PrEP interest*

As for PrEP awareness, only participants with a complete set of answers for the explanatory and outcome variables were included in the logistic regression analyses for PrEP interest. As discussed above, only participants who reported being sexually active in the preceding six months and reported their HIV status as negative or unknown were included in the analyses. Interest in PrEP was similar between this sample and the total survey population (12.6% vs 11.2%). Sample composition, and the results of the univariable and multivariable analyses are included in Table 18.

Table 18: Associations with PrEP interest among the sexually active sample (unadjusted and adjusted odds ratios) (N=454)

Characteristic	Sample composition (col%, n)	Interest in PrEP (row%, n)	OR	95% CI	P-value	AOR	95% CI	P-value
Total (454)	100% (454)	12.58% (61)						
Age								
18-25	26.80% (130)	17.69% (23)	1		0.2	1		0.7
26-35	49.07% (238)	10.50% (25)	0.55	0.3-1.01		0.84	0.40-1.79	
36-45	18.35% (89)	12.36% (11)	0.66	0.29-1.40		0.99	0.39-2.45	
45 +	5.77% (28)	7.14% (2)	0.36	0.06-1.32		0.41	0.05-1.89	
Gender identity								
Cisgender	94.02% (456)	10.96% (50)	1		<0.001	1		0.014
Transgender, Nonbinary, or identifies in another way	29 (5.98%)	37.93% (11)	4.96	2.16-11.0		3.31	1.28-8.23	
Sexual identity								
Straight/heterosexual	50.01% (243)	9.88% (24)	1		0.071	1		0.6
Gay, Lesbian, Bisexual, or identifies in another way	49.90% (242)	15.29% (37)	1.65	0.96-2.88		1.21	0.62-2.38	
Ethnicity								
White	82.47% (400)	11.25% (45)	1		0.029	1		0.073
Asian	5.15% (25)	32.00% (8)	3.71	1.44-8.87		3.72	1.30-9.86	
Black	3.15 (17)	23.53% (4)	2.43	0.66-7.20		1.36	0.31-4.74	
Mixed, or other	8.87% (43)	9.30% (4)	0.81	0.23-2.13		0.62	0.16-1.90	
Region of England								
London	34.64% (168)	14.29% (24)	1		0.4	1		0.5
Outside London	65.36% (317)	11.67% (37)	0.79	0.46-1.39		0.81	0.43-1.53	
Urban/Rural classification								
Urban	90.52% (439)	12.30% (54)	1		0.6	1		0.7
Rural	9.48% (46)	15.22% (7)	1.28	0.50-2.84		1.21	0.43-2.99	
Education level								
Degree or higher	76.08% (369)	11.65% (43)	1		0.3	1		0.3
Less than degree level	23.92% (116)	15.52% (18)	1.39	0.75-2.49		0.69	0.32-1.44	
Employment Status								
Full/Part time employed	67.42% (327)	8.87% (29)	1		<0.001	1		0.006
Not in employment	32.58% (158)	20.25% (32)	2.61	1.51-4.52		2.4	1.29-4.48	

OR = odds ratio, CI = confidence interval, AOR = adjusted odds ratio

Characteristic	Sample composition (col%, n)	Interest in PrEP (row%, n)	OR	95% CI	P-value	AOR	95% CI	P-value
Total (454)	100% (454)	12.58% (61)						
Religion								
Not religious or actively practicing a religion	91.75% (445)	12.36% (55)	1		0.6	1		0.9
Actively practising a religion	8.25% (40)	15.00% (6)	1.25	0.46-2.92		0.92	0.30-2.44	
Relationship status								
Married/in a committed relationship	66.19% (321)	8.10% (26)	1		<0.001	1		0.2
Single/In >1 type of relationship	33.81% (164)	21.34% (35)	3.08	1.79-5.37		1.6	0.76-3.36	
Level of social support								
Poor	23.30% (113)	20.35% (23)	1		0.022	1		0.3
Moderate	41.65% (202)	10.89% (22)	0.48	0.25-0.91		0.59	0.28-1.22	
Strong	35.05% (170)	9.41% (16)	0.41	0.20-0.80		0.56	0.25-1.21	
Enough money to meet expense and needs								
Some of the time/No	9.07% (44)	15.91% (7)	1		0.5	1		0.9
Always/Most of the time	90.93% (441)	12.24%(54)	0.74	0.33-1.88		0.94	0.38-2.64	
Experienced housing instability, past year								
No	89.69% (435)	11.72% (51)	1		0.12	1		0.3
Yes	10.31% (50)	20.00% (10)	1.88	0.85-3.87		1.55	0.65-3.43	
Disability								
No/Unsure	69.48% (337)	9.50% (32)	1		0.003	1		0.032
Yes	30.52% (148)	19.59% (29)	2.32	1.34-4.01		1.97	1.06-3.63	
Experienced IPV, past year								
No	90.52% (439)	11.62% (51)	1		0.067	1		0.5
Yes	9.48% (46)	21.74% (10)	2.11	0.94-4.38		1.36	0.54-3.17	
Ever visited a SHC								
No	28.04% (136)	11.76% (16)	1		0.7	1		0.4
Yes	71.96% (349)	12.89% (45)	1.11	0.62-2.09		1.42	0.67-3.12	
Ever had an HIV test								
No	37.11% (180)	11.11% (20)	1		0.5	1		0.1
Yes	62.80% (305)	13.44% (41)	1.24	0.71-2.23		1.8	0.90-3.71	

OR = odds ratio, CI = confidence interval, AOR = adjusted odds ratio, IPV = intimate partner violence, SHC = sexual health clinic

Characteristic	Sample composition (col%, n)	Interest in PrEP (row%, n)	OR	95% CI	P-value	AOR	95% CI	P-value
Total (454)	100% (454)	12.58% (61)						
Perceived risk of HIV								
Not very/Not at all at risk	93.40% (453)	10.38% (47)	1		<0.001	1		0.007
Greatly/Quite a lot at risk	6.60% (32)	43.75% (14)	6.72	3.10-14.4		3.57	1.43-8.70	
Number of sexual partners								
1	73.20% (355)	9.30% (33)	1		<0.001	1		0.019
2 to 3	19.38% (94)	14.89% (14)	1.71	0.85-3.28		1.4	0.66-2.84	
4+	7.42% (36)	38.89% (14)	6.21	2.86-13.2		3.94	1.54-9.78	
Condomless sex with partners of unknown HIV status								
No	76.91% (373)	11.8% (44)	1		0.4	1		0.7
Yes	23.09% (112)	15.18% (17)	1.34	0.71-2.41		0.86	0.40-1.76	
Difficulties negotiating condom use								
No	92.16% (447)	11.19% (50)	1		0.005	1		0.2
Yes	7.84% (38)	28.95% (11)	3.23	1.46-6.77		1.82	0.68-4.49	
Aware of PrEP								
No	24.74% (120)	14.17% (17)	1		0.5	1		0.14
Yes	75.26% (365)	12.05% (44)	0.83	0.46-1.55		0.58	0.29-1.20	

OR = odds ratio, CI = confidence interval, AOR = adjusted odds ratio,

7.5.11.2.1 Univariable analysis

PrEP interest was higher among participants reporting their gender identity as trans, nonbinary, or in another way^{xxxi} (hereafter referred to as trans and/or gender diverse participants). Participants who were of Asian ethnicity reported higher PrEP interest compared to white participants (32.0% vs 11.25%, OR = 3.77, CI 1.44 – 8.87), as did participants who were not in employment compared to those who were (20.3% vs 8.9%, OR = 2.61, CI 1.51 – 4.52), and participants who were single or in >1 kind of relationship compared to those in a committed relationship (21.3% vs 8.1%, CI 1.79 – 5.37). Participants who considered themselves to have a mental or physical disability were also more likely to be interested in PrEP compared to those not reporting a disability (19.6% vs 9.5%, OR = 2.32, CI 1.34 – 4.01).

Participants who reported higher levels of social support reported lower levels of PrEP interest. One-fifth of participants whose level of social support was “poor” were interested in taking PrEP, vs 10.9% of participants with a “moderate” level of social support (OR = 0.48, CI 0.25 – 0.91) and 9.4% of participants with “strong” level of social support (OR = 0.41, CI 0.20-0.80).

Unlike for awareness, there was no significant association between engaging in sexual health seeking behaviour and PrEP interest. However, participants who perceived themselves to be “greatly” or “quite a lot” at risk of HIV reported higher PrEP interest than those who perceived themselves to be “not very” or “not a lot” at risk (43.8% vs 10.4%, OR = 6.72, CI 2.86 – 13.2). Participants with four or more partners were also more likely to be interested compared to those reporting one partner (38.9% vs 9.3%, OR = 6.21, CI 2.86 – 13.2). Difficulty negotiating condom use with partners was also associated with PrEP interest; 28.9% of participants reporting difficulties negotiating condom use were interested in PrEP, compared to 11.2% of participants without difficulties negotiating condom use (OR = 3.23, CI 1.46 – 6.77).

There was no significant association between PrEP awareness and PrEP interest.

^{xxxi} This includes participants who identified as gender fluid, gender diverse, or identified in another way, i.e., all participants who did not identify as cisgender.

7.5.11.2.2 Multivariable analysis

The final multivariable analysis was adjusted for PrEP awareness, gender identity, employment status, disability status, ever having an HIV test, self-perceived HIV risk, and partner number.

The association with identifying as trans and/or gender diverse persisted in the multivariable model (aOR = 3.31, CI 1.28 – 8.23), as did the association with not being in employment (aOR = 2.4, CI 1.29 – 4.48), and having a disability (aOR = 1.97, CI 1.06 – 3.63). After adjustment in the multivariable model, there was no significant association with ethnicity, relationship status, or level of social support.

The association with perceived risk of HIV also persisted in the multivariable model, although it was less strong (aOR = 3.57, CI 1.43 -8.70), and similar was observed for reporting four or more sexual partners (aOR = 3.94, CI 1.54 – 9.78). After adjustment, there was so significant association between difficulties negotiating condom use and interest in PrEP.

7.6 Discussion

I conducted a non-probability, self-completion, online convenience survey of 977 women in England, reported the sociodemographic, sexual behaviour, and HIV testing/perception and baseline characteristics of the sample, and compared key demographic variables to the census data. To my knowledge, this analysis presents the first cross-sectional survey of women's awareness, interest, and preferences for PrEP in England, that investigates the association between these outcomes and socio-demographic and other PROGRESS-Plus factors that can impact health equity.

7.6.1 Summary of findings

PrEP awareness was high in the survey population, with over 70% of participants aware of PrEP before taking part in the survey. Very few participants had ever used PrEP, but just over 40% of participants expressed an interest in learning more about PrEP, and just over one in ten respondents were interested in using PrEP. The majority of participants who were aware of PrEP learned about it from the news or the internet.

Among participants who expressed either interest in learning about or using PrEP, there was variation in preference and venue for receiving PrEP; however, the most preferred methods for modality were long-acting injectable and event-based PrEP, neither of which are currently available for women. Similarly, preferred venues for accessing PrEP included pharmacies and GP surgeries, neither of which are routinely available for PrEP access in England.

In the multivariable analyses for the general survey sample, there were differences in PrEP awareness by age group, sexual identity, socioeconomic status, relationship status, education level, and ethnicity. However, in the sample that had sex in the previous six months, only the association between identifying as LGB+ and being educated to less than degree level persisted. In both populations, participants who engaged in health seeking behaviour (i.e., attending a SHC and testing for HIV) had higher odds of PrEP awareness.

PrEP interest was associated with identifying as gender diverse, having a mental or physical disability, and not being in employment in the multivariable model. Participants who perceived themselves as at risk of HIV and/or had four or more partners in the preceding six months had higher odds of PrEP interest.

7.6.2 Discussion of findings in the context of the published literature

7.6.2.1 Recruitment and response

As above the recruitment strategy for this study was modelled on McCarthy et al.'s reproductive health survey¹⁹. In my study, there were 1404 survey initiations and 988 completed (submitted) surveys, a 70% completion rate compared to 13,962 initiations and 11,578 completions (an 83% completion rate) in the reproductive health survey. Despite having a lower overall spend the reproductive health survey was able to recruit more participants; with a total budget of £4068.41 across Facebook and Instagram^{xxxii}, the reproductive health survey spent £0.29 per survey initiation and £0.35 per completion. Conversely, for my project, there was a total budget of £5300 across all platforms at a cost of £3.49 per initiation and £5.60 per completion.

^{xxxii}The reproductive health survey took place before Facebook Inc was renamed Meta Inc

There are several possible reasons for the large discrepancy in survey initiations between the two studies. The survey in my study was presented as an “HIV prevention survey”, rather than a reproductive survey, and this may have contributed to the comparatively lower rate of survey initiations and completions. In the UK, HIV is still highly misunderstood and stigmatised among the general population⁴⁶⁴, and it is possible that women encountering the study advertisements did not feel that a survey focused on HIV prevention was relevant to them. This is discussed further in the “Limitations” below. The time of year in which the survey was run is another possible reason for the difference in initiations. The survey and advertisements ran in late November/December, and there may have been more advertising competition from retailers promoting gifts and items for the Christmas season, therefore fewer women may have encountered the study advertisements. Although I had used the Meta advertising platform previously when recruiting for the qualitative study (Chapter 6), those advertisements were run at a much smaller scale. I was also less familiar with Google advertising platforms, which were used in this study, and the adverts may not have been optimised for the target audience. Google advertising optimisation requires a level of data collection and tracking, which was not only incompatible with the UCL DSH version of REDCap but would also compromise the confidentiality of the survey.

In the reproductive health survey, item non-response was less than 1% for most survey items¹⁹. Although both studies asked participants to supply their postcodes, 99% of participants in the reproductive health survey obliged, compared to approximately 80% of participants in my study. Both surveys included questions that were of a sensitive nature (e.g., participant’s level of sexual activity, questions on sexual behaviour), however, it is possible that that emphasis on HIV prevention made participants less willing to provide their postcode.

In the reproductive health survey, respondents identifying as white were overrepresented compared to the national census estimates, and participants identifying as black were under-represented¹⁹. However, in my study, the distribution of participant ethnicity was more similar to the 2021 census estimates. In both studies, women who were educated to degree level or higher were over-represented.

7.6.2.2 HIV testing

Over half of the survey population reported ever having had an HIV test. The equivalent prevalence estimate from the 2010-2012 Natsal-3 data is 23.2% of women age 16 -74. Although these samples are not directly comparable, the results of this sample do suggest that my survey over-sampled women who had previously engaged with HIV prevention. It is important to note that the survey did not collect data on the reasons why participants had previously tested for HIV, so it is not possible to know the proportion of women who tested as part of antenatal screening, vs those who sought out, or were offered, an HIV test in another setting.

7.6.2.3 PrEP awareness

Just under three-quarters of the survey population were aware of PrEP prior to taking part in the study. Estimations of women's PrEP awareness vary widely in published studies; as discussed in Chapter 3, studies conducted in the six years following the FDA's approval of Truvada in the USA (i.e., up to 2018), PrEP awareness among women in the USA was estimated to be between 0%-33%^{14,193-196}, although more recent studies indicate that awareness has increased with time. For example, the early results from an ongoing survey in the USA reported that 71% of respondents were previously aware of PrEP¹⁹⁷, which is similar to the proportion reported in this study's sample.

There are few comparable quantitative studies among women in England. As above, in a survey conducted among women who experienced concerns around HIV from the Women and HIV Invisible No Longer report¹⁶², 74% of 151 women had previously heard of PrEP, whereas 22% of women surveyed in London in 2018⁴⁹⁵. More recently, among attendees of a SHS in Brighton in 2022, 32% of female respondents were aware of PrEP⁵⁴⁷.

PrEP awareness was associated with ever having an HIV test and similar findings were reported in a recent study from the USA surveying sexually active women in Miami; the study identified an association between a lifetime history of HIV testing and PrEP awareness¹⁹⁸. As discussed above, a high proportion of women in this sample had ever tested for HIV and/or had ever visited a SHC, and the survey likely over-sampled women who had engaged in sexual health seeking behaviour,

including HIV prevention. The Developing HIV Literacy Framework⁴⁴⁹, introduced in Chapter 6, provides a possible explanation for why women with a lifetime history of HIV testing had higher odds of PrEP awareness in these studies – testing for HIV implies a certain level of HIV literacy, and shows both willingness to engage with HIV and the ability to use and apply HIV information. Therefore, these women may be more likely to notice or encounter information about PrEP and HIV prevention in general (e.g., when engaging with HIV testing). This may also account for the relatively high level of PrEP awareness among women who had experienced concerns about HIV in the Women and HIV Invisible No Longer report¹⁶², as their concerns about HIV indicate that they have engaged with and applied HIV information.

There were differences in PrEP awareness across several sociodemographic and PROGRESS-Plus characteristics. For example, participants who identified as LGB+ had higher odds of PrEP awareness compared to those who identified as heterosexual or straight, and this association was significant in both the general survey sample and the sample of sexually active participants. Higher odds of awareness have also been reported for non-heterosexual identifying men⁵⁴⁸ and women¹⁹⁸ in studies from the USA. In general, there is a higher level of PrEP messaging that is targeted towards sexual minorities, particularly GBMSM^{140,466,549–551}, and it may be that LGB+ women who engage with sexual minority resources or spaces have more exposure to this messaging. This has an additional impact, as the majority of participants in this study learned about PrEP from the media, and as the majority of messaging and media coverage is focused on GBMSM, women may not realise that PrEP is relevant to them or recognise themselves as PrEP candidates.

Participants who were educated to less than degree level were less likely to be aware of PrEP compared to participants who were educated to degree level or higher, and the association was significant in both the general survey sample and the sexually active survey sample. Lower levels of education have been associated with lower levels of PrEP awareness in GBMSM^{354,552,553}, and in men and women more generally⁵⁴⁸. This finding suggests that RSE in schools may present an opportunity to introduce PrEP and address potential disparities in PrEP awareness among people who do not go on to pursue a degree or equivalent qualification. It must be noted, however, that additional interventions may be needed to improve

awareness among people who have already left formal education, particularly as women age 45 or over were less likely to be aware of PrEP in the general survey sample.

There were differences in PrEP awareness by participants' ethnicity. Differences in PrEP women's PrEP awareness by ethnicity have also been reported in studies from the USA^{548,554,555}, with women who belong to an ethnic minority group reporting lower levels of PrEP awareness than their white counterparts. For the general survey sample in this study, Asian participants had lower odds of PrEP awareness compared to white participants. Although the survey likely over-sampled women who were engaged with or familiar with HIV prevention, the association persisted after adjustment for ever having an HIV test. This suggests that there may be disparities in PrEP awareness for Asian women. However, as discussed in the results, fewer Asian participants supplied their postcode data in the survey, and therefore fewer Asian participants were included in the logistic regression analyses. Therefore, the sample may be biased, and these results should be interpreted with caution. Heterosexual women belonging to ethnic minorities are disproportionately affected by HIV in England^{23,133}, and further research into how ethnicity impacts not only PrEP awareness but also downstream outcomes such as PrEP uptake, may be important to ensure that women of all ethnicities are supported in engaging with their preferred methods of HIV prevention.

PrEP awareness was not significantly associated with social network support in this study, however, other studies have found evidence that social capital and social engagement can contribute to higher levels of PrEP engagement. For example, it has been reported that for GBMSM that more social network connections are associated with higher PrEP awareness^{556,557}, and engagement with peers can support learning information about PrEP⁵⁵⁸. For women, awareness of PrEP has been shown to be associated with having peers who are aware of PrEP³⁶⁹, and social support has been shown to be a correlate of increased PrEP interest and uptake^{369,459,558}. Therefore, social support itself may be less important for PrEP awareness than having members of a social network who are aware of PrEP. Therefore, social support itself may be less important for PrEP awareness than having members of a social network who are aware of PrEP. This means that social networks could be harnessed to improve PrEP awareness and knowledge among

women and that educational campaigns could be designed to take advantage of women's existing social networks.

Not all of the associations with sociodemographic and PROGRESS-Plus factors persisted between the general sample and the sample that was sexually active, however, it may still be important to identify these associations. As discussed in previous chapters, an individual's HIV risk may not be static; a person can go through "seasons of risk", wherein changes in their behaviour or circumstances may increase or decrease their risk of HIV acquisition^{559,560}. By identifying disparities in PrEP awareness for the general population, it makes it possible to design interventions or educational campaigns to address these disparities and improve equity in PrEP awareness, so that more women are equipped with information to make decisions about PrEP if or when it becomes relevant to them.

7.6.2.4 Interest

Just over one in ten participants in this study expressed an interest in using PrEP, and there is a lack of comparable studies among women in England to compare these results. Much of the research on women's interest in PrEP has been qualitative, and this is especially true for research on women in the UK¹⁶. Qualitative research has shown that women are generally positive about PrEP once they become aware of it^{14,200,202}, but less is known about the level of PrEP interest among women. As discussed in the background section of this chapter, the community-based "Flash! PrEP in Europe" survey reported that 18% of respondents expressed an interest in using PrEP, but this was only among a sample of 28 participants in the UK.

In the USA, studies investigating PrEP interest among women often focus on populations that are considered at elevated risk of HIV acquisition, such as women who use drugs⁵⁶¹, women who have experienced intimate partner violence^{303,328,329}, or women experiencing housing instability³¹⁹. In studies where the eligibility criteria do not include a specific risk factor for HIV, women are often recruited from family planning or sexual health services in the USA^{280,315,318,350,562}, and in these studies, PrEP interest or intent ranged from 32% - 76%. It is worth noting that interest and willingness were defined slightly differently in each of these studies, therefore conclusions about the overall level of PrEP interest among women attending SHS in

the USA should be interpreted with caution. For example, in one study, 76% of women responded that they would be “willing to try” PrEP, but only 22.4% of women in the same survey believed that they would benefit from taking PrEP³³⁵. Regardless, these estimates of PrEP interest are higher than the 11% of women in this study, but this is likely in part due to the differences in populations of interest and recruitment methods – in the studies from the USA, the women were recruited from SHS, and therefore were likely actively engaging in sexual health seeking behaviour and/or addressing a sexual health need at or near the time of participating, whereas this was not necessarily the case in my study’s sample.

As with awareness, there were differences in PrEP interest across several sociodemographic and PROGRESS-Plus characteristics, however, there was no overlap between the variables associated with PrEP awareness and PrEP interest in the multivariable models. PrEP interest was significantly associated with identifying as transgender, non-binary, or gender diverse. A recent global scoping review reported that willingness to take PrEP was high (80%) among transgender women⁵⁶³, however, studies that include both transgender and gender diverse women are scarce^{16,206} and transgender women are more often included in studies of GBMSM²⁰⁶. Given that transgender and gender diverse women face specific barriers to healthcare and sexual healthcare access^{206,563} compared to cisgender women, interventions to improve PrEP access among women must consider the impact of gender identity to ensure they do not introduce further inequities to PrEP engagement.

Having a disability was associated with an interest in PrEP. There is recognition that people with disabilities experience health disparities^{564,565}, and little is known about how having a disability might impact access to PrEP for women. The results of this survey suggest that care must be taken to ensure that competing health priorities do not hinder PrEP access for women who have a disability. Similarly, participants who were not in employment were more likely to be interested in PrEP. A lack of regular employment has been associated with early loss to follow up in a PrEP demonstration project³⁴³. Further investigation may be warranted into the barriers to PrEP access and continuation for people with a disability and/or who are not in employment.

Participants who perceived themselves to be greatly or quite a lot at risk of HIV had higher odds of being interested in PrEP compared to those who perceived themselves to be not very or not at all at risk. Higher risk perception has been identified as an association with PrEP interest for GBMSM^{267,368}, men and women generally^{352,566}, and women specifically³²⁶. However, research has shown that congruency between self-perceived risk and reported or objective HIV risk is often low^{567–571}, i.e., people considered at risk of HIV against a given criteria do not reliably perceive themselves to be at risk of HIV. This has implications for HIV prevention in general, as people who do not perceive themselves at risk of HIV may be less likely to engage in combination HIV prevention methods such as HIV testing, regardless of their “actual” or “objective” risk^{567,572}. Analysis of Natsal-3 data shows that women’s perceived risk of HIV is associated with reporting higher partner numbers and reporting condom-less sex with a new partner, but not other markers of sexual risk such as overlapping or concurrent partnerships⁵⁷³. Therefore, improving women’s ability to assess their own HIV risk may be as important to improving PrEP engagement as interventions to facilitate PrEP access. Further investigation into how women assess their HIV-risk may be warranted, and opportunities to assess this (e.g., from the upcoming Natsal-4 data, or through secondary analysis of this survey data) may help inform strategies to improve self-assessment of HIV risk and therefore engagement with combination HIV prevention services.

This study found that there was no association between PrEP awareness and PrEP interest. A lack of PrEP awareness has been identified as a barrier to PrEP uptake for women^{190–192}, and the results of this study further support the need to raise PrEP awareness among women as a way to improve women’s engagement with PrEP.

7.6.2.5 Preferences for PrEP among women

As with other aspects of PrEP implementation, much of the research on PrEP preferences in high-income countries had focused on GBMSM^{530,574–576}. Research focusing on women has mainly been conducted in areas of high HIV prevalence, such as Sub-Saharan Africa⁵⁷⁷ and/or included women considered at high risk of HIV acquisition, e.g., sex workers⁵⁷⁸).

Preference for modality varies depending on population and setting. For example, in the USA, one study found that black women found oral PrEP to be the most

preferred modality⁵⁷⁹, whereas LAI PrEP was preferred among a sample of women in Kenya⁵⁸⁰. Rather than identifying one ideal PrEP modality or service setting, many studies that investigate PrEP preferences emphasise that no one method will meet the needs of every individual and emphasise the importance of choice and options for PrEP and HIV prevention in general^{487,559,581}. In this study, there was no one modality or provision setting that was most preferred over others and given that over half of the participants chose >1 type of modality and setting, these results indicate that a variety of modalities and settings may need to be available to meet the HIV prevention preferences of women.

Similarly, expanding provision settings may encourage more women to engage with PrEP. The results of this study indicate that women would prefer a range of settings for accessing PrEP, and this is also true for contraception. A reproductive health survey conducted among women in England showed that there was variation in women's preferences for sourcing contraception⁴⁹⁸, and the move to provide the contraceptive pill over the counter in England has been seen as a positive step towards increasing access to contraception⁵⁸².

Currently, there is no option for women who want to take PrEP as event-based PrEP, or on-demand. However, the results of this study indicate that there is demand for alternative forms of PrEP that allow women to take it only during acute periods when they feel they will need it.

7.6.3 Strengths and limitations

A strength of this study is that, to my knowledge, this is the first cross-sectional study to gauge awareness, interest, and preferences for PrEP among a general sample of women in England since PrEP became routinely available on the NHS. The data presented on women's awareness, interest, and preferences for PrEP complement existing surveillance data and may be useful in planning and improving PrEP service delivery for women.

Running the survey online meant that it was possible to recruit a diverse sample of women, however, it did mean that women experiencing digital poverty, (e.g., with little or no access to digital technologies and/or internet access), might have been excluded. This is particularly important from an equity viewpoint, as people

experiencing digital poverty often experience other kinds of deprivation and social inequities more broadly⁵⁸³, and this would not have been captured in the survey. Similarly, only people who could read and comprehend English well enough to give informed support were able to participate in this study.

The online self-completion aspect of the survey offered a high degree of privacy and anonymity, which likely minimised the effect of social-desirability bias, however, there are other potential sources of bias in the survey. Although efforts were made to advertise the survey to a wide audience, it is possible that the subject matter (i.e., HIV prevention) meant that people with low HIV literacy may not have thought the survey was relevant to them, or that HIV-related stigma may have meant that people who were knowledgeable to comfortable discussing HIV were more likely to participate. This was found to be possible, as people who had previously tested for HIV were over-represented in the sample.

As no data was collected from people who initiated but did not complete the survey, it was not possible to determine the effect that non-response bias had on the final sample (i.e., if the people who initiated but did not complete the survey differed significantly from participants who completed the survey). However, it was possible to compare the sample who provided their postcode data to the 20% of respondents who did not. Non-response to the postcode question was associated with participant ethnicity, and this therefore introduced further bias into the final analyses on PrEP interest and awareness.

The convenience sampling method allowed for the recruitment of a large number of participants in a short span of time with limited resources. However, the sampling method (combined with sources of bias mentioned above) also means that there is limited generalisability to the wider population of women in England. The population recruited in this study was highly educated, and oversampled people who identified as LGB+ and/or trans or gender diverse and does not allow for comment on the level of PrEP awareness and interest among women more generally. This also meant that it was not possible to provide more granular analyses for key communities for HIV prevention, such as black African women or women engaging in exchange sex, due to the low number of respondents in these groups. However, although the results are

not more widely generalisable, they still provide a valuable benchmark for future studies investigating women's awareness of and interest in PrEP.

The limitations of cross-sectional surveys also apply to this study, for example, although it was possible to identify relationships between the explanatory and outcome variables, no causality can be inferred, and it is not possible to determine the temporal relation between the outcomes and associated explanatory variables (e.g., if a person in a committed relationship became aware of PrEP before or after entering that relationship)

7.7 Conclusions

In this chapter, I have demonstrated that PrEP awareness was high in a sample of women in England, but that awareness was strongly associated with previous engagement with HIV prevention. Interest in PrEP was associated with self-perceived HIV risk. Therefore, improving women's engagement with HIV prevention more generally may be a key facet to improving PrEP awareness and access for women in England.

In the next chapter, I present an integrated discussion of the three studies presented in this thesis. I discuss the strengths and limitations of the thesis overall and discuss the implications of the findings for sexual health promotion, public health and HIV policy, and future research directions.

Chapter 8 Discussion

8.1 Chapter overview

This thesis has presented the findings from three methods that I conducted to explore awareness, knowledge, and perceptions of PrEP among women in England through an equity lens. In this chapter, I first present a summary of findings from each study, and then consider the overall implications of the studies in an integrated narrative synthesis of the findings. The strengths and weaknesses of the whole thesis are discussed, as are the implications of the thesis findings for HIV prevention outreach, healthcare policy and practice, and future research.

8.2 Summary of the rationale and aims of the thesis

As discussed in Chapter 1, my initial thesis project was designed to develop and evaluate a health equity framework for identifying inequities in PrEP provision, to support and optimise PrEP implementation and HIV prevention programmes. However, a lack of research focused on women and PrEP generally, and women and PrEP in England, became apparent while conducting the background literature review and the first research project (Chapter 5). To address these gaps in the literature, the focus of my PhD research shifted to developing our understanding of PrEP awareness, knowledge, and perceptions among women in England. Prior to this, there had been very little research focused on PrEP engagement among women in England, and how PrEP fit into women's existing HIV strategies was not well characterised. In the few studies where women were included, the populations often focused on groups considered to be "at risk" based on demographic characteristics (e.g., ethnicity), or the data did not disaggregate data on women from the rest of the study population. Furthermore, existing research on women in the UK was mainly qualitative and/or had small sample sizes, and there was a lack of quantitative research investigating women's PrEP awareness. Finally, little work had been carried out after PrEP was routinely made available in sexual health clinics in England, and relatively little was known regarding factors that influenced women's awareness and engagement with PrEP and PrEP information. Therefore, this thesis aimed to address the following research questions:

1. What are the current levels of PrEP awareness, interest, and knowledge among women in England?
2. How can gaps in women's PrEP awareness and knowledge be addressed?
3. What are women's perceptions of PrEP provision in England?
4. How can PrEP provision be made more acceptable and accessible to women?

To address these research questions, the following objectives were set:

1. Describe how the PrEP outcome measures "awareness" and "interest" are defined and reported in real-world settings in high-income countries
2. Qualitatively explore levels of PrEP awareness, knowledge, and interest, and preferences for PrEP provision among a sample of women in England
3. Quantitatively describe the levels of PrEP awareness and interest, and preferences for PrEP provision among a sample of women in England
4. Identify potential barriers and enablers to women's PrEP engagement (i.e., PrEP awareness, interest, knowledge, and use)
5. Employ an equity lens to consider the implications of these findings for public health policy and practice

Three distinct methods were employed to address the research questions and objectives. Table 19 illustrates which method(s) were used to address each research question. The specific aims, methods, and findings from each study are described in the sections below, followed by an integrated discussion²¹⁵. The integrated discussion provides a comprehensive understanding of the research findings overall, and within the wider context of PrEP and HIV prevention for women in England.

Table 19: Thesis research questions, objectives, and methods

Research Question	Objectives addressing the research question	Method(s) addressing the objective
1. What are the current levels of PrEP awareness, interest, and knowledge among women in England?	1. Describe how the PrEP outcome measures “awareness” and “interest” are defined and reported in real-world settings in high-income countries	Systematic review (Chapter 5)
	2. Qualitatively explore levels of PrEP awareness, knowledge, and interest, and preferences for PrEP provision among a sample of women in England	Qualitative interviews (Chapter 6)
	3. Quantitatively describe the levels of PrEP awareness and interest, and preferences for PrEP provision among a sample of women in England	Quantitative survey (Chapter 7)
2. How can gaps in women’s PrEP awareness and knowledge be addressed?	4. Identify potential barriers and enablers to women’s PrEP engagement (i.e., PrEP awareness, interest, knowledge, and use)	Qualitative interviews (Chapter 6) and quantitative survey (Chapter 7)
	5. Employ an equity lens to consider the implications of these findings for public health policy and practice	Qualitative interviews (Chapter 6) and quantitative survey (Chapter 7)
3. What are women’s perceptions of PrEP provision in England?	2. Qualitatively explore levels of PrEP awareness, knowledge, and interest, and preferences for PrEP provision among a sample of women in England	Qualitative interviews (Chapter 6)
	3. Quantitatively describe the levels of PrEP awareness and interest, and preferences for PrEP provision among a sample of women in England	Quantitative survey (Chapter 7)
4. How can PrEP provision be made more acceptable and accessible to women?	4. Identify potential barriers and enablers to women’s PrEP engagement (i.e., PrEP awareness, interest, knowledge, and use)	Qualitative interviews (Chapter 6) and quantitative survey (Chapter 7)
	5. Employ an equity lens to consider the implications of these findings for public health policy and practice	Qualitative interviews (Chapter 6) and quantitative survey (Chapter 7)

8.3 Main findings

8.3.1 Main findings from Chapter 5

In Chapter 5, I summarised how PrEP awareness and interest had been defined in PrEP provision programmes in high-income countries in previously published literature, and how PROGRESS-Plus factors were considered when reporting these definitions. To accomplish this, I conducted a PRISMA-E systematic review of peer-reviewed articles on PrEP awareness and interest published between 2012 and 2020. This review was originally designed to explore definitions for each stage of the PrEP Care-Continuum (from awareness through to retention), however, given the focus of this thesis, only the results for awareness and interest were included.

The findings from my review indicate that no standard definitions for PrEP awareness and interest are used in the existing published literature. Terms such as “awareness” and “knowledge” are often used interchangeably, although I argued that these terms should be used to describe different, but related, phenomena; the former to describe whether an individual knows about the existence of PrEP as an HIV prevention method, whereas the latter describes what, or how much information an individual knows about PrEP (e.g., who can take PrEP or how to access PrEP). Similarly, the term “interest” was used to describe several distinct outcomes, such as an individual’s interest in taking PrEP, interest in learning about PrEP, or intention to take PrEP. There is a need for researchers to be clear about which outcome measure is being reported, to ensure that accurate comparisons can be made between different studies and settings, and to better design interventions to address disparities in PrEP engagement that meet the specific needs of distinct populations.

Factors influencing health equity such as age, gender, and ethnicity are often included in studies investigating PrEP awareness and interest however, other factors such as social capital and religion are less well represented. Furthermore, most research has focused on GBMSM, while women (including cisgender and transgender women) are underrepresented in PrEP literature.

8.3.2 Main findings from Chapter 6

In Chapter 6, I explored awareness, knowledge, and perceptions of PrEP among women living in England. To accomplish this, I conducted 18 one-to-one semi-structured interviews. With the data generated from these interviews, I undertook an inductive, thematic analysis. The three main themes were: information gaps, information flow, and meeting people where they are. The developed themes were mapped to the domains of the Developing HIV Literacy Framework⁴⁴⁹, to describe how women's PrEP awareness and perceptions relate more widely to HIV prevention and HIV literacy, and to identify any barriers and facilitators to improving women's awareness, knowledge, and access to PrEP.

The findings from Chapter 6 indicate that improving PrEP awareness and knowledge among women requires improving HIV literacy among women more generally. Additionally, PrEP information should be embedded within wider conversations around HIV and women's sexual health. Participant's perceptions of PrEP were influenced by their knowledge and perceptions of HIV and HIV prevention, meaning that barriers to the development of good HIV literacy, such as HIV-related stigma, are also barriers to PrEP awareness and knowledge. This study also found a need to increase opportunities for women to encounter information on both HIV and PrEP, but that any information campaigns must be inclusive (e.g., regarding language and accessibility of content), and specific (e.g., regarding outlining factors that increase the risk of HIV acquisition, PrEP eligibility criteria, and when or why a person might want to take PrEP).

The study also highlights the importance of choice, both in terms of where to access PrEP and the availability of PrEP modalities, to accommodate a range of individual needs and preferences among women. Finally, the routinization of HIV prevention and PrEP conversations into primary care and other settings that women access for their sexual and reproductive health was identified as a key strategy to address inequities in HIV literacy and PrEP awareness, knowledge, and access.

8.3.3 Main findings from Chapter 7

In Chapter 7, I conducted an online, self-completed, cross-sectional convenience survey to explore levels of PrEP awareness and interest and preferences for PrEP

among a sample of women living in England. I used logistic regression to identify associations between sociodemographic, and other factors influencing health equity and two outcomes: PrEP awareness and PrEP interest.

PrEP awareness among the sample was high, with 71% reporting that they were aware of PrEP. PrEP interest was lower, with 43% reporting an interest in learning more about PrEP and just over one in ten participants expressing an interest in using PrEP. The findings indicate that PrEP awareness is associated with reporting an LGB+ sexual identity and engagement in sexual health-seeking behaviours (i.e., history of HIV testing or sexual health clinic attendance). PrEP interest was associated with a greater perceived risk of HIV, not being in employment, and reporting a gender identity other than cisgender. Among participants who were interested in learning more about or using PrEP, there was no single ideal modality or setting to receive PrEP. The most preferred modalities were event-based PrEP and long-acting injectable PrEP, and the most preferred settings to access PrEP were GP surgeries and pharmacies. However, neither modalities nor settings are currently available for women to access in England at the time of writing, and most participants chose greater than one preference for both modality and setting, indicating that having a range of choices may be important.

8.4 Integrated discussion of awareness, knowledge, and preferences for PrEP among women in England

8.4.1 Improve engagement with combination HIV prevention to improve PrEP awareness and knowledge among women

Raising PrEP awareness alone is not sufficient to improve women's engagement with PrEP. As discussed in Chapter 5, there is an important distinction between PrEP awareness and knowledge, and both must be developed and supported so that women can make informed decisions concerning their HIV prevention and PrEP needs. In addition to being aware of PrEP, women need to know who PrEP is suitable for, the circumstances or behaviours that might make a person want to take PrEP, and how PrEP is accessed (Chapter 6). The findings of this thesis suggest that supporting the development of HIV literacy and engagement with HIV prevention more generally is important for improving both PrEP awareness and knowledge

among women. Women's knowledge of and perceptions of HIV shape their perceptions of PrEP (Chapter 6), and engagement with HIV testing is associated with PrEP awareness (Chapter 7).

Research has shown that an individual's perceived risk of acquiring HIV influences their uptake of combination HIV prevention methods such as HIV testing and condom use^{584–586}, and the findings of this thesis suggest that self-perceived risk influences both whether women recognise themselves as a PrEP candidate (Chapter 6), and women's interest in taking PrEP (Chapter 7). However, studies have shown that women's self-perceived risk is not always congruent with reported risk^{567,568,585,587}, therefore, improving women's ability to correctly and confidently assess their risk of HIV acquisition may in turn help them recognise when PrEP may be beneficial to them.

For many of the participants in both the qualitative and quantitative studies, their knowledge and perceptions of HIV were acquired and shaped by how HIV is portrayed or represented in the media, and often these perceptions were based on outdated media campaigns and/or stereotypes (Chapter 6). Women were interested in learning more about HIV and PrEP from a variety of sources, including signposting in healthcare settings, from healthcare professionals, and from social media (Chapter 6). However, the majority of women who were aware of PrEP learned about it from the news or internet (Chapter 7). After the results of the PROUD trial were published, articles on PrEP in the UK newsprint media focused mainly on GBMSM, and discussions of other groups that could benefit were limited⁷. There is a need for increased opportunities for women to encounter and engage with information on both HIV prevention and PrEP, specifically information that provides information that is specific to and relevant for women. Women specific resources, such as the "Women and PrEP"⁴⁷⁰ website and videos have been developed, however, such resources often require an initial awareness of PrEP to seek them out. Among the qualitative sample, PrEP knowledge varied widely (Chapter 6), and although there was no formal assessment of PrEP knowledge in the survey, 40% of participants were interested in learning more about PrEP, indicating that some women may have self-perceived knowledge gaps (Chapter 7). The limited reach of existing resources means that there may be a need for more widespread and/or mainstream campaigns to improve awareness and knowledge.

Furthermore, developing HIV and PrEP literacy among women may have a snowball effect, wherein women share information and knowledge with their peers and informal social networks²⁰⁰, and women who were previously unaware of PrEP are often enthusiastic about sharing their knowledge with people they know once they've learned about it (Chapter 6) further increasing PrEP awareness. Strategies to support developing HIV and PrEP literacy more broadly across the population are discussed below.

8.4.2 The importance of choice and meeting people where they are

The findings of this thesis indicate that the current PrEP provision in England may not meet the preferences of women. Women's needs and preferences vary between individuals, and expanding the range of both settings in which PrEP can be accessed and available PrEP modalities may be important for increasing women's access to and engagement with PrEP (Chapters 6 and 7).

Regarding PrEP modality, better choice is needed to ensure that individuals have access to options that meet their specific needs and preferences⁵⁸⁸. Individual women's preferences varied (Chapter 7), and women wanted options that they were confident and comfortable using; in some cases, this aligned with their preferences for contraception or other medication modalities (Chapter 6). This supports existing research that found women prefer PrEP modalities that are similar to their chosen contraception method⁴⁸⁷. Research has shown that women's use of contraception increases as more methods become available¹⁰, and the findings from this thesis suggest that it may be similar for PrEP; i.e., increasing available PrEP modalities may increase PrEP use.

Although women were interested in using a range of modalities, such as long-acting injectable PrEP or event-based PrEP (Chapters 6 and 7), at the time of writing, only daily PrEP is available for women to use in England, and the current event-based PrEP regimens and formulations cannot be used by women. However, the results of this thesis indicate that expanding the availability of modality and regimens will better meet the varying lifestyles and preferences of women. Given the pharmacokinetic limitations of the current PrEP formulations in vaginal tissue^{188,189} (as discussed in Chapter 3), current on-demand regimens are not suitable for women, however, interest in on-demand PrEP options may encourage further research and

development of options for women, such as the fast-dissolving vaginal insert that is currently being assessed in a Phase 1 clinical trial^{589,590}.

Increased options for accessing PrEP are also needed to better meet the preferences of women, as currently, PrEP is only available from sexual health clinics. As with PrEP modality, women's preferences for PrEP access varied, with GP surgeries, pharmacies, and sexual health clinics being commonly named preferences (Chapters 6 and 7), and women preferred settings that were both comfortable and convenient to access. Although sexual health clinics were preferred by some, only being able to access PrEP from them presented a barrier for many women. Women's reasons for not attending sexual health clinics included stigma associated with attending sexual health services, difficulties accessing sexual health services (e.g., due to distance from clinic, clinic opening hours), and attending other services for their sexual and reproductive healthcare (Chapter 6). Introducing PrEP into settings that women already attend for their sexual and reproductive healthcare needs, such as GP surgeries, could help mitigate some of these barriers⁵⁹¹.

The findings of this thesis suggest that offering a range of modalities and settings for PrEP is more important than identifying and promoting a single "ideal" way of providing PrEP, which is in accordance with calls for HIV prevention to be rooted in choice⁵⁵⁹. Similar recommendations have been made regarding contraception provision, and other lessons learned from contraception development and implementation may be useful in the planning and delivery of PrEP services^{581,592,593}. For example, it is necessary to consider the social context when introducing new prevention technologies. The potential of both contraception and PrEP modalities to provide benefits can be undermined when the dynamic interplay between potential users, their partners, service providers, and the modalities themselves are not accounted for^{581,594}.

8.4.3 Improving equity in PrEP awareness and knowledge for women

The inequities for women and PrEP are not restricted to inequities in the implementation of PrEP; historically, there has been an absence of women from clinical trials, and there is a lack of research focused on women in high-income countries. Of the research that has been conducted, the majority has been from the USA and/or has been qualitative with limited transferability to settings with different

models of providing healthcare (Chapters 3 and 5), such as the UK. Therefore, to investigate inequities in PrEP provision, there is a need to address the inequities in PrEP research.

Findings from this thesis highlighted disparities in PrEP awareness across sociodemographic and other factors that can drive inequities in health, such as sexual identity, age, education level, and ethnicity (Chapter 7). Effectively addressing these disparities will rely on a combination of approaches, including widespread strategies to improve HIV literacy and PrEP knowledge among women more generally, and specific campaigns aimed to improve PrEP awareness among groups where disparities have been identified.

Widespread strategies can help address disparities in a number of ways, for example, they can give women more opportunities to encounter and engage with HIV prevention and PrEP information, which is particularly useful for women who address their sexual and reproductive healthcare needs outside of venues where PrEP is currently available, such as GP surgeries. Widespread and generalised campaigns and approaches can also help normalise conversations around HIV prevention and PrEP, which in turn can help reduce HIV-related stigma, improve social norms around HIV prevention and PrEP, and mitigate the impact of provider bias by ensuring information is provided to everyone who could benefit from it⁴²⁴ (Chapter 6). Widespread approaches could include routinizing, or embedding conversations about PrEP and HIV prevention into women's sexual and reproductive healthcare (e.g., STI screenings or contraceptive counselling¹⁹⁸), and standardised inclusion of combination HIV prevention methods (including PrEP) in the RSE curriculum in schools (Chapter 6).

Conversely, targeted approaches would help directly address disparities in PrEP engagement amongst groups for whom these disparities have been identified. Targeted approaches can help ensure that no one is left behind, boosting awareness and engagement amongst populations where the need is greatest. To prevent targeted approaches from creating or reinforcing HIV-related stigma, they must be balanced with more general approaches, and designed and/or co-produced with the community and populations of interest, centring the needs and concerns of those communities within the knowledge-building process²¹³.

Based on the findings of this thesis, further research is warranted into the specific communities that may benefit from targeted knowledge-building approaches. Although the quantitative study in Chapter 7 identified disparities in PrEP awareness, little is known about how these factors impact downstream engagement with PrEP (e.g., uptake, access), and whether these disparities also exist amongst women with a PrEP need. Further research into disparities in PrEP engagement among women who are eligible for PrEP or have an identified PrEP need should be undertaken to prioritise targeted campaigns to communities where they will have the most impact.

That being said, the thesis findings do support the development of widespread or routinized strategies for improving HIV prevention and PrEP awareness among women. Engagement with HIV testing was identified as an association with PrEP awareness (Chapter 7) and these results are supported by the findings that increasing HIV literacy and engagement with HIV prevention methods more generally may in turn improve PrEP awareness and knowledge (Chapter 6). Furthermore, as discussed previously, an individual's HIV risk can change over time⁵⁹⁵, therefore it is important that all women are equipped and empowered with information that allows them to identify and make decisions around their changing HIV prevention needs (Chapter 6).

8.5 Strengths and limitations of the thesis

The strengths and limitations for each individual study were discussed in the corresponding chapter (Chapters 5 – 7). The following discussion relates to the strengths and limitations of the thesis as a whole.

8.5.1 Strengths of the thesis

A strength of this thesis is that it helped to address a lack of scientific literature regarding the awareness, knowledge, and perceptions of PrEP among women in England. The majority of previous literature had focused on GBMSM, and when women were included, results were often not disaggregated by gender.

Using a mixed methods approach to address the research aims and objectives was another strength of the thesis. By taking this approach, I was able to explore both how women's awareness, perceptions, and preferences for PrEP are influenced and

shaped, but also the level of awareness and interest in PrEP among a sample of women in England. The convergent mixed-method design allowed for the findings to be reported individually for each piece of research while allowing for further insight to be gained by considering the findings together in the discussion.

The collection and analysis of primary data was another strength of the thesis. Although it proved time consuming and resource intensive, by collecting primary data I was able to tailor the study designs and subsequent analyses specifically to address the research aims and objectives of the thesis.

The inclusion of PPI throughout the thesis is another strength. The input of PPI advisors was invaluable for identifying research priorities, improving the accessibility and acceptability of all study materials, and helping to ensure that the study findings are relevant to the population of interest. Ideally, I would have included PPI advisors in the interpretation and analysis stages to further increase the likelihood that the findings will have beneficial impacts, but this was not possible given the time and resources that were available to me while undertaking this thesis.

8.5.2 Limitations of the thesis

As discussed in Chapter 1, the research aim and objectives of this thesis changed after the systematic review (Chapter 5) was underway. Although some findings from the review were ultimately relevant to the thesis as it is presented here, if my initial research proposal had focused on women and PrEP, I would have designed a scoping or systematic review focused on women's awareness and interest in PrEP so as to better integrate the findings with the subsequent studies.

Another limitation is that this thesis only explored women's engagement with PrEP from the demand or (hypothetical) user's perspective. As noted above, successful delivery of PrEP relies on the dynamic relationship between users, services, and healthcare providers. Although it was beyond the scope of this thesis to include all of these perspectives, the findings of this thesis must be considered within the wider context of women's health, their interactions with providers, and vice-versa. Furthermore, the findings from this thesis can only comment on women's preferences for PrEP generally, while the specific preferences of women who intend

to, or currently used PrEP were not explicitly captured. This is discussed in more detail in the implications for future research section below.

Although in some ways, the convergent mixed-method design was a strength, it also had limitations. For example, due to time constraints, the design and analysis of the qualitative and quantitative studies occurred concurrently at times. This meant that it was not possible to integrate the findings of the qualitative study into the design of the quantitative survey. As a result, themes and concepts that were found to be significant in the qualitative study, such as HIV-related stigma, HIV literacy, and the gap between women's PrEP awareness and PrEP knowledge, were not explored or captured in the survey. Given more time, I would have preferred to undertake an exploratory sequential design, where the qualitative study is completed and used to design the quantitative instrument. As it stands, the findings from this study cannot comment on the level of PrEP knowledge among women more generally beyond the qualitative sample. Investigating the level of PrEP knowledge among women may be important to consider when developing resources or campaigns to improve PrEP awareness and interest among women.

8.5.2.1 Overall generalisability and transferability of the findings

The generalisability and transferability of the findings indicate how, and to what extent, they can be applied to other settings and populations. The generalisability and/or transferability of each individual study is discussed in their respective chapters.

Although the findings of this thesis are not generalisable, given the non-probability design of the survey, the integrated narrative of the findings means that they may be transferable to other settings. Both the qualitative and quantitative studies included a diverse range of women of different ages, ethnicities, and geographic locations within England. The findings are likely to be relevant to other settings with similar healthcare systems and PrEP provision as England, such as the devolved nations.

8.5.2.2 Potential sources of bias

The findings of this thesis may be influenced by bias from a number of sources. Given the subject matter (i.e., HIV prevention), sensitive nature of questions, and

participant self-selection for the qualitative and quantitative studies, participants who took part may have differed from the unsampled population in their comfort discussing or answering questions about their sexual behaviour and HIV. Furthermore, the majority of participants for both studies were recruited via the internet, and data collection primarily took place online. Although the most recent data on internet use in the UK reports near universal internet usage among adults age 16 – 44 (i.e., 99%)⁵⁹⁶, it is estimated that 75% of adults are social media users⁵⁹⁷. This means that people who do not use social media, or who do not have internet access and/or are experiencing digital exclusion would not have encountered the study advertisements, which were mainly circulated on social media platforms. Digital exclusion itself can be a driver of health inequity⁵⁹⁸, and this would not have been represented in my findings.

Similarly, only women with a working proficiency in English (i.e., able to consent to taking part, able to understand and respond to the study questions) were eligible to take part in either study. Language barriers are a major source of health inequity and can impact the quality of healthcare delivery and patient safety⁵⁹⁹. Although the percentage of people living in England who do not speak English is relatively small, i.e., 1.5% of people living in England and Wales do not speak English well according to the 2021 census⁶⁰⁰), the experiences of this group would not be represented in my studies. Language barriers have been shown to impact how people receive HIV care⁶⁰¹, and people who do not speak English may have other vulnerabilities that impact their ability to engage with and access HIV prevention.

8.6 Implications of the thesis findings

In this section, I discuss the implications of my research for HIV prevention outreach and health promotion, practice and policy, and future research directions.

8.6.1 Implications for HIV prevention outreach and health promotion

Developing women's HIV literacy and increasing their engagement with combination HIV prevention more generally is a key factor in improving women's PrEP awareness and knowledge. PrEP information should be embedded within conversations on HIV

prevention, and these in turn could be delivered as part of a more holistic approach to women's sexual and reproductive healthcare.

There is a need to increase opportunities for women to encounter HIV and PrEP information. Approaches must be carefully balanced to ensure that they are inclusive in their audience (e.g., avoid stigmatising certain groups or behaviours), but specific in terms of the information provided (e.g., allow women to see themselves reflected in the information, describe risk acquisition factors). One example of an inclusive approach is making conversations about HIV prevention and PrEP a routine part of the discussions that women currently have around their sexual and reproductive health and wellbeing, for example as part of contraception pathways, or when someone discloses IPV. This also mitigates challenges faced by providers when trying to determine a patient's HIV prevention needs or PrEP eligibility⁴²⁴.

Another example is the discussion of combination HIV prevention methods, including PrEP, in RSE in secondary schools. These broad approaches have the benefit of developing HIV literacy more generally, and prevents potential PrEP candidates from missing out on relevant information, while also preventing individuals from feeling targeted or singled out.

There may still be women who are not reached by these inclusive approaches, and so additional more specific campaigns may be necessary. For example, women who have left school, who migrated to the UK, or were not educated in England would not benefit from enhanced RSE, and women who do not usually seek sexual and reproductive health advice or services may not benefit from routinized embedding of HIV prevention into these services. Utilizing women's informal social networks may be another approach to improving PrEP awareness and knowledge in this population. Peer education and peer mobilisation projects have been successful in improving both HIV literacy generally⁶⁰², and for women specifically²¹³, however, community knowledge building is a slow process that requires sustained funding and resources to have an impact.

HIV-related stigma is still a major barrier for women engaging with and recognising the relevance of information related to HIV, including information on PrEP. Tackling HIV-related stigma is crucial for improving combination HIV prevention services more generally, and for women specifically, but requires dedicated interventions to

address stigma at the individual, environmental, and policy levels. However, these efforts are necessary, otherwise existing stigma will undermine other health promotion and outreach efforts.

8.6.2 Implications for policy and practice

Expanding options for PrEP access, both in terms of modality and setting, will be important for increasing PrEP engagement among women. However, it is important to note that any expansion of PrEP services must happen alongside dedicated funding for capacity building and training for healthcare staff to ensure that services are able to PrEP services confidently and competently, and safely. Additionally, it will be important to consider the cost-effectiveness and feasibility of any changes or additions to the current PrEP provision services. For example, expanding PrEP services may have an impact on commissioning models and funding (e.g., how would drug costs be covered in primary care settings vs delivery costs), and clinical pathways (e.g., would other aspects of PrEP provision such as STI testing and renal monitoring also be performed in primary care, or would patients move between settings). Changes in PrEP provision would also raise issues around surveillance. For example, currently, PrEP provision is monitored using data from the GUMCAD surveillance system (run by UKHSA), which is not used in e.g., primary care. Monitoring and evaluation of PrEP provision is a key facet in identifying and addressing inequities in PrEP access, so additional systems or strategies for surveillance may need to be developed alongside PrEP expansion into other settings.

8.6.3 Implications for future research

While this thesis explored awareness, knowledge, and preferences for PrEP among women in England, the studies sampled a general population of women, and further research is needed to understand the preferences and requirements of women with an identified PrEP need, or who intend to or currently use PrEP. This will be particularly important when planning for additional PrEP provision services, to ensure that the needs of women who could most benefit from PrEP are met. More efforts will also be needed to identify women who are at an elevated risk of HIV and/or may benefit from taking PrEP. There are few validated risk assessment tools for

women¹³⁵, and the development of tools that allow women to better assess their own HIV risk may increase engagement with PrEP and help practitioners identify women with a PrEP need during consultation, minimising missed opportunities for PrEP engagement. One such tool, a questionnaire distributed among women attending a SHS in London, has proved successful in identifying PrEP candidates and improving uptake⁴⁷⁵, and further research to validate the questionnaire and assess the feasibility of expanding the use of such a tool may be beneficial.

The findings of this thesis also support further research into improving women's engagement with HIV prevention more generally. Engagement with HIV prevention and HIV literacy was shown to be important for PrEP awareness and knowledge, but surveillance data shows that women are the most likely group to refuse an offer of an HIV test in SHS²³. Strategies might include research with women who are newly or recently diagnosed with HIV, in order to identify and address missed opportunities for HIV prevention. A recent study from Scotland reviewed and compared the characteristics of individuals who were newly diagnosed with HIV before and after the implementation of PrEP provision as a way to inform future HIV strategies and PrEP delivery⁶⁰³, and running a similar study using English data may provide valuable insight into how combination HIV prevention could be improved generally, or for women specifically.

As discussed throughout this thesis, there are important social (e.g., type and level of social support, HIV stigma), and structural considerations (e.g., rurality, access to healthcare services) in PrEP awareness and provision. Many of these considerations will not be exclusive to PrEP, e.g., barriers to PrEP engagement among people living in rural areas may also act as barriers to accessing sexual and reproductive health services in general. Further investigation into how to best address these barriers, in order to design appropriate interventions to address them, is warranted.

Finally, healthcare providers play an important role in providing and supporting PrEP use, and any changes or additions to PrEP provision in England will require research and engagement with providers to determine the acceptability, feasibility, and cost-effectiveness of new provision models; and to determine if and how new provision models will impact health equity.

8.7 Conclusions

In this thesis, I employed a mixed methods approach to investigate awareness, knowledge, and perceptions of PrEP among women in England through an equity lens. This thesis has demonstrated the importance of developing HIV literacy and engagement with HIV prevention more generally among women as a way of supporting PrEP awareness and knowledge, and that current PrEP provision in England may not be meeting the diverse and varied preferences of women. To improve equitable access to PrEP, education and awareness campaigns should include women-specific information and clear indications for PrEP candidacy. Addressing HIV stigma, integrating HIV prevention in conversations around sexual health and reproductive health, and expanding PrEP provision outside of SHS may help increase the accessibility of PrEP and PrEP information for women. This in turn may equip and empower women to recognise themselves as candidates for PrEP or other combination HIV prevention methods, helping to ensure that England's ambitious goal of zero new transmissions of HIV by 2030 is met.

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Appendices

Appendix 1. Patient and Public Involvement Planning and Assessment Form^{xxxiii}

1.	Did the PPI activity meet your objectives? Please explain why, or why not	
2.	What impact do you think the PPI activity had on your study? Did this differ from your expected impact? Did your research plans change as a result of the activity? Include: – impact on research processes and outcomes – positive and negative impacts – short and long-term impacts	

^{xxxiii} Adapted from McDonagh et. al.⁶⁰⁴

3.	What impact did this activity have on the patients/public who were involved? Include positive and negative reports of impact	
4.	What impact did this activity have on the research staff (including yourself) who were involved? What have you learned from this activity? Include positive and negative reports of impact	

5.	What challenges did you face during this activity? Please explain	
6.	What suggestions do you have for future PPI activities? What worked well? What would you do differently?	
7.	If no impact was reported, please explain why this may have been the case	

BMJ Open Equity considerations in outcome measures of the HIV pre-exposure prophylaxis care continuum in high-income countries: a systematic review protocol

Melissa Cabecinha ¹, Danielle Solomon,² Greta Rait,^{1,3} John Saunders,^{3,4} Hamish Mohammed,^{5,6} Lorraine Katherine McDonagh^{1,3}

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For numbered affiliations see end of article.

Correspondence to
Melissa Cabecinha;
m.cabecinha@ucl.ac.uk

ABSTRACT

Introduction HIV pre-exposure prophylaxis (PrEP) is an effective intervention to reduce acquisition of HIV. PrEP provision has increased in recent years, however, it is not known whether PrEP implementation has been equitably implemented across all risk groups, particularly groups experiencing high levels of health inequality. A PrEP care continuum (PCC) has been proposed to evaluate the success of PrEP implementation programmes, but the extent to which health equity characteristics are currently taken into account in the PCC has not been described. The objectives of this proposed systematic review are to (i) identify and collate outcome measure definitions for the main stages of the PCC (awareness, acceptability, uptake, adherence and retention), (ii) describe how equity characteristics are considered in outcome definitions of the PCC and (iii) describe data sources for capturing equity characteristics.

Methods and analysis Quantitative studies published between 1 January 2012 and 3 March 2020 will be included. Five databases (MEDLINE, PubMed, Embase, Cumulative Index to Nursing and Allied Health Literature, Applied Social Sciences Index and Abstracts) will be searched to identify English language publications that include an outcome measure definition of at least one of the five main stages of the PCC. Risk of bias will be assessed using the Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies. Data on outcome measure definitions and equity characteristics will be extracted. Results will be presented in a narrative synthesis and all findings will be reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.

Ethics and dissemination Ethical approval is not required. The results will be disseminated via submission for publication to a peer-reviewed journal when complete. The review findings will have relevance to healthcare professionals, policymakers and commissioners in informing how to best evaluate PrEP implementation programmes and inform new implementation strategies for vulnerable and less advantaged populations.

PROSPERO registration number CRD42020169779.

Strengths and limitations of this study

- This systematic review will be the first to collate outcome measures for the HIV pre-exposure prophylaxis (PrEP) care continuum from real-world settings and investigate how equity characteristics are considered within existing measures.
- The findings from this review will help inform evaluation and monitoring of PrEP programmes and how to view these evaluations through an equity lens.
- This protocol has been written in accordance with published Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols guidelines, and the review will be reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement guidelines and the 2012 Preferred Reporting Items for Systematic Reviews and Meta-Analyses Equity extension.
- This review will not provide specific information on the effectiveness of existing PrEP programmes at reducing health inequality or population vulnerability.

INTRODUCTION

Oral HIV pre-exposure prophylaxis (HIV PrEP) is a highly effective biomedical intervention for reducing HIV acquisition, and is recommended by the WHO as part of a comprehensive approach to HIV prevention.¹ The efficacy of PrEP has been demonstrated in clinical trials,^{2,3} and PrEP provision has been increasing globally in recent years.⁴ However, questions remain as to whether real-world implementation strategies are reaching some high-risk and vulnerable populations,⁵ particularly those populations experiencing high levels of health inequality.

Health inequality and HIV

Health inequities are disparities in health status or access to healthcare that are considered unnecessary, avoidable, unfair and

unjust.⁶ Health equity is an important consideration in HIV prevention, as HIV disproportionately affects marginalised populations. Gender and sexual minorities,^{7–9} ethnic minorities,^{7 10} vulnerable populations such as people who inject drugs,¹¹ people experiencing housing instability¹² and other social disadvantages¹³ are at a greater risk of HIV acquisition compared with the general population. These categories are not mutually exclusive; an individual may identify with multiple categories concurrently¹⁴ and the experience of belonging to multiple marginalised groups may contribute to an increased risk of acquiring HIV.¹⁵ HIV prevention programmes, including PrEP provision programmes, must address the needs of marginalised populations and communities in order to have a sustained impact on the decline of HIV transmission.¹¹

Measurable outcomes for PrEP implementation

A PrEP care continuum (PCC) has been proposed^{16 17} to evaluate the implementation of PrEP. The main stages of the PCC are as follows: awareness (knowledge of PrEP and indication of relevance), acceptability (whether an individual views PrEP as an acceptable tool for prevention), uptake (engagement in PrEP related care and initiation of PrEP) and adherence (retention in PrEP related care and adherence to treatment). Although the PCC provides a useful framework, in practice the outcomes have been reported with varying definitions. For example, in evaluating the 'uptake' stage of the continuum, a study of veterans in the US reports uptake as the absolute number of people initiating on PrEP within a given time-frame,¹⁸ whereas the South Africa Programme defines uptake within a given programme as the proportion initiating PrEP after both a negative test for HIV and an offer of oral PrEP.¹⁹ In England, the PrEP Impact Trial defines uptake as the proportion initiating oral PrEP among those meeting the eligibility criteria in participating sexual health clinics.²⁰ A common definition of uptake has been proposed for monitoring PrEP delivery to adolescent girls and young women in sub-Saharan Africa ('the number who initiate oral PrEP among those offered PrEP')²¹ and consistent definitions for the outcome measures of the PCC would be beneficial for comparing the relative success of PrEP provision programmes.

Health inequity and PrEP

These outcome measures are important for evaluating the overall success of PrEP programmes, identifying populations with low engagement, and ensuring that programmes do not increase health inequity among at-risk populations. The latter can be achieved, in part, by considering health equity characteristics when evaluating PrEP provision programmes. Structural and environmental factors that contribute to discrepancies in HIV rates have been shown to affect HIV treatment uptake and adherence,^{22 23} uptake of HIV prevention strategies in general²³ and for PrEP specifically. For example, lower levels of education, anticipated stigma,

and higher PrEP cost have been associated with lower willingness to take PrEP.²⁴ Low adherence to PrEP has been associated with competing survival needs (eg, financial instability, housing)²⁵ and substance use.²⁶ It is likely that other structural, social and environmental factors influence engagement at each stage of the PCC, such as those summarised by the PROGRESS-Plus framework.^{27 28}

The PROGRESS-Plus framework describes a sample of characteristics that drive disparities in health.^{28 29} The acronym PROGRESS refers to Place of residence (eg, rural/urban/inner city), Race/ethnicity/culture/language, Occupation, Gender/sex, Religion, Education, Socioeconomic status and Social capital. The 'Plus' suffix includes additional categories that can attract discrimination for consideration: personal characteristics (such as age or having a disability), features of a relationship (such as being excluded from school or having unpaid care responsibilities) and time dependent relationships (such as having recently been hospitalised or receiving respite care).

Currently, the extent to which characteristics influencing health equity, such as those in the PROGRESS-Plus framework, are being investigated in outcome measures of the PCC is not well characterised. The evaluation of health equity within PrEP implementation programmes could be improved by collating current approaches for evaluating outcome measures of the PCC and existing approaches to considering health equity within them.

In order to minimise heterogeneity, this review will focus on outcome measures of the PCC in high-income countries. Although factors influencing health equity in high-income countries are likely to be similar to those in low-income and middle-income countries, how PrEP programmes are monitored, and the way vulnerable populations experience health inequity, may differ between these settings.

Aim

This paper is a protocol for a systematic review that aims to identify and collate definitions for outcome measures of the PCC and describe how, and the extent to which, characteristics that influence health equity are taken into account in these measures in high income countries.

Objectives

The objectives of this proposed systematic review are:

- ▶ To identify and collate definitions of outcome measures used to evaluate the main stages of the PCC (awareness, acceptability, uptake, adherence and retention) for real-world settings in high-income countries.
- ▶ To explore whether and how studies reporting outcome measures of the PCC consider the effects of health equity characteristics when reporting PrEP awareness, acceptability, uptake, adherence and retention.

- To describe the sources of data and methods used for capturing equity characteristics (eg, self-reported survey data, administrative data, linked datasets).

This review aims to describe how outcome measures for the PCC are defined and to describe how health equity characteristics are currently taken into account for these measures. This review is not intended to summarise the effectiveness of PrEP programmes at reducing health inequity or population vulnerability.

METHOD DESIGN

Patient and public involvement

This protocol was informed by input from a patient and public involvement (PPI) representative. A one-off PPI session was held to discuss the acceptability and accessibility of investigating equity considerations in the PCC and the appropriateness of using the PROGRESS-Plus framework to do so.

Protocol and registration

This protocol was reported according to the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols 2015 statement³⁰ (online supplemental appendix 1, online supplemental file 3) and has been registered with the PROSPERO international prospective register of systematic reviews (available at: https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=169779).

The review will be conducted and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement guidelines³¹ and the 2012 Preferred Reporting Items for Systematic Reviews and Meta-Analyses Equity extension (PRISMA-E).³²

Eligibility criteria

To be included in the review, papers will have to meet the following population, intervention, context, outcomes and study design elements.

Population

Inclusion criteria: people resident in high-income countries with a national PrEP provision programme (ie, where the national governing body has approved PrEP for use and it is available from healthcare facilities and/or bespoke initiatives) or demonstration/implementation project, regardless of sexual orientation/identity, age, gender identity or occupation.

Exclusion criteria: people resident in countries without a national PrEP provision programme or demonstration/implementation project; people resident in low-income or middle-income countries.

Intervention

The issue to be reviewed is outcome measures for five stages of the PCC (awareness, acceptability, uptake, adherence and retention). Definitions of outcome measures for the PCC in real-world settings will be collated and reviewed,

rather than the reported outcomes. For example, in studies reporting PrEP awareness, the definition of awareness and the metrics used to determine awareness are relevant to this review, whereas the reported level of awareness is not. As such, studies which include descriptions of how the main stages of the PCC will be evaluated but do not report these outcomes (eg, study protocols) will be included.

Inclusion criteria: studies reporting an outcome measure definition for at least one stage of the PCC in a real-world setting.

Exclusion criteria: studies that do not report an outcome measure definition for the PCC, randomised controlled trials (RCTs).

Context

Inclusion criteria: studies conducted in high-income countries, as defined by the World Bank country classifications.³³ Inequity is a relative concept, and inequities experienced by vulnerable populations in lower and middle-income countries may differ from that experienced by vulnerable populations in high-income countries with well-resourced healthcare settings.

Exclusion criteria: studies conducted in low-income or middle-income countries.

Outcomes

Primary outcomes: studies will be included if they report at least one outcome measure definition for the PCC relating to PrEP provision in a real-world setting, that is, an implementation trial, demonstration project or national programme. Studies only reporting absolute numbers for stages of the PCC will not be included.

Secondary outcomes: data on whether factors influencing health equity (defined by the PROGRESS-Plus framework) are considered for the description of baseline characteristics of participants and/or when reporting measurable outcomes for the PCC.

Study design

Inclusion criteria: quantitative research studies including non-experimental observational studies (eg, cohort, cross-sectional and longitudinal studies) and abstracts from key international HIV/STI conferences (eg, HIV/STI World Congress, International AIDS society, Conference on Retroviruses and Opportunistic Infections). Mixed method studies will be included providing a quantified outcome measure of the PCC is reported. Studies resulting from demonstration and/or implementation trials will also be included. Study protocols, policy frameworks and clinical guidelines will be included if they include definitions of outcome measures in relation to a real-world programme; for example, definitions for how the numerator (eg, the number of people with high adherence to PrEP) and denominator (eg, the number of people taking PrEP) will be defined in a measure of PrEP adherence.

Exclusion criteria: qualitative studies, review articles, case studies, studies not involving oral emtricitabine/tenofovir

disoproxil fumarate as PrEP, and commentary or opinion pieces that do not contain a definition for an outcome measure of the PCC. RCTs will also be excluded, as RCTs in high-income countries predominately focus on safety and efficacy, rather than outcome measures of the PCC.

Information sources

Electronic searches

To identify studies, the following electronic databases will be searched: MEDLINE (via Ovid), EMBASE (via Ovid), PubMed, Cumulative Index to Nursing and Allied Health Literature (via EBSCO Host) and Applied Social Sciences Index and Abstracts (via ProQuest).

Search strategy

Restrictions on English language articles as well as for articles published between 1 January 2012 (the year the US Federal Drug Administration approved Truvada (emtricitabine/tenofovir disoproxil) fumarate for PrEP use³⁴) and 3 March 2020 will be applied. The searches will be re-run prior to the final analyses and further studies retrieved for inclusion.

Medical Subject Headings, subject headings and keyword lists will be created by using language that describes (i) oral PrEP and (ii) the following outcome measures of the PCC: awareness, acceptability, uptake, adherence and retention. Boolean combinations will be employed to refine the search strategy. Several key articles will be identified in the preliminary searches and used to test the sensitivity of the search strategy.

The search strategy that will be used to search MEDLINE (via the Ovid platform) is presented in online supplemental appendix 2. Search terms will be modified for databases where the indexing of subject headings differs from the terms used in MEDLINE.

The references of articles meeting the inclusion criteria will be searched to identify any relevant papers missed in the electronic searches.

Study selection

All citations retrieved from the electronic searches will be imported into an EndNote database. After duplicates are removed, the remaining studies will be screened by title and abstract by one reviewer, with a random sample independently reviewed by a second reviewer. Reviewers will compare their decisions throughout the process and discuss all references where there was a disagreement. A third reviewer will be asked to adjudicate where discrepancies cannot be resolved. Studies remaining after the initial title and abstract screen will undergo full text screening. Following the full-text screening, data will be extracted from all studies that meet the inclusion criteria. A flow diagram will be produced to show selection process, according to PRISMA guidelines,³⁵ with explanation for those excluded at each stage.

Data extraction and management

Data will be extracted into a pilot-tested, standardised form by one reviewer with a random sample checked by a second reviewer. Any discrepancies will be resolved by discussion or adjudication by a third reviewer where necessary.

All studies that meet the inclusion criteria will be described in terms of:

- ▶ Bibliographic information (first author, year of study, country of study).
- ▶ Study aims and design (including study population, sample size and data collection methods).
- ▶ Participants, demographic characteristics and number of baseline PROGRESS-Plus equity characteristics reported
- ▶ Outcome measure definitions (for PrEP awareness, acceptability, uptake, adherence and retention).
- ▶ Whether the study considered PROGRESS-Plus equity characteristics when measuring outcomes of the PCC.

For studies that consider PROGRESS-Plus equity characteristics in outcome measures, further data extraction detailing how the PROGRESS-Plus characteristics are expressed, and additional information on the study methods and study results will be extracted into an expanded data collection form.

Risk of bias assessment of included studies

The quality of each paper included in the data extraction stage will be assessed independently by two reviewers, using the Effective Public Health Practice Project 'Quality Assessment Tool for Quantitative Studies'.³⁶ Individual studies will be categorised as 'strong', 'moderate' or 'weak' in the following domains: selection bias, study design, confounders, blinding, data collection method, and withdrawals and drop outs. Studies will also be given a global score to indicate overall quality. Any discrepancies between the two reviewers will be resolved by consensus, or by a third reviewer if necessary.

Data synthesis and analysis

A narrative synthesis of results will be conducted. Individual study characteristics and outcomes will be summarised and presented in an evidence table.

To assess the extent to which studies consider the effects of PROGRESS-Plus equity characteristics in the outcome measures of the PCC, a two-stage analysis will be carried out. At the first stage, data will be presented on PCC outcome measure definitions and whether the study considers any of the PROGRESS-Plus equity characteristics for the description of baseline characteristics of study participants. The second stage we will describe whether the study considered PROGRESS-Plus characteristics in outcome measures of the PrEP continuum, and which methods were used (eg, consideration as confounders by adjusting in multivariable analysis, as effect modifiers in stratified analysis, using interaction terms in multivariable analysis, etc). The ways in which inequities are expressed (ie, whether absolute or relative) will also be reported, as the decision about whether to measure inequity in relative or absolute terms may influence their interpretation.

DISCUSSION

To the best of the author's knowledge, this is the first systematic review to collate definitions for outcome measures of the PCC and describe the extent to (and ways in which) equity

characteristics are considered in these outcomes. The findings will have relevance to healthcare professionals, policy-makers and commissioners in informing how to evaluate PrEP implementation programmes, and how to view these evaluations through an equity lens to optimise HIV prevention strategies and inform new implementation strategies for vulnerable and less advantaged populations.

ETHICS AND DISSEMINATION

Ethical approval is not required for this study. When complete, the review results will be submitted for publication in a peer-reviewed journal and submitted to be presented at national and international conferences (where eligible). The findings, dissemination strategy, and lay summary will be discussed with a PPI panel.

Author affiliations

¹Research Department of Primary Care and Population Health, University College London, London, UK

²Institute for Global Health, University College London, London, UK

³National Institute for Health Research Health Protection Research Unit in Blood Borne and Sexually Transmitted Infections at University College London, University College London, London, UK

⁴UCL Centre for Clinical Research in Infection and Sexual Health, Institute for Global Health, University College London, London, UK

⁵Blood Safety, Hepatitis, Sexually Transmitted Infections (STI) and HIV Division, National Infection Service, Public Health England, London, UK

⁶Research Department of Infection and Population Health, Institute of Global Health, University College London, London, UK

Contributors MC and LKM designed the study. MC developed and refined the study protocol with contributions from all coauthors (DS, JS, GR, HM and LKM). MC prepared the manuscript. MC will undertake data collection (literature search, data extraction), analysis, interpretation and report writing. All coinvestigators will contribute to the design, analysis, interpretation and report writing. All authors read and approved the final manuscript. This protocol was informed by input from a patient and public involvement (PPI) representative. A one-off PPI session was held to discuss the acceptability and accessibility of investigating equity considerations in the PCC and the appropriateness of using the PROGRESS-Plus framework to do so. The authors would like to thank the PPI representative for their contributions to the research question and study design.

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ORCID iD

Melissa Cabecinha <http://orcid.org/0000-0001-6869-4692>

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Appendix 3: Example search strategy for systematic review

The following is the search used for Ovid databases (MedLine, Embase)

1. exp HIV Infections/
2. Pre-Exposure Prophylaxis/
3. Chemoprevention/
4. Anti-HIV Agents/
5. Anti-Retroviral Agents/
6. 1 or 4 or 5
7. 2 or 3
8. 6 and 7
9. ((pre-exposure or preexposure or pre exposure) adj2 prophyla*).tw
10. PrEP.tw
11. ((pre-exposure or preexposure) adj2 chemoprophyla*).tw
12. 10 or 11
13. chemoprophylaxis.tw
14. chemo-prophylaxis.tw
15. chemoprevention.tw
16. chemo-prevention.tw
17. 12 or 13 or 14 or 15 or 16
18. truvada.tw
19. Emtricitabine/
20. Tenofovir/
21. 19 and 20
22. 18 or 21

23. (HIV or Human Immunodeficiency virus).tw
24. 17 and 23
25. 8 or 9 or 22 or 24
26. limit 25 to yr="2012 -Current"
27. limit 26 to (english language and humans)
28. exp Attitude to Health/
29. exp "Treatment Adherence and Compliance"/
30. Program Evaluation/mt, st, sn [Methods, Standards, Statistics & Numerical Data]
31. ((care or care-) adj2 (cascade or continuum)).tw
32. ((prevention or prevention-) adj2 (cascade or continuum)).tw
33. (non-adherence or nonadherence or non adherence).tw
34. (noncompliance or non-compliance or non compliance).tw
35. access.tw
36. adhere*.tw
37. attitude*.tw
38. aware*.tw
39. compliance.tw
40. compliant.tw
41. demand.tw
42. disengage*.tw
43. enable*.tw
44. engage*.tw
45. evaluat*.tw
46. experience*.tw

47. implement*.tw

48. interest.tw

49. knowledge.tw

50. measure*.tw

51. perception*.tw

52. retain*.tw

53. retention.tw

54. uptake.tw

55. 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or
42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54

56. 27 and 5

Appendix 4. Studies included in the systematic review

Table 20: Summary of studies included in the systematic review

First author (year), location and date of data collection	Study sample	Design	PROGRESS- Plus collected for baseline population	Awareness definition	PROGRESS-Plus included when reporting awareness		Interest definition	PROGRESS-Plus included when reporting interest	
					Characteristic	How characteristics were included		Characteristic	How characteristics were included
Adams (2016) ²⁷² USA, 2014-2014	GBMSM	Cross- sectional	R,O,G,SC,HE,SU	-	-	-	Interested in or willing to take PrEP	O,E,SC,A,HE	Analytic
Algarin (2019) ³⁷⁵ USA, 2018	GBMSM	Cross- sectional	P,R,G,E,A,SU	-	-	-	Interested in or willing to take PrEP	-	-
Arnold (2018) ³⁵² USA, not reported	General (no gender or sexual identity criteria)	Cross- sectional	P,R,O,G,E,SS	-	-	-	Interested in or willing to take PrEP	-	-
Arrington-Sanders (2016) ²⁶⁷ USA, 2014-2015	Black GBMSM	Cross- sectional	P,G,A	"Have you heard of PrEP before today?"	G,A	Analytic	Interested in or willing to take PrEP with caveats	G,A	Analytic

P = Place of residence, R = Race or ethnicity, O = Occupation, G = Gender or sexual identity, RE = Religion, E = Education, SS = Socioeconomic status, SC = Social capital, A = Age, D = physical or mental disability, HI = History of incarceration, HE = Experience of housing instability, TS = History of transactional sex, SU = Substance use, IPV = Experience of intimate partner violence

First author (year), location and date of data collection	Study sample	Design	PROGRESS- Plus collected for baseline population	Awareness definition	PROGRESS-Plus included when reporting awareness		Interest definition	PROGRESS-Plus included when reporting interest	
					Characteristic	How characteristics were included		Characteristic	How characteristics were included
Atefi (2019) ³⁹³ Australia, 2017-2107	GBMSM and transgender individuals	Cohort	G	-	-	-	Likelihood of taking or intention to take	-	-
Azariah (2019) ⁴⁰⁹ New Zealand, 2017-2019	GBMSM	Cohort	R	-	-	-	Acceptability of PrEP (perception)	-	-
Bauermeister (2013) ³⁵⁴ USA, 2012-2013	GBMSM	Cross- sectional	P,R,G,E,SS,A,HI	Given a description of PrEP and asked "Have you heard about PrEP?"	P,R,E,SS,A,HI	Analytic	Interested in or willing to take PrEP with caveats	R,E,SS,A,HI	Analytic
Berg (2019) ²⁷⁴ USA, 2014- 2015	GBMSM	Cross- sectional	P,R,E,SS	"Have you heard of PrEP before today?"	P,R,E,SS,A	Analytic	Interested in or willing to take PrEP	P,R,E,SS,A	Descriptive

P = Place of residence, R = Race or ethnicity, O = Occupation, G = Gender or sexual identity, RE = Religion, E = Education, SS = Socioeconomic status, SC = Social capital, A = Age, D = physical or mental disability, HI = History of incarceration, HE = Experience of housing instability, TS = History of transactional sex, SU = Substance use, IPV = Experience of intimate partner violence

First author (year), location and date of data collection	Study sample	Design	PROGRESS-Plus collected for baseline population	Awareness definition	PROGRESS-Plus included when reporting awareness		Interest definition	PROGRESS-Plus included when reporting interest	
					Characteristic	How characteristics were included		Characteristic	How characteristics were included
Biello (2019) ³⁶⁸ USA, 2014- 2016	GBMSM	Cohort	R,G,SS,A,SU	Given a description of PrEP and asked "Have you heard about PrEP?"	-	-	Likelihood of taking or intention to take	-	-
Blashill (2020) ³⁷³ USA, 2017	Latino GBMSM	Cross- sectional	P,R,O,G,E,SS,SC,D,HI,SU,IPV	"Have you heard of PrEP before today?"	G,SC,D,HI,SU,IPV	Analytic	Likelihood of taking or intention to take	G,SC,D,HI,SU,IPV	Analytic
Braksmajer (2018) ³⁷⁹ USA, 2014	General (no gender or sexual identity criteria)	Cross- sectional	R,E,SS,A	-	-	-	Interested in or willing to take PrEP	R,G,E,SS,A	Analytic

P = Place of residence, R = Race or ethnicity, O = Occupation, G = Gender or sexual identity, RE = Religion, E = Education, SS = Socioeconomic status, SC = Social capital, A = Age, D = physical or mental disability, HI = History of incarceration, HE = Experience of housing instability, TS = History of transactional sex, SU = Substance use, IPV = Experience of intimate partner violence

First author (year), location and date of data collection	Study sample	Design	PROGRESS-Plus collected for baseline population	Awareness definition	PROGRESS-Plus included when reporting awareness		Interest definition	PROGRESS-Plus included when reporting interest	
					Characteristic	How characteristics were included		Characteristic	How characteristics were included
Brantley (2019) ³⁷⁴ USA, 2017	General (no gender or sexual identity criteria)	Cohort	P,R,G,A	-	-	-	Interested in or willing to take PrEP	P,R,G,E,SS,A	Analytic
Brogan (2019) ³⁹¹ Canada, 2017- 2018	GBMSM	Cross- sectional	P,R,O,G,SS,SC,A	"Have you heard of PrEP before today?"	P	Descriptive	Likelihood of taking or intention to take (with caveats)	-	-
Brooks (2015) ³⁴⁴ USA, 2012-2013	Black/African American GBMSM	Cross- sectional	O,G,E,SS,A	"Have you heard of PrEP before today?"	-	-	Likelihood of taking or intention to take (with caveats)	G,E,A	Analytic

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Brooks (2018) ³²² USA, 2012-2013	Black/African American GBMSM	Cross- sectional	E,A	"Have you heard of PrEP before today?"	-	-	Interested in or willing to take PrEP	R,E,A	Analytic
Brooks (2019) ³⁴⁹ USA, 2015-2017	Latino GBMSM	Cross- sectional	R,O,RE,E,SS,A,SU	"Have you heard of PrEP before today?"	R,O,E,SS,A,SU	Analytic	Interested in or willing to take PrEP	P,O,E,SS	Descriptive
Bull (2018) ⁴⁰² England, 2015-2016	GBMSM	Cross- sectional	P,R,G,E,A,SU	"Have you heard of PrEP before today?"	A	-	Acceptability of PrEP (perception)	R,E,SU	Analytic
Bullinger (2019) ⁴⁰⁷ Belgium, 2016-2017	GBMSM and Transgender individuals	Cross- sectional	P,R,E	"Have you heard of PrEP before today?"	-	-	Interested in or willing to take PrEP	-	-

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Calabrese (2018) ³¹⁸ USA, 2017	Women	Cross- sectional	P,R,O,G,E,SS,SC,A	"Have you heard of PrEP before today?"	-	-	Likelihood of taking or intention to take	-	-
Calabrese (2019) ²⁹³ USA, 2017	Cisgender and transgender women	Cross- sectional	P,R,O,G,E,SS,A	-	-	-	Interested in or willing to take PrEP	-	-
Callander (2019) ⁴⁰⁰ France, 2016	GBMSM	Cross- sectional	R,O,G,SC,A	"Have you heard of PrEP before today?"	-	-	Likelihood of taking or intention to take (with caveats)	-	-
Carley (2019) ³²⁶ USA, 2018	Women	Cross- sectional	R,G,E,SS,A	"Have you heard of PrEP before today?"	R,E,SS,A	Analytic	Interested in or willing to take PrEP	-	-

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Chan (2016) ³²³ USA, 2013-2014	GBMSM	Cohort	R,G,SS,A	-	-	-	Interested in learning more about PrEP	R,A	Analytic
Chandran (2019) ²⁸⁹ USA, 2016-2017	GBMSM	Cross- sectional	R,G,E,A	"Have you heard of PrEP before today?"	R,G,E,A	Analytic	Interested in or willing to take PrEP	-	-
Chang (2018) ⁴⁰⁸ Korea, 2016	GBMSM	Cross- sectional	E,SS,A	"Have you heard of PrEP before today?"	-	-	Likelihood of taking or intention to take	-	-
Chen (2019) ³⁴⁰ USA, 2013-2015	Black/African American GBMSM	Cross- sectional	O,E,SC,A,D	Given a description of PrEP and asked "Have you heard about PrEP?"	P,SS,SC	Analytic	-	-	-

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Closson (2019) ³⁹² Canada, 2012-2017	GBMSM	Cross- sectional	R,O,G,E,SS,SC,A,TS	"Have you heard of PrEP before today?"	G,SS,A	Analytic	-	-	-
Cohen (2015) ³¹³ USA, 2012- 2014	GBMSM and transgender women	Cross- sectional	P,R,G,E,A,	"Have you heard of PrEP before today?"	-	Descriptive	-	-	-
Crosby (2014) ²⁷¹ USA, 2013- 2014	Black/African American GBMSM	Cross- sectional		-	-	-	Acceptability of PrEP (perception)	-	-
D'Avanzo (2019) ²¹¹ USA, not reported	Transgender women	Cross- sectional	R,G,E,SS,TS	PrEP knowledge	-	-	Interested in or willing to take PrEP	-	-

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Davey (2016) ³⁵⁷ USA, 2014	Black or Hispanic GBMSM	Cross- sectional	R	"Have you heard of PrEP before today?"	R	Analytic	-	-	-
Doblecki- Lewis (2016) ³¹⁹ USA, 2014- 2014	Women	Cross- sectional	R,G,E,SC,A,D,HI,HE	Given a description of PrEP and asked "Have you heard about PrEP?"	-	-	Interested in or willing to take PrEP	-	-
Doblecki- Lewis (2018) ³⁴³ USA, 2012- 2014	GBMSM and transgender women	Cohort	P,R,O,E,SS,A,D,HE	"Have you heard of PrEP before today?"	-	-	-	-	-

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Eaton (2014) ³⁶³ USA, 2012-2012	Black/African American GBMSM	Cross- sectional	P,O,G,E,SS,A,SU	Given a description of PrEP and asked "Have you heard about PrEP?"	-	-	Interested in or willing to take PrEP with caveats	P,O,G,E,SS	Analytic
Eaton (2015) ³³⁸ USA, 2012-2014	Black/African American GBMSM	Cross- sectional	R,O,G,E,SS,A,TS,SU	Given a description of PrEP and asked "Have you heard about PrEP?"	O,G,E,SS,A,TS,SU	Analytic	Interested in or willing to take PrEP	-	-
Eaton (2017) ²⁶⁸ USA, 2014	Black men and transgender women	Cross- sectional	O,G,E,SS,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"	P,O,G,E,SS,SC,A	Analytic	-	-	-

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Eaton (2017) ²⁶⁸ USA, 2014	Black men and transgender women	Cross- sectional	O,G,E,SS,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"	P,O,G,E,SS,SC,A	Analytic	-	-	-
Eaton (2017) ³⁷¹ USA, 2015-2015	GBMSM and transgender women	Cross- sectional	R,O,G,E,SS,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"	R	Descriptive	Interested in or willing to take PrEP	G,E,SS,SC	Analytic
Eaton (2018) ³⁰¹ USA, 2014-2015	Black/African American GBMSM	Cross- sectional	O,G,E,SS,SC,A,D,SU	Given a description of PrEP and asked "Have you heard about PrEP?"	-	-	-	-	-

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Escudero (2015) ⁴¹⁷ Canada, 2012-2013	People who inject drugs	Cross- sectional	R,G,E,SC,A,HI,HE,SU	"Have you heard of PrEP before today?"	-	-	Interested in or willing to take PrEP	R,G,E,SC	Analytic
Farhat (2017) ³³¹ USA, 2015	General (no gender or sexual identity criteria)	Cross- sectional	R,G,E,SC,A	Knowledge of PrEP	R,G,E,SC,A	Descriptive	-	-	-
Ferrer (2016) ⁴⁰³ Spain, 2013-2014	GBMSM	Cross- sectional	P,R,O,G,E,A	"Have you heard of PrEP before today?"	P,R,O,G,E,A	Descriptive	Interested in or willing to take PrEP	P,O,E,A	Analytic
Finlayson (2019) ²⁸⁸ USA, 2014-2017	HIV negative GBMSM	Cross- sectional	P,R,G,E,SS,A	"Have you heard of PrEP before today?"	P,R,G,E,SS,A	Analytic	-	-	-

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Flash (2018) ²⁹¹ USA, 2013-2015	General (no gender or sexual identity criteria)	Cohort	P,R,O,G,E,SS,A,HE,SU	-	-	-	Interested in or willing to take PrEP with caveats	-	-
Friedman (2019) ³⁶² USA, 2014-2017	Black/African American GBMSM	Cross- sectional	P,R,SS,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"	P,G,SS,SC,A,D,SU,IPV	Analytic	-	-	-
Garfinkel (2017) ³⁵⁰ USA, 2014	Women	Cross- sectional	R,G,E,SC,A	-	-	-	Interested in or willing to take PrEP	R,G,E,SC,IPV	Analytic

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Garnett (2018) ³³² USA, 2012	Black GBMSM and transgender women	Cross-sectional	R,O,G,E,SS,SC,A,HE	Given a description of PrEP and asked "Have you heard about PrEP?"	R,O,E,SS,SC,A,SU	Analytic	-	-	-
Giuseppe (2019) ²⁰² England, not reported	General (no gender or sexual identity criteria), Black African	Cross-sectional	R,G,SC	"Have you heard of PrEP before today?"	A	Descriptive	-	-	-
Goedel (2016) ³²⁰ USA, 2015-2015	GBMSM	Cross-sectional	R,O,G,E,SS	Knowledge of PrEP	R,O,G,E,SS	Descriptive	-	-	-
Goedel (2016) ²⁹⁰ USA, not reported	GBMSM	Cross-sectional	R,G,E,SS,A	Given a description of PrEP and asked "Have you heard about PrEP?"	R,G,E,SS,A	Analytic	Interested in or willing to take PrEP	R,G,E,SS,A	Analytic

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Goedel (2018) ³⁹⁷ France, 2016-2016	GBMSM	Cross- sectional	R,O,G,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"	R,G,A	Analytic	Likelihood of taking or intention to take (with caveats)	-	-
Goedel (2019) ⁴⁰¹ England, 2016	GBMSM	Cross- sectional	R,O,G,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"	-	Analytic	Likelihood of taking or intention to take	-	-
Golub (2013) ³¹⁰ USA, 2012-2012	GBMSM and transgender women	Cross- sectional	R,G,E,SS,SC,A	-	-	-	Likelihood of taking or intention to take (with caveats)	R,G,E,SS,SC	Descriptive
Golub (2015) ³²⁷ USA, 2012-2013	GBMSM	Cross- sectional	R,G,E,SS,A,SU	-	-	-	Interested in or willing to take PrEP	R,G,E,SS,A,SU	Analytic

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Griffin (2020) ³⁴⁵ USA, 2016	GBMSM	Cross- sectional	R,G,E,SS,A	Given a description of PrEP and asked "Have you heard about PrEP?"	R,G,E,SS	Analytic	-	-	-
Gupta (2017) ³³⁴ USA, 2013	GBMSM	Cross- sectional	R,G,A	Given a description of PrEP and asked "Have you heard about PrEP?"	R,A	Analytic	-	-	-
Hambrick (2018) ³⁹⁸ France, 2016	GBMSM	Cross- sectional	R,O,G,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"	R,O,G,SC,A	Analytic	Likelihood of taking or intention to take	R,O,G,SC,A	Analytic

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Hammack (2018) ³²¹ USA, 2016-2017	GBMSM	Cross- sectional	P,R,G,E,SC,A	Knowledge of PrEP	P,R,G,E,SC,A	Analytic	-	-	-
Hampel (2017) ⁴¹⁰ Switzerland, 2017	GBMSM	Cross- sectional	P,R,A	Given a description of PrEP and asked "Have you heard about PrEP?"	R,A	Analytic	Interested in or willing to take PrEP with caveats AND learning more	R,A	Analytic
Harris (2017) ³⁵³ USA, not reported	Latino/Hispanic GBMSM	Cross- sectional	R,O,E,SS,SC,A	"Have you heard of PrEP before today?"	-	Analytic	Interested in or willing to take PrEP	-	-
Henwood (2019) ³⁶⁷ USA, not reported	General (no gender or sexual identity criteria)	Cross- sectional	P,R,G,E,A,HE	Knowledge of PrEP	-	-	Interested in or willing to take PrEP	-	-

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Hoff (2015) ²⁷⁹ USA, 2012-2013	GBMSM	Cross- sectional	R,O,E,SS,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"	-	-	Likelihood of taking or intention to take	-	-
Holder (2019) ²⁹⁷ USA, not reported	Transgender women	Cross- sectional	R,E,SS,A	Given a description of PrEP and asked "Have you heard about PrEP?"	R	Descriptive	Interested in or willing to take PrEP with caveats	R	Descriptive
Holloway (2017) ³⁰⁷ USA, 2015	GBMSM	Cross- sectional	R,O,G,E,SS,A,HE,SU	"Have you heard of PrEP before today?"	-	-	Likelihood of taking or intention to take	P,R,O,G,E,SS, A,HE,SU	Descriptive
Holt (2016) ³⁹⁵ Australia, 2015-2015	GBMSM	Cross- sectional	P,O,E,A	Knowledge of PrEP	P,R,O,E,A	Analytic	-	-	-

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Holt (2019) ³⁹⁴ Australia, 2015-2017	GBMSM	Cross- sectional	P,R,O,G,E,SC,A,SU	-	-	-	Interested in or willing to take PrEP	-	-
Holt (2020) ²⁵⁵ Australia, 2014-2018	GBMSM	Cross- sectional	P,R,O,G,E,A	"Have you heard of PrEP before today?"	-	Analytic	Interested in or willing to take PrEP	P,R,O,G,E,A	Analytic
Hood (2016) ³⁰⁰ USA, 2012-2015	GBMSM	Cross- sectional	P,R,E,A	"Have you heard of PrEP before today?"	P,R,E,SS,A	Analytic	-	-	-
Hood (2018) ³¹¹ USA, 2017-2018	Transgender women	Cross- sectional	R,G,SS,A,HE,SU	Given a description of PrEP and asked "Have you heard about PrEP?"	P,R,SS,A,SU	Analytic	Interested in or willing to take PrEP	P,R,SS,A,SU	Analytic

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Hoots (2016) ³⁸⁰ USA, 2014-2014	GBMSM	Cross-sectional		-	-	-	Interested in or willing to take PrEP	P,E,SS,A,SU	Analytic
Huebner (2018) ³¹⁶ USA, 2015	GBMSM	Cross-sectional	R,G,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"	R,G,SC,A	Analytic	-	-	-
Iniesta (2018) ⁴⁰⁴ Spain, 2017-2017	GBMSM and transgender women	Cross-sectional	P,G,E,A	-	-	-	Interested in or willing to take PrEP	P,E,A	Analytic
Jaiswal (2018) ³⁷² USA, 2014-2016	GBMSM	Cross-sectional	R,G,SS,SC	"Have you heard of PrEP before today?"	R,O,G,SS	Descriptive	-	-	-

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Johnson (2019) ²⁸⁰ USA, 2018-2018	Black/African American Women	Cross- sectional	P,SS,A	Given a description of PrEP and asked "Have you heard about PrEP?"	P,SS,A	Descriptive	Likelihood of taking or intention to take	P,SS,A	Descriptive
Kanny (2019) ³⁶⁶ USA, 2017- 2017	GBMSM	Cross- sectional	P,R	"Have you heard of PrEP before today?"	R	Analytic	-	-	-
Khanna (2016) ³⁵¹ USA, 2013-2014	Black/African American GBMSM	Cross- sectional	E,SS,A	"Have you heard of PrEP before today?"	SC,A,D	Analytic	-	-	-
Klevens (2018) ³⁰⁹ USA, 2014-2014	GBMSM	Cross- sectional	R,G,E,A	Given a description of PrEP and asked "Have you heard about PrEP?"	R,E,A	Analytic	Interested in or willing to take PrEP	R,E,A	Analytic

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Koren (2018) ³¹⁵ USA, 2017-2017	Women	Cross-sectional	R,A	Given a description of PrEP and asked "Have you heard about PrEP?"	-	-	Interested in or willing to take PrEP	-	-
Kuo (2016) ³⁸¹ USA, 2012-2012	General (no gender or identity criteria), people who inject drugs	Cross-sectional	R,O,G,E,SS,A,HI,HE,SU	-	-	-	Likelihood of taking or intention to take (with caveats)	R,O,G,E,SS,A,HI,HE,SU	Analytic
Kwakwa (2016) ¹⁹⁹ USA, 2012-2014	General (no gender or sexual identity criteria)	Cross-sectional	R,O,A	-	-	-	Interested in or willing to take PrEP	R,O,G,A	Analytic

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Kwakwa (2018) ³⁰² USA, 2014-2015	General (no gender or sexual identity criteria)	Cohort	R,G,SS,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"	-	-	Interested in or willing to take PrEP		
Lachowsky (2016) ³⁸⁵ Canada, 2012-2014	GBMSM	Cross-sectional	P,R,G,E,SS,A	Given a description of PrEP and asked "Have you heard about PrEP?" And PrEP knowledge	P,R,G,E,SS,SC,A	Analytic	-	-	-
Lachowsky (2019) ³⁸⁶ Canada, 2017	GBMSM	Cross-sectional	SS,SC,SU	"Have you heard of PrEP before today?"	-	-	Interested in or willing to take PrEP	SS,SC	Descriptive

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Lebouché (2016) ³⁸⁷ Canada, 2012-2013	GBMSM	Cross-sectional	P,G,E,SS,SC	"Have you heard of PrEP before today?"	-	-	Interested in or willing to take PrEP with caveats	P,G,E,SS,A	Analytic
Lee (2017) ⁴⁰⁵ Taiwan, 2016	General (no gender or sexual identity criteria)	Cross-sectional	O,G,E,SS,A,TS	Given a description of PrEP and asked "Have you heard about PrEP?"	-	-	-	A,TS	Analytic
Lelutiu-Weinberger (2020) ³⁷⁷ USA, 2014-2015	Black/African American GBMSM	Cross-sectional	O,G,E,SC,A	"Have you heard of PrEP before today?"	O,G,E,SC,A	Analytic	-	-	-
Liu (2016) ³¹⁷ USA, 2012-2014	GBMSM	Cohort	P,R,G,E,SS,A,HE,SU	"Have you heard of PrEP before today?"	-	-	-	-	-

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Macapagal (2020) ³⁵⁶ USA, 2018	GBMSM	Cross- sectional	R,G,E,SC	Given a description of PrEP and asked "Have you heard about PrEP?"	-	-	Interested in or willing to take PrEP with caveats	R,G,E	Analytic
Maksut (2020) ⁴¹² USA, 2014-2017	Black/African American GBMSM	Cross- sectional	SS,A,HE,SU	Given a description of PrEP and asked "Have you heard about PrEP?"	SU	Descriptive	-	-	-
Mansergh (2019) ⁴¹² USA, 2014	GBMSM	Cross- sectional	P,R,G,E,A	"Have you heard of PrEP before today?"	R,G,E,A	Analytic	-	-	-

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Maria (2019) ⁴¹³ USA, 2016- 2017	General (no gender or sexual identity criteria)	Cross- sectional	P,R,G,A,HE	PrEP knowledge	P,G,A,HE	Analytic	Interested in or willing to take PrEP AND Likelihood	P,R,G,A,HE	Descriptive
McFarland (2019) ³³⁶ USA, 2018	General (no gender or identity criteria), people who inject drugs	Cross- sectional	R,G,SU	"Have you heard of PrEP before today?"	-	Descriptive	-	-	-
McMahan (2020) ³⁴⁶ USA, 2017	GBMSM	Cross- sectional	R,G,E,SS,A,IPV	"Have you heard of PrEP before today?"	R,G,SS,A,IPV	Descriptive	-	-	-
Mgbako (2019) ³⁹⁹ France, 2016	GBMSM	Cross- sectional	R,O,G,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"	R,O,G,A	Analytic	Likelihood of taking or intention to take	-	-

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Moore (2019) ²⁹⁹ USA, not reported	General (no gender or sexual identity criteria)	Cross- sectional	R,G,SS,A,SU	-	-	-	-	-	-
Morgan (2018) ³⁸⁸ Canada, 2014- 2015	GBMSM	Cross- sectional	P,R,G,E,SS,A	Given a description of PrEP and asked "Have you heard about PrEP?"	P,R,G,E,SS,A	Analytic	Interested in or willing to take PrEP	P,R,G,E,SS,A	Analytic
Mosley (2018) ³⁸⁹ Canada, 2012- 2016	GBMSM	Cohort	R,G,E,SS,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"AND PrEP knowledge	P,R,G,SS,A	Analytic	-	-	-

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Newman (2018) ⁴⁰⁶ Taiwan, 2014-2014	GBMSM	Cross- sectional	G,E,SS,SC,A	Given a description of PrEP and asked "Have you heard about PrEP?"	G,E,SS,SC,A	Analytic	Likelihood of taking or intention to take	G,E,SS,SC	Analytic
Ojikutu (2018) ³⁰⁶ USA, 2016	General (no gender or sexual identity criteria)	Cross- sectional	P,R,O,G,E,SS,SC,D,SU	PrEP knowledge	-	Descriptive	Interested in or willing to take PrEP	O,G,SS,SC,A,D,HI	Analytic
Oldenburg (2016) ²⁹⁴ USA, 2012-2013	GBMSM, substance users	Cross- sectional	R,G,E,SS,SC,HE	"Have you heard of PrEP before today?"	P,R,G,E,SS,SC,HE	Analytic	Likelihood of taking or intention to take	-	-

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Parsons (2017) ³⁷⁸ USA, 2015	GBMSM	Cross- sectional	P,R,G,E,SS,A	-	-	-	Interested in or willing to take PrEP with caveats	P,R	Descriptive
Patel (2019) ²⁸⁶ USA, 2014-2015	Women	Cross- sectional	P,R,E,SS,SC,SU	"Have you heard of PrEP before today?"	-	-	Interested in or willing to take PrEP	-	Analytic
Pathela (2020) ⁴¹⁴ USA, 2017-2018	GBMSM	Cohort	R,SS,A	-	-	-	Interested in or willing to take PrEP	R,SS,A	Analytic
Poteat (2019) ²⁶⁶ USA, 2015-2017	Black/African American or Latina transgender women	Cross- sectional	P,R,O,G,E,SS,TS	"Have you heard of PrEP before today?"	-	-	Interested in or willing to take PrEP	P,R,G,TS	Analytic

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Raifman (2017) ³¹² USA, 2015	GBMSM	Cross- sectional	R,E,SS,A	"Have you heard of PrEP before today?"	R,E,SS,A	Analytic	Interested in or willing to take PrEP	-	-
Raifman (2019) ³⁶⁵ USA, 2013-2016	Women	Cohort	R,A	"Have you heard of PrEP before today?"	R,A	Analytic	-	-	-
Raifman (2019) ²⁸⁵ USA, 2017	GBMSM	Cross- sectional	R	"Have you heard of PrEP before today?"	R	Analytic	-	-	-
Rana (2018) ³⁹⁰ Canada, 2013-2016	GBMSM	Cross- sectional	R,O,E,A,SU	Given a description of PrEP and asked have you heard about PrEP?	R,O,E,SS	Analytic	Interested in or willing to take PrEP	R,O,E,SS	Analytic

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Ranjit (2020) ³⁴¹ USA, 2016	General (no gender or sexual identity criteria), people who use drugs	Cross- sectional	R,G,E,SC,A,HE,SU	"Have you heard of PrEP before today?"	-	-	Interested in or willing to take PrEP	-	-
Ransome (2019) ³⁴² USA, 2014	GBMSM	Cross- sectional	R,E,SS,SC,A	"Have you heard of PrEP before today?"	R,E,SS,SC,A	Analytic	Interested in or willing to take PrEP	R,E,SS,SC,A	Analytic
Ransome (2019) ²⁷⁶ USA, 2016	General (no gender or sexual identity criteria), Black/African American	Cross- sectional	G,E,SS,A	PrEP knowledge	-	-	Interested in or willing to take PrEP	G,E,SS,A	Analytic

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Rao (2019) ³³⁹ USA, 2017	GBMSM	Cross- sectional	P,R,G,E,SS,A,TS	"Have you heard of PrEP before today?"	P,R,G	Descriptive	Interested in or willing to take PrEP OR wanting to learn more	-	-
Read (2019) ³⁹⁶ Australia, 2016	General (no gender or sexual identity criteria), people who inject drugs	Cross- sectional	R,G,A,SU	"Have you heard of PrEP before today?"	R,G,A,SU	Analytic	Interested in or willing to take PrEP	R,G,A,SU	Descriptive
Reisner (2019) ³¹⁴ USA, 2017	Transgender men	Cross- sectional	P,R,G,E,SS,SC,A,D,SU	"Have you heard of PrEP before today?"	-	-	-	-	-

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Rendina (2017) ²⁹⁸ USA, 2015	GBMSM	Cross- sectional	P,R,G,E,SS,SC,A,SU	-	-	-	Interested in or willing to take PrEP with caveats AND intention to take PrEP	P,R,G,E,SS,SC,A,SU	Analytic
Restar (2018) ²⁷⁰ USA, 2012- 2015	Transgender women	Cross- sectional	R,O,G,E,SS,A,HI,HE,TS	Given a description of PrEP and asked have you heard about PrEP?	-	-	Interested in or willing to take PrEP	P,R,O,G,E,SS, A,HI,HE,TS	Analytic
Ridgway (2018) ³⁰⁴ USA, 2015- 2017	General (no gender or sexual identity criteria)	Cohort	R,G,A	-	-	-	Interest in learning more	G,A	Analytic

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Rolle (2017) ³⁸³ USA, 2012- 2013	Black and white GBMSM	Cross- sectional	R,G,E,SS,A,HE,SU	-	-	-	Interested in or willing to take PrEP	P,R,E,SS,A,HE,SU	Analytic
Rolle (2017) ⁴¹⁵ USA, 2015- 2019	Black GBMSM	Cohort	G,E,SS,SC,A,HE	"Have you heard of PrEP before today?"	-	-	Interested in or willing to take PrEP or learning more	-	-
Roth (2018) ²⁷³ USA, 2015- 2016	General (no gender or sexual identity criteria), people of colour, people who inject drugs	Cross- sectional	P,R,G,E,SS,A,HE	-	-	-	Interested in or willing to take PrEP with caveats	G	Analytic

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Roth (2019) ³⁰⁸ USA, 2015	General (no gender or sexual identity criteria), people of colour, people who inject drugs	Cross-sectional	R,G,E,SS,A,HE, TS,SU	"Have you heard of PrEP before today?"	P,R,G,E,SS,A,HE,TS,SU	Analytic	-	-	-
Roth (2019) ³⁴⁸ USA, 2016	General (no gender or sexual identity criteria), people of colour	Cross-sectional	R,G,E,SS,A,HE, TS,SU	"Have you heard of PrEP before today?"	G	Analytic	-	-	-
Sales (2018) ³⁵⁸ USA, 2012-2014	General (no gender or sexual identity criteria)	Cross-sectional	E,A	-	-	-	Likelihood of taking or intention to take (with caveats)	-	-

P = Place of residence, R = Race or ethnicity, O = Occupation, G = Gender or sexual identity, RE = Religion, E = Education, SS = Socioeconomic status, SC = Social capital, A = Age, D = physical or mental disability, HI = History of incarceration, HE = Experience of housing instability, TS = History of transactional sex, SU = Substance use, IPV = Experience of intimate partner violence

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Sales (2019) ¹⁹⁰ USA, 2017-2017	Women	Cross- sectional	R	"Have you heard of PrEP before today?"	-	-	Interested in learning more AND interest in taking	-	-
Santa Maria (2019) ³²⁴ USA, 2016	General (no gender or sexual identity criteria)	Cross- sectional	P,R,G,A,HE,TS	PrEP knowledge	P	Descriptive	Interested in or willing to take PrEP	-	-
Saw (2019) ³⁷⁰ USA, not reported	Latino GBMSM	Cross- sectional	R,E	"Have you heard of PrEP before today?"	E,SS	Analytic	Interested in or willing to take PrEP	SS	Analytic
Schueler (2019) ³⁴⁷ USA, 2014-2016	General (no gender or sexual identity criteria)	Cross- sectional	R,O,G,E,SC,A	Given a description of PrEP and asked have you heard about PrEP?	R,O,G,E,SC,A	Analytic	-	-	-

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Shah (2019) ²⁶⁹ USA, 2016	General (no gender or sexual identity criteria)	Cross- sectional	R,G,A	-	-	-	Acceptability of PrEP (perception)	R,G,A	Descriptive
Shende (2019) ³⁶⁰ USA, 2018	General (no gender or sexual identity criteria)	Cross- sectional	R,G,SS,A,SU	"Have you heard of PrEP before today?"	R,G,SS	Analytic	-	-	-
Sherman (2019) ³⁵⁵ USA, 2016	General (no gender or sexual identity criteria), people who inject drugs	Cross- sectional	P,R,O,G,E,SS,SC,A,D,HE,SU	"Have you heard of PrEP before today?"	-	-	Interested in or willing to take PrEP	P,R,O,G,E,SS, SC,A,D,HE,SU	Analytic

P = Place of residence, R = Race or ethnicity, O = Occupation, G = Gender or sexual identity, RE = Religion, E = Education, SS = Socioeconomic status, SC = Social capital, A = Age, D = physical or mental disability, HI = History of incarceration, HE = Experience of housing instability, TS = History of transactional sex, SU = Substance use, IPV = Experience of intimate partner violence

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Sheth (2019) ²⁷⁸ USA, 2012-2014	Black/African American women	Cross- sectional	E,A	-	-	-	Likelihood of taking or intention to take (with caveats)	-	-
Shrestha (2017) ²⁹² USA, 2016	General (no gender or sexual identity criteria), people who use drugs	Cross- sectional	R,O,G,E,SS,SC,A,SU	"Have you heard of PrEP before today?"	-	-	Interested in or willing to take PrEP	-	-
Shrestha (2018) ³³⁷ USA, 2016	General (no gender or sexual identity criteria), people who use drugs	Cross- sectional	R,O,G,E,SS,SC,A,SU	"Have you heard of PrEP before today?"	-	-	Acceptability of PrEP (perception)	-	-

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Snowden (2017) ³⁶¹ USA, 2014	GBMSM	Cross- sectional	R,E,SS,A	-	-	-	Interested in or willing to take PrEP	R	Descriptive
Stein (2014) ³⁸² USA, 2013	General (no gender or sexual identity criteria), people who use drugs	Cross- sectional	R,G,E,A,SU	"Have you heard of PrEP before today?"	-	-	Interested in or willing to take PrEP with caveats	R,G,E,A	Descriptive
Strauss (2017) ³⁰⁵ USA, 2013-2015	GBMSM	Cross- sectional	P,R,O,G,E,A	PrEP knowledge	R,O,G,E,A	Analytic	Interested in or willing to take PrEP	-	-
Tekeste (2019) ²⁹⁵ USA, 2017	Black or White Women	Cross- sectional	R,O,G,E,SS,SC	Given a description of PrEP and asked "Have you heard about PrEP?"	R	Descriptive	Interested in learning more AND intention to take	R,O,E,SS,SC	Descriptive

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Tomko (2019) ²⁸¹ USA, 2016-2017	Women	Cross- sectional	R,E,SS,A,D,HI,HE,TS,SU,IPV	Given a description of PrEP and asked "Have you heard about PrEP?"	P,R,E,SS,SC, A,D,HI,HE,TS, SU, IPV	Analytic	Interested in or willing to take PrEP	P,R,E,SS,SC, A,D,HI,HE, TS,SU, IPV	Analytic
Udeagu (2017) ²⁹⁶ USA, 2015-2017	General (no gender or sexual identity criteria)	Cohort	R,G,A,SU	"Have you heard of PrEP before today?"	R,G,A,SU	Analytic	-	-	-
Walsh (2019) ²⁷⁵ USA, 2016	GBMSM	Cross- sectional	P,R,O,G,E,SS,SC,A	PrEP knowledge	-	-	Interested in or willing to take PrEP	P,R,O,G,E,SS, SC,A	Analytic

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Walters (2017) ²⁸³ USA, 2015-2015	Cisgender men and women, people who inject drugs	Cross- Sectional	R,G,E,SS,A,HI,HE,TS,SU	"Have you heard of PrEP before today?"	P,R,G,E,SS,A, HI,HE,TS,SU	Analytic	-	-	-
Watson (2020) ³³³ USA, 2017-2019	Black/African American GBMSM	Cross- sectional	G,E,SS,A	Given a description of PrEP and asked "Have you heard about PrEP?"	G,E,SS,A	Analytic	-	-	-
Willie (2017) ³²⁸ USA, 2014	Black/African- American women	Cross- sectional	G,E,SC,A,IPV	-	-	-	Interested in or willing to take PrEP	IPV	Analytic

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					Characteristic	How characteristics were included		Characteristic	How characteristics were included
Willie (2018) ³⁰³ USA, 2016	Heterosexual men and women	Cross- sectional	R,G,E,SC,A,IPV	Given a description of PrEP and asked "Have you heard about PrEP?"	R,O,G,E,SS,SC,A,IPV	Analytic	Interested in or willing to take PrEP	-	Analytic
Willie (2019) ³⁶⁹ USA, 2017-2018	Women	Cross- sectional	R,O,G,E,SS,SC,A,IPV	Given a description of PrEP and asked "Have you heard about PrEP?"	R,O,G,E,SS,SC,A,IPV	Analytic	Likelihood of taking or intention to take AND interest in learning more	R,G,E,SS,SC,A,IPV	Analytic
Willie (2020) ³²⁹ USA, 2017-2018	Women	Cross- sectional	R,O,E,SS,SC,A	"Have you heard of PrEP before today?"	IPV	Descriptive	Likelihood of taking or intention to take	IPV	Analytic

P = Place of residence, R = Race or ethnicity, O = Occupation, G = Gender or sexual identity, RE = Religion, E = Education, SS = Socioeconomic status, SC = Social capital, A = Age, D = physical or mental disability, HI = History of incarceration, HE = Experience of housing instability, TS = History of transactional sex, SU = Substance use, IPV = Experience of intimate partner violence

First author (year), location and date of data collection	Study sample	Design	PROGRESS-Plus collected for baseline population	Awareness definition	PROGRESS-Plus included when reporting awareness		Interest definition	PROGRESS-Plus included when reporting interest	
					Characteristic	How characteristics were included		Characteristic	How characteristics were included
Wilson (2015) ³³⁰ USA, 2013	Transgender women	Cross- sectional	P,R,G,SS,A,HE,SU	Given a description of PrEP and asked "Have you heard about PrEP?"	P,R,G,SS,A,HE,SU	Descriptive	Interested in or willing to take PrEP	-	-
Wilson (2016) ²⁸² USA, 2012-2014	Transgender women	Cross- sectional	P,R,G,E,SS,A,HE,TS	Given a description of PrEP and asked "Have you heard about PrEP?"	-	-	Interested in or willing to take PrEP	P,R,G,E,SS,A, HE,TS	Descriptive

P = Place of residence, R = Race or ethnicity, O = Occupation, G = Gender or sexual identity, RE = Religion, E = Education, SS = Socioeconomic status, SC = Social capital, A = Age, D = physical or mental disability, HI = History of incarceration, HE = Experience of housing instability, TS = History of transactional sex, SU = Substance use, IPV = Experience of intimate partner violence

First author (year), location and date of data collection	Study sample	Design	PROGRESS-Plus collected for baseline population	Awareness definition	PROGRESS-Plus included when reporting awareness		Interest definition	PROGRESS-Plus included when reporting interest	
					Characteristic	How characteristics were included		Characteristic	How characteristics were included
Zarwell (2019) ³⁵⁹ USA, 2014	GBMSM	Cross- sectional	R,E,SS,SC,A	"Have you heard of PrEP before today?"	R,E,SS,SC,A	Analytic	Interested in or willing to take PrEP	R,G,E,SS,SC,A	Analytic
Zhang (2019) ³⁶⁴ USA, 2015-2016	General (no gender or sexual identity criteria), people who use drugs	Cross- sectional	R,G,E,SS,A	"Have you heard of PrEP before today?"	R,G,E,SS,A	Analytic	-	-	-

P = Place of residence, R = Race or ethnicity, O = Occupation, G = Gender or sexual identity, RE = Religion, E = Education, SS = Socioeconomic status, SC = Social capital, A = Age, D = physical or mental disability, HI = History of incarceration, HE = Experience of housing instability, TS = History of transactional sex, SU = Substance use, IPV = Experience of intimate partner violence

Appendix 5: Topic guide for HIV negative participants

Topic Guide: Women and PrEP v 1.2

Thank you for taking the time to talk with me today. I'm Melissa, and I'm a research student at UCL. My project is about ways we can prevent HIV. One of these ways is by using a medication called HIV Pre-Exposure Prophylaxis, or PrEP. PrEP is taken by HIV negative people only to prevent infection with HIV. The aim of this research is to discuss what women, including people who identify as women or feminine, know about PrEP, and what they think of it as a treatment option for preventing the acquisition of HIV.

Today we'll be exploring three main areas: your general thoughts and experiences accessing sexual health and HIV prevention information and services; PrEP as a prevention option for HIV; and lastly, how we can identify things that could make it easier or more difficult to access HIV prevention services. I want to understand what women think about HIV prevention, what we can do to improve services for women, and ultimately improve women's health.

- Go through information sheet
- Go through consent form. Have they signed/given verbal consent?
- Ask them the demographic questions/Confirm they've completed them on opinio

Before we get started, I just want to remind you again that everything you share with me will be confidential. No personal information that could identify you will be included in the typed interview transcripts, and no one should be able to tell who you are from the interview.

Also, I want to let you know that there are no right or wrong answers. We're just exploring this topic and I'm really interested in hearing about your opinions and experiences. I am not going to judge any of your answers. If I ask why you gave a particular answer, it's just because I want to know more about this. If there's anything I ask that you don't want to talk about, it's fine to just tell me that and we can go on to the next question. Or if you'd like a break or to end the interview at any time, that's absolutely fine, just tell me. Do you have any questions before we start?

Check ok to record.

[Turn on recorder]

OPENING QUESTIONS

1. Can you start by telling me how you found out about this research?

↳ *Prompt:* Why did you want to take part?

2. When you hear the phrase “sexual health” what do you think of?

↳ *Prompts:* STIs, having pleasurable sex, contraception, HIV, having choices, freedom, positive self-esteem, sexual function, consent, testing

↳ *Probes:* What aspects are most important to you?

HIV awareness and knowledge

I'd now like to talk a bit about HIV in general.

3. Can you tell me what you know about HIV?

↳ *Prompts:* What is HIV? Who does it affect? How is transmitted?

↳ *Prompts:* Can you tell me what you know about HIV prevention? (e.g. ways of preventing HIV, condoms, testing, etc)

↳ *Probes:* Where did you learn this information?

4. Are you (or have you ever been) concerned about HIV?

↳ *Probes:* Can you tell me more about that? Why/Why not?

↳ *Probes:* Why do you think that you are more concerned about that?

↳ *Probes:* Has that concern ever prevented you from having the kinds of sex you want to have?

↳ *Probes:* Did you do anything because of that concern?

↳ *Prompts:* Attend clinic, find out more information, speak to e.g. friends, family, partners, healthcare professionals, looked online

↳ *Probes:* What did you find helpful? What could have been done to help your concern/make the process easier?

5. Have you ever had an HIV test?

↳ **Probes:** Have you ever been offered a test?

↳ **Probes:** Have you ever declined a test? If so, why?

↳ **Prompts:** Perceived risk, consistent condom use, low knowledge of HIV risk

6. HIV tests are sometimes offered routinely (e.g., at the GP, in the Emergency Room, antenatal)

- ↳ **Probes:** If you were offered an HIV test as part of another appointment/excursion would you accept it? Why or why not?
 - ↳ **Prompts:** Perceived risk, consistent condom use, not sexually active

Go through the National AIDS Trust Leaflet with information on HIV/HIV prevention

7. Is there any information on this leaflet that you found surprising?

PrEP Awareness and Knowledge

Now I'd like to talk a bit more about HIV prevention – in particular I'd like to talk about PrEP. PrEP is a medication that is taken by people who are HIV-negative. Go through the leaflet with people.

8. Prior to hearing about this research, had you ever heard of PrEP?

- *Prompts:* If yes, Can you tell me how you heard about it? Or where did you learn this information?
- *Prompts:* If no, How do you feel about not having access to this information?
- *Probes:* friends, family, internet, school, sexual health clinic, GP, marketing and/or adverts?

9. What do you think of PrEP as a way to prevent HIV infection?

- *Probes:* good idea, bad idea? Complimentary to other prevention strategies such as condoms? Can you tell me more about that?
- *Probes:* What do you think of the different ways of taking it that are described? Is having more options good/bad?

10. Who do you think could benefit from taking PrEP?

- ↳ *Prompts:* Generally, who would benefit, women who would benefit (e.g., women who have multiple partners, or can't/don't use condoms, in poly relationships or with partners in poly relationships)
- ↳ *Probes:* Can you think of other benefits besides HIV prevention (e.g., peace of mind)

11. Have you ever taken, PrEP OR is PrEP something you would ever consider

taking?

– **If taken PrEP:**

↳ Can you tell me more about that?

- Probes: Why did you decide to take it, where was it accessed from, was it offered or did you seek it out?

↳ What was your experience of accessing PrEP like?

- Probes: How could it have been improved? What worked well? What didn't work well?

↳ Were you provided with any information specific for women?

- Did you feel there was information that could have supported you more?

– **If have not taken it:**

↳ What were your reasons for not taking it? Would you consider it or why not?

- Probes: stigma associated with HIV, risk perception (perceived or otherwise)

↳ Is there any information that we've discussed that would make you interested in learning more about PrEP?

- Probes: Would increased options make you more or less likely to take PrEP (e.g., the ring, injectables, etc)?

↳ Have you ever discussed taken PrEP with a health care professional?

↳ If you were interested, or became interested in PrEP who would you like to discuss PrEP with?

- *Probes:* GP, sexual health services staff (e.g. doctors, nurses, healthcare assistants), pharmacists, friends/social networks)

Sexual Health Service needs and preferences

We've discussed that PrEP is available at sexual health clinics, but there are lots of other places where people can go for their sexual health care or to get advice.

12. Can you tell me about your experiences accessing sexual and

reproductive health services? This can be any of the things we talked about relating to sexual health.

- ↳ *Prompts:* Advice, information, treatment, contraception, prevention, support following DV/SV or assault, support for adjusting to diagnosis
- ↳ *Prompts:* Going to a SHS, GP, Pharmacist, online
- ↳ *Prompts:* Contraception, cervical smear, pleasure, STI prevention (testing, treatment etc), HIV prevention for partners who are HIV negative.
- ↳ *Probes:* You mentioned going to x, why did you go there?
- ↳ *Probes:* What was the experience like? How could it be improved? What made it difficult? What could make it easier?
- ↳ *Probes:* Difficulties with access? Not knowing where to go, or not being able to access services? Cultural/language barriers? Social pressure/social stigma experienced as a person living with HIV?
- ↳ *Probes:* Who helps you make those decisions?
- ↳ *Probes:* If HIV prevention mentioned- ask about that experience

13.If you were interested in PrEP, where would you prefer to learn more about it?

- ↳ *Prompts:* Sexual health services, GP, pharmacist, community group, online information, friends, maternity services, menopause services?
- *Probes:* You mentioned you go to x for sexual health care, would you want to learn about it or talk about it there?

14.If you were interested in PrEP, where would you prefer to get a prescription?

- ↳ *Prompt:* Sexual health services, GP, pharmacist, other
- ↳ *Probes:* Why that location?

15.Where do you think PrEP should be available from?

- *Prompts:* Is at SHS enough? Why or why not?
- *Probes:* Could this make it easier for someone to learn or access PrEP?
- *Probes:* Could this deter/exclude someone from learning about PrEP?
- *Probes:* Could this deter/exclude someone from seeking out PrEP?

Given that PrEP is only available on the NHS at sexual health clinics:

16. What could make it difficult for someone who wanted to take PrEP?

- ↳ *Prompts:* Access to services, preferences for SRH services, comfort discussing sexual health needs, eligibility criteria, stigma around HIV/PrEP, difficult relationships/partners, not having autonomy re: sexual and reproductive health
- ↳ *Probes:* How would that make it difficult? What could improve that?

17. What could make it easier for someone who wanted to take PrEP?

- ↳ *Prompts:* eligibility criteria, getting PrEP from a GP or pharmacy, online PrEP
- ↳ *Probes:* How would that make it easier?

Factors Influencing Health Equity

I'd like to continue talking about things that might make it more or less difficult to access HIV prevention and PrEP for women. I'm going to show you an image. These are some things that we know can influence a person's ability to be healthy and access healthcare. Go through the image and explain what each one is.

18. Have (or do) any of these characteristics impact how you access sexual health services/HIV prevention

- ↳ *Prompts:* You mentioned x could make it difficult/easier- do you have experience with this?
- ↳ *Probes:* Could you tell me more about that? How has that made you feel?

19. How would these things impact how a person learns about PrEP

- ↳ *Prompts:* Specific characteristics how can a person's community/friends impact what they know about PrEP? How can a person's age or religion impact what they know/how they get PrEP?
 - ↳ *Which are more important?*
 - ↳ *Which are less important?*
- ↳ *Probes:* How would it make things more difficult?
 - ↳ How would they make it easier?
 - ↳ You mentioned x should impact how a person learns about

PrEP? Is this something you've experienced?

20. How would these things impact whether a person can access PrEP?

- ↳ *Prompts*: Specific characteristics (e.g., how can a person's community/friends impact what they know about PrEP? How can a person's age impact what they know/how they get PrEP? Which are more/less important?
- ↳ *Probes*: How would it make things more difficult?
 - ↳ How would they make it easier?
 - ↳ You mentioned x could impact how a person accesses PrEP. Is this something you have experience with?

21. Are there other factors that we haven't discussed (i.e., not listed on the diagram) that could impact how a person accesses HIV prevention services and PrEP?

- ↳ *Probes*: How would it make things more difficult? How would they make it easier?

Closing

We have come to the end of the interview, thank you very much for giving us your time, your contribution is *very important* to our research. Before you go,

22. Is there anything you would like to add or share that we have not touched on during the interview?

[Turn off recorder]

Debrief:

- Reminder about confidentiality and right to withdraw
- Thank for time and invaluable input
- £20 thank you gift voucher.

- Remind of list of services to contact should they require further support with issues discussed.
- If you would like to receive a copy of the final report, please give me your email address.

Appendix 6. Topic guide for participants living with HIV

Topic Guide: Women LWHIV and PrEP v 1.0

Thank you for taking the time to talk with me today. I'm Melissa, and I'm a research student at UCL. My project is about ways we can prevent HIV. One of these ways is by using a medication called HIV Pre-Exposure Prophylaxis, or PrEP. PrEP is taken by HIV negative people only to prevent infection with HIV. The aim of this research is to discuss what women, including people who identify as women or feminine, know about PrEP, and what they think of it as a treatment option for preventing the acquisition of HIV.

Today we'll be exploring three main areas: your general thoughts and experiences accessing sexual health and HIV prevention information and services; PrEP as a prevention option for HIV; and lastly, how we can identify things that could make it easier or more difficult to access HIV prevention services. I want to understand what women think about HIV prevention, what we can do to improve services for women, and ultimately improve women's health.

- Go through information sheet
- Go through consent form. Have they signed/given verbal consent?
- Ask them the demographic questions/Confirm they've completed them on opinio

Before we get started, I just want to remind you again that everything you share with me will be confidential. No personal information that could identify you will be included in the typed interview transcripts, and no one should be able to tell who you are from the interview.

Also, I want to let you know that there are no right or wrong answers. We're just exploring this topic and I'm really interested in hearing about your opinions and experiences. I am not going to judge any of your answers. If I ask why you gave a particular answer, it's just because I want to know more about this. If there's anything I ask that you don't want to talk about, it's fine to just tell me that and we can go on to the next question. Or if you'd like a break or to end the interview at any time, that's absolutely fine, just tell me. Do you have any questions before we start?

Check ok to record.

[Turn on recorder]

OPENING QUESTIONS

23. Can you start by telling me how you found out about this research?

↳ *Prompt:* Why did you want to take part?

24. When you hear the phrase “sexual health” what do you think of?

↳ *Prompts:* STIs, having pleasurable sex, contraception, HIV, having choices, freedom, positive self-esteem, sexual function, consent, testing.

↳ *Probes:* What aspects are most important to you?

Personal experiences with HIV

I'd now like to talk a bit about HIV in general.

25. Can you tell me about your experiences living with HIV?

↳ *Probes:* How long have you known that you are HIV positive?

↳ *Probes:* Where did you test? Had you attended a service multiple times before testing positive?

↳ *Probes:* Who did you talk to for information about your diagnosis?

↳ *Probes:* Did you learn anything about HIV that surprised you after you were diagnosed? Where did you learn this from? How did it make you feel?

↳ *Prompts:* U = U, PrEP, having children, ART

26. Before you tested positive, were you concerned about HIV?

↳ *Probes:* Can you tell me more about that? Why/Why not?

↳ *Probes:* Why did you decide to get tested?

↳ *Probes:* What advice would you give to your past self? What would you have wanted to know?

PrEP Awareness and Knowledge

Now I'd like to talk a bit more about HIV prevention – in particular I'd like to talk about PrEP. PrEP is a medication that is taken by people who are HIV-negative. Go through the example with people (Figure 1).

27. Prior to hearing about this study, had you ever heard of PrEP for

preventing HIV?

- *Prompts:* If yes, Can you tell me how you heard about it? Or where did you learn this information?
- *Prompts:* If no, How do you feel about not having access to this information?
- *Probes:* friends, family, internet, school, sexual health clinic, GP, marketing and/or adverts?

28. What do you think of PrEP as a way to prevent HIV?

- *Probes:* good idea, bad idea? Complimentary to other prevention strategies such as condoms? Can you tell me more about that?

29. Who do you think could benefit from taking PrEP?

- ↳ *Prompts:* Generally, who would benefit, women who would benefit (e.g., women who have multiple partners, or can't/don't use condoms, in poly relationships or with partners in poly relationships)
- ↳ *Probes:* Can you think of other benefits besides HIV prevention

Sexual Health Services needs and preferences

We've discussed that PrEP is available at sexual health clinics, but there are lots of other places where people can go for their sexual health care or to get advice.

30. Can you tell me about your experiences accessing sexual and reproductive health services? This can be any of the things we talked about relating to sexual health.

- ↳ *Prompts:* Advice, information, treatment, contraception, prevention, support following DV/SV or assault, support for adjusting to diagnosis
- ↳ *Prompts:* Going to a SHS, GP, Pharmacist, online
- ↳ *Prompts:* Contraception, cervical smear, pleasure, STI prevention (testing, treatment etc), HIV prevention for partners who are HIV negative.
- ↳ *Probes:* You mentioned going to x, why did you go there?
- ↳ *Probes:* What was the experience like? How could it be improved? What made it difficult? What could make it easier?
- ↳ *Probes:* Difficulties with access? Not knowing where to go, or not being

able to access services? Cultural/language barriers? Social pressure/social stigma experienced as a person living with HIV?

↳ *Probes*: Who helps you make those decisions?

↳ *Probes*: If HIV prevention mentioned- ask about that experience

31. Where do you think PrEP should be available from?

– Prompts: Is at SHS enough? Why or why not?

– *Probes*: Could this make it easier for someone to learn or access PrEP?

– *Probes*: Could this deter/exclude someone from learning about PrEP?

– *Probes*: Could this deter/exclude someone from seeking out PrEP?

Given that PrEP is only available on the NHS at sexual health clinics:

32. What could make it difficult for someone who wanted to take PrEP?

↳ *Prompts*: Access to services, preferences for SRH services, comfort discussing sexual health needs, eligibility criteria, stigma around HIV/PrEP, difficult relationships/partners, not having autonomy re: sexual and reproductive health

↳ *Probes*: How would that make it difficult? What could improve that?

33. What could make it easier for someone who wanted to take PrEP?

↳ *Prompts*: getting PrEP from a GP or pharmacy, online PrEP, eligibility criteria, language barriers? Cultural barriers?

↳ *Probes*: How would that makes it easier?

Factors Influencing Health Equity

I'd like to continue talking about things that might make it more or less difficult to access HIV prevention and PrEP for women. I'm going to show you an image These are some things that we know can influence a person's ability to be healthy and access healthcare. Go through the image and explain what each one is.

34. We know these characteristics can impact how a person accesses sexual health. Which 3 do you think are the most important? The impact can be positive or negative.

- ↳ *Prompts*: Positive Impact?
- ↳ *Prompts*: Negative Impact?
- ↳ *Prompts*: Specific characteristics (e.g., how can where you live impact how they access sexual health services? How can a person's ethnicity or culture impact how they access HIV prevention?
- ↳ *Prompts*: Which are more important/less important? Why is that/Can you tell me more?
- ↳ *Probes*: How would it make things more difficult? How would they make it easier?

35. Do any of these characteristics impact how you access sexual health services

- ↳ *Prompts*: You mentioned x could make it difficult/easier- do you have experience with this?
- ↳ *Probes*: Could you tell me more about that? How has that made you feel?

36. How would these things impact how a person learns about PrEP

- ↳ *Prompts*: Specific characteristics how can a person's community/friends impact what they know about PrEP? How can a person's age or religion impact what they know/how they get PrEP?
 - ↳ *Which are more important?*
 - ↳ *Which are less important?*
- ↳ *Probes*: How would it make things more difficult?
 - ↳ How would they make it easier?
 - ↳ You mentioned x should impact how a person learns about PrEP? Is this something you've experienced?

37. How would these things impact whether a person can access PrEP?

- ↳ *Prompts*: Specific characteristics (e.g., how can a person's community/friends impact what they know about PrEP? How can a person's age impact what they know/how they get PrEP? Which are more/less important?
- ↳ *Probes*: How would it make things more difficult?
 - ↳ How would they make it easier?
 - ↳ You mentioned x could impact how a person accesses PrEP. Is this something you have experience with?

38. Are there other factors that we haven't discussed (i.e., not listed on the diagram) that could impact how a person accesses HIV prevention services and PrEP?

↳ *Probes:* How would it make things more difficult? How would they make it easier?

Closing

We have come to the end of the interview, thank you very much for giving us your time, your contribution is *very important* to our research. Before you go,

39. Is there anything you would like to add or share that we have not touched on during the interview?

[Turn off recorder]

Debrief:

- Thank for time and invaluable input and remind about confidentiality
- £20 thank you gift voucher.
- Remind of list of services to contact should they require further support with issues discussed.
- If you would like to receive a copy of the final report, please give me your email address.

Appendix 7. Five HIV Facts Poster



Figure 11: Five HIV Facts poster from the National AIDS Trust⁴³⁶ used in the qualitative interviews

PrEP for HIV Prevention

What is PrEP?

PrEP is medicine that can be taken to prevent HIV. It is one of many safer sex tools that can be used for HIV prevention during periods of life when you feel it might be right for you. PrEP is made up of antiretroviral drugs that are used to treat HIV.

What does taking PrEP involve?

In England, PrEP is available as a tablet that is taken every day on an on-going basis. When taken as prescribed, it is over 90% effective at preventing HIV. PrEP does not protect against STIs, so people taking PrEP need to test regularly for HIV and other STIs.

Who can take PrEP?

PrEP can be taken by people who are not living with HIV. It can be used by anyone of any gender, including women, men, and non-binary people. PrEP only needs to be taken during times when sex is happening. If a person is going through long periods where they are not having sex, there's no need to take PrEP. PrEP is safe to use with other hormones.

How can I access PrEP?

PrEP is available through the NHS at sexual health clinics. If you're interested in PrEP, a sexual health clinician will discuss your risk for HIV with you to help you decide if PrEP is right for you at this point in your life.

What is the future of PrEP?

New options for PrEP will be introduced as research develops. In some parts of the world, a vaginal ring for PrEP has been approved for use, and so has an injectable PrEP that only needs to be taken once every few months. Formulations are also being developed for use as both HIV prevention and contraception.

Figure 12: Information leaflet used in the qualitative interviews

Appendix 9: PROGRESS-Plus Diagram

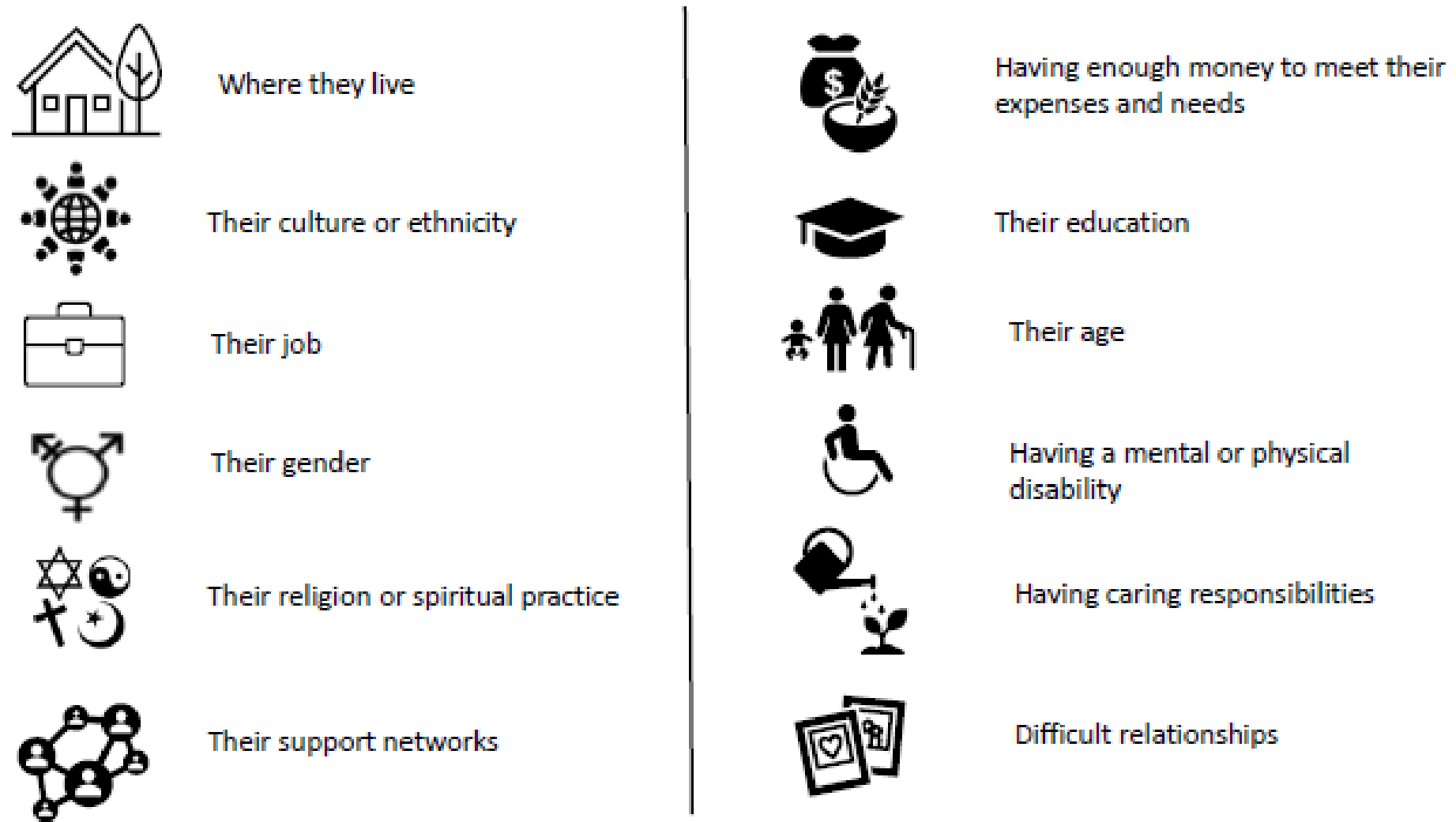


Figure 13: PROGRESS-Plus diagram used in qualitative interviews

Appendix 10: Distress Protocol

Understanding women's awareness and interest in HIV-PrEP

Distress Protocol

The interview covers topics about sexual behaviour, sexual health, and HIV prevention. These topics have the potential to be sensitive; participants may find some topics embarrassing or difficult to discuss, or the discussion may arouse an emotional response. We have developed a procedure to minimise distress, and to respond to any participant who becomes distressed. This procedure draws on the Framework of Essential Elements in Qualitative Interviewing for conducting sensitive interviews⁶⁰⁵, and existing distress protocols from qualitative studies on sensitive topics^{605–607}, which are applicable for this study.

The researcher conducting the interviews has received training in qualitative research methods, and is supported by the Principal Investigator, who is very experienced conducting qualitative research on sensitive topics, such as sexual health.

Prior to interview

Prior to the interview, participants will be given a full explanation of the purpose of the interview and study. Participants will be informed that the interview may be emotional and tiring and to think about and agree on avenues of post-interview support. Prior to the interview, participants will also be asked to make the interviewer aware if they want to pause the recording.

During the interview

During the course of the interview, we will not ask participants questions which we think will cause distress. This has been carefully considered during the development of the topic guide, but also will be judged on meeting the participant at the interview.

During the interview, for participants who appear upset, distressed, or appear to be tiring, we will immediately:

- 1) Offer the opportunity to take a break
- 2) Offer to postpone the interview
- 3) Offer to withdraw their participation

If the participant would like to continue, we will begin a less upsetting part of the discussion and interview with less sensitive topics. We will ask if the participant would like to return to that part of the discussion at a later point (being sure to provide them with the option and not pre-determine this for them).

We will also ask these two questions from an above mentioned framework⁶⁰⁶ at the end of the interview:

- Did you find talking in the interview helpful?
- Did you feel the interview caused you distress?

If we discover issues that cause the interviewer to worry that someone is in danger of harm (self or otherwise), we will in this circumstance be required to break confidentiality and inform the relevant authorities, following whichever standard local authority safeguarding procedures are in operation.

Following the interview

At the end of the interview, participants will be offered information on local women's, sexual health, and HIV support agencies. If they are experiencing distress, they will be advised to contact their GP. We will facilitate this process if necessary.

If specific topics arise which are causing distress, then we will direct the participant to specific avenues of support for these. The project advisory group includes

clinicians, and we will liaise with clinical members of the team to seek their advice on specific issues.

We will revise the protocol and topic guides if we are finding that this study is causing greater distress, burden, and is unhelpful. This will be discussed amongst the research team. If substantial changes to the protocol are needed, we will seek approval of proposed changes from the Research Ethics Committee.

We will ask participants if they would like a follow-up after the interviews, and for those who agree, we will call them two days later to check whether thinking about the interview has raised any concerns or questions for them.

Appendix 11: Participant Information Leaflet for qualitative interviews

Participant Information Leaflet for interviews with women

UCL Research Ethics Committee Approval ID Number: **20443/001**

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: Understanding women's awareness and interest in HIV-PrEP

Department: Research Department of Primary Care & Population Health

Researcher: Melissa Cabecinha (PhD student)

Principal Researcher:

UCL Data Protection Officer: data-protection@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee:

Project ID number: 20443/001

1. Invitation Paragraph

We would like to invite women (aged 18+) to take part in a research project. You should only take part if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it

is important to read the following information carefully and discuss it with others if you want to. Ask us if there is anything that is not clear or if you would like more information.

2. What is the project's purpose?

The aim of this project is to explore women's awareness and potential interest in HIV PrEP and discuss factors that influence their knowledge and attitudes around HIV PrEP and HIV prevention. It is hoped that the results of this study will improve understanding of women's decision-making regarding HIV PrEP and HIV prevention, and ultimately help us improve sexual health for women.

3. Why have I been chosen?

You have contacted us to take part in this study, in response to an advertisement or other invitation. You are eligible to take part in this study if you are aged 18 years or older and identify as female. We are aiming to recruit 20-30 participants.

4. Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw at any time, up to one month after the interview, without giving a reason and without it affecting any benefits that you are entitled to. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up to that point.

5. What will happen to me if I take part?

Participation involves a confidential one-to-one discussion with the researcher. This can take place over the phone, via an internet conference platform (i.e., Microsoft Teams), by telephone, or in person (if permitted) at a convenient time for you. This should take approximately an hour. In person interviews will follow all government safety regulations.

It is up to you whether to take part or not. If you decide to take part, you are still able to withdraw at any time, up to one month after the interview, and without giving a reason. If you decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. As a thank you for your time, you will receive a £20 voucher.

You can withdraw up to one month after the interview. If you decide to withdraw, any personal data you have provided up to that point will be deleted unless you agree otherwise. If you decide

to withdraw, you may keep the £20 voucher as a thank you for your time. If you decide to withdraw, you may keep the £20 voucher as a thank you for your time.

6. Will I be recorded and how will the recorded media be used?

The audio recordings of your interview will be used only for analysis. Anonymised quotes may be used in conference papers, presentations, and lectures. No other use will be made of them without your written permission. The audio recordings will be professionally transcribed by an external professional transcription service which will be destroyed after they have been transcribed. The transcription service will sign a confidentiality agreement and the independent typist will observe strict confidentiality.

If you do not wish to be audio recorded, the interviewer will take written or typed notes during the interview.

With your consent, you may be contacted by Melissa Cabecinha or Dr Lorraine McDonagh for future research projects exploring HIV prevention in women. Your details will not be shared with other researchers.

7. What are the possible disadvantages and risks of taking part?

Some people can find talking about sex and sexual health embarrassing or upsetting. At the end of the interview we will provide all participants with information where you can seek support if needed. If you become upset during the interview, you can pause or end the interview at any time. The researcher will be available before, during, and after the interview to discuss any concerns you might have, and can help you find support or information if needed. The principal investigator (Dr Lorraine McDonagh) will also be available to discuss any questions or concerns that you might have regarding the research or the interview. You can also contact UCL Ethics Committee Chair, citing project ID 20443/001 with any concerns about the study.

Researcher: Melissa Cabecinha (), Telephone:

Principal Investigator: Dr. Lorraine McDonagh ()

UCL Ethics Committee Chair: ethics@ucl.ac.uk, Telephone: 02076798717. Ext 28717

8. What are the possible benefits of taking part?

Whilst there are no immediate benefits for those participating in the project, it is hoped that this work will help improve sexual health services and make a difference for women. Also, you may find discussing HIV PrEP and sexual health interesting, empowering and enlightening.

9. What if something goes wrong?

If you have any questions regarding this research, require advice, or would like to raise a complaint, please contact the principal investigator: Dr Lorraine McDonagh:

If this individual is not able to address your concerns satisfactorily or you have concerns about the study that you wish to discuss with an independent party, you may contact the Chair of the UCL Ethics Committee, Academic Services, UCL, Gower Street, London WC1E 6BT, or email ethics@ucl.ac.uk.

10. Will my taking part in this project be kept confidential?

Yes. All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. Any contact details you have provided us will be stored on the UCL Data Safe Haven, with access restricted only to those involved with the study. This information will be destroyed as soon as it is no longer necessary. The recording device used to record the interview will be encrypted and password-protected. The audio recording of your interview will be securely destroyed once it has been transcribed. The transcript of your interview will be anonymised, meaning any information that could be used to identify you will be removed. The external professional transcription service who transcribe the interview will be bound by a confidentiality agreement. Your signed consent form will be scanned in and stored as a PDF on the UCL Data Safe Haven in a separate location from the main dataset. All paper consent forms will then be shredded. Information provided on the pre-interview questionnaire will be entered into a spreadsheet stored in the UCL Data Safe Haven, and then the paper copy securely destroyed.

11. Limits to confidentiality

Please note that confidentiality will be maintained as far as it is possible, unless during your interview the interviewer hears anything which makes them worried that someone might be in danger of harm. In such cases they might have to inform relevant authorities of this.

12. What will happen to the results of the research project?

The anonymized results of this study may be shared with other organizations. With your consent your data may be shared with future ethically approved studies. They will also be presented at conferences, and published in a PhD thesis and academic journal articles. If you wish to have a copy of the study results sent to you, please let the research team know. It will not be possible to identify individuals who have participated in the study. All data will be held on a secure database on a password-protected computer at UCL. The information will be archived at a UCL safe and secure off-site location. Storage time of this data is in line with university regulations (10 years). Access to stored records is strictly controlled.

13. Local Data Protection Privacy Notice

Notice:

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice: For participants in research studies, click [here](#). The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows:

Name	Religion
Address	Ethnicity
Phone number	Highest level of education
Age	HIV status
Sexual orientation	Living situation
Relationship status	Country of birth

The lawful basis that would be used to process your *personal data* will be performance of a task in the public interest. The lawful basis used to process *special category personal data* will be for scientific and historical research or statistical purposes. *Your personal data will be processed so long as it is required for the research project.* If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

14. Who is organising and funding the research?

This study is funded by the Medical Research Council (grant number: MR/N013867/1).

15. Contact for further information

If you require further information, please contact the principal investigator: Dr Lorraine McDonagh:

16. Resources for further support

a) SXT Sexual Health Services

- Description: Online service that helps you find your nearest sexual health clinic or services.
- Website: <https://sxt.org.uk/>

b) Test.HIV

- Description: Service offering free self-sampling HIV test kits to residents of many areas in the UK. Test kits are sent in the mail in discreet packaging with no identifying markings or logos. Once you've collected a small blood sample, you then send the sample back in the packaging provided, and receive results a few days later.
- Website: <https://www.test.hiv>

c) Sexual Health London

- Description: Service offering free, discreet at-home sexual health screening for anyone living in eligible areas of London. Test kits are sent in the mail in discreet packaging with no identifying markings or logos. You collect your samples at home and send the samples back in the provided freepost box. You'll then receive your results a few days later via your preferred contact details.
- Website: <https://shl.uk>

d) SH:24

- Description: Service offering free, discreet at-home sexual health screening for anyone living in eligible areas in the UK. Test kits are sent in the mail in discreet packaging with no identifying markings or logos. You collect your samples at home and send the samples back in the provided freepost box. You'll then receive your results a few days later via your preferred contact details.
- Website: <https://sh24.org.uk/>

e) Terrence Higgins Trust

- Description: HIV and sexual health charity which provides services relating to HIV and sexual health.
- General website: <https://www.tht.org.uk>
- Direct helpline: 0808 802 1221, open 10am-8pm Monday to Friday

f) NAZ Project London

- Description: A sexual health charity in London offering culturally-specific sexual health services and programmes for men and women from BAME communities. They offer free and confidential HIV testing, support groups, and counselling for those needing to talk to someone.
- Website: <https://www.naz.org.uk/>
- Helpline: 020 8741 1879

g) PrEPster

- Description: An organisation that aims to educate and agitate for PrEP access in England
- Website: <https://prepster.info/about/>

h) Women's Aid

- Description: A grassroots federation working to build a future where domestic abuse is not tolerated. Provides support and services to women experiencing domestic abuses.
- Website: <https://www.womensaid.org.uk/>
- Email: helpline@womensaid.org.uk

i) Refuge

- Description: Organisation committed to ending domestic violence against women and girls. Refuge provides services to women and children who have experienced violence and provides education, training and awareness-raising.
- Website: <https://www.refuge.org.uk/>
- Telephone Helpline: 0808 2000 247 (24-hours/7 days a week)

j) IMKAAN

- Description: Women's organisation dedicated to addressing violence against black and Minoritised women and girls (i.e., women who are defined in policy terms as Black and "Minority Ethnic")

- Website: <https://www.imkaan.org.uk/>

k) Young Women's Trust

- Description: A feminist organisation working to achieve economic justice for young women and offering support to young women aged 18 to 30 who are living on low or no pay and want to build a better future.
- Website: <https://www.youngwomenstrust.org/>

l) The Survivors Trust

- Description: Charity that provides information, advice or emotional support to survivors of sexual violence.
- Website: <https://www.thesurvivorstrust.org/>
- Helpline: 08088 010818. Monday, Tuesday and Wednesday: 10am-7:30pm. Thursday: 10am-6pm. Friday: 10am-2pm.

m) Women's Trust

- Description: Charity which runs a range of confidential, specialist services designed specifically to support women who have experienced domestic abuse.
- Website: <https://womanstrust.org.uk/>

If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.

**Thank you for reading this information sheet and for
considering to take part in this research study**

Appendix 12: Demographic Questionnaire

Demographic Questions

1. How old are you (in years)? _____

2. Is your gender identify the same what you were assigned at birth?
 - ☐ Yes
 - ☐ No
 - ☐ Unsure

3. Which gender do you most identify with?
 - ☐ Male (Including transgender male)
 - ☐ Female (Including transgender female)
 - ☐ Non-binary
 - ☐ Gender Fluid
 - ☐ Genderqueer
 - ☐ Not listed (please state)_____
 - ☐ Prefer not to say

4. How would you describe your ethnicity?

5. How would you describe your sexual orientation?
 - ☐ Heterosexual or straight
 - ☐ Gay
 - ☐ Lesbian
 - ☐ Bisexual
 - ☐ Queer
 - ☐ Asexual
 - ☐ Pansexual
 - ☐ Questioning
 - ☐ Not listed (please state)_____
 - ☐ Prefer not to say

6. What is the highest level that you have been educated to?

7. What is your current occupational status? *(Tick all that apply)*

- ☐ Full-time employed
- ☐ Part-time employed
- ☐ Self-employed/Freelance
- ☐ Flexible contract (e.g. don't work set hours)
- ☐ Full-time student
- ☐ Part-time student
- ☐ Vocational training or apprenticeship
- ☐ Not in education, employment or training
- ☐ Not listed (please state)_____

8. What is your current relationship status?

- ☐ Single
- ☐ Polyamorous
- ☐ Dating one person exclusively
- ☐ In an open relationship
- ☐ Living with romantic partner
- ☐ Engaged or planning to marry
- ☐ Married
- ☐ Divorced
- ☐ Not listed (please state)_____

9. How would you describe the area you live in?

- ☐ Urban (Population > 10,000)
- ☐ Rural (Population ≤10,000)

10. What region of England do you live in?

11. What is the nearest city to you?

12. Do you consider yourself to have a disability

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

13. Why would you like to take part in this study?

Appendix 13: Example qualitative study advertisement

RESEARCH DEPARTMENT OF PRIMARY CARE AND POPULATION HEALTH



Women and HIV Prevention

Do you want to help us improve women's health?

- Are you 18 years or older and currently living in England?
- Do you want to contribute to research that improves HIV prevention information and services for women?

Researchers at University College London (UCL) are studying women's views of, and experiences with, HIV prevention options. We want to hear from as many women as possible, including women from all ethnicities, ages, religions, sexual identities, gender identities, and nationalities! We welcome participation from cis and transgender women, and gender diverse people who were assigned female at birth.

If you would like to participate, you will be invited to take part in a confidential interview. This should take around an hour of your time, and you will receive a £20 life:style voucher as a 'thank you' for participating.

Interested? Contact Melissa Cabecinha at m.cabecinha@ucl.ac.uk, or visit: <https://bit.ly/34lf80m>



Please note: The information you give and results from the study will be kept confidential and anonymous. No one will be able to link your name with your information and no names will be used in the final report. All data will be collected and stored in accordance with the UK Data Protection Act 2018. This study is being conducted as part of Melissa Cabecinha's PhD research and has been approved by the UCL Research Ethics Committee (UCL Ethics Project ID number: 20443/001)

Figure 14: Twitter (now X) qualitative study advertisement

Appendix 14: Consent form for qualitative interviews

CONSENT FORM FOR INTERVIEWS WITH STUDY PARTICIPANTS

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Understanding women's awareness and interest in HIV-PrEP

Department: Research Department of Primary Care & Population Health

Researcher: Melissa Cabecinha (PhD student)

Principal Researcher:

UCL Data Protection Officer: data-protection@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee:

Project ID number: 20443/001

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Tick Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and I would like to take part in an individual interview.	
2.	I understand that I will be able to withdraw my data up to 1 month after the interview.	
3.	I consent to participate in the study. I understand that my personal information will be used for the purposes explained to me. I understand that according to data protection legislation, 'public task' will be the lawful basis for processing personal data and 'for research purposes' for special category data'	
4.	I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified.	
5.	I understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.	

6.	I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	
7.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.	
8.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
9.	I understand the direct/indirect benefits of participating.	
10.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
11.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	
12.	I understand that I will be compensated for the portion of time spent in the study or fully compensated if I choose to withdraw.	
13.	I agree that my anonymised research data may be used by others for future research or teaching purposes. No one will be able to identify you when this data is shared.	

14.	I understand that the information I have submitted will be published in a PhD thesis and other publications and I wish to receive a copy of them. Yes/No	
15.	I consent to my interview being audio recorded and understand that the recordings will be destroyed following transcription.	
16.	I confirm that I understand the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher, and I confirm that I meet these inclusion criteria.	
17.	I am aware of who I should contact if I wish to lodge a complaint.	
18.	I would be happy for the anonymised data I provide to be securely archived on the UK Data Service online repository. I understand that other authenticated researchers will have access to my anonymised data.	
19.	I voluntarily agree to take part in this study.	

If you would like your contact details to be retained so that you can be contacted in the future by Melissa Cabecinha or Dr Lorraine McDonagh to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below. Your details will not be shared with other researchers.

Yes, I would be happy to be contacted in this way	

No, I would not like to be contacted	

Name of participant

Date

Signature

Researcher

Date

Signature

Appendix 15: Qualitative concept map

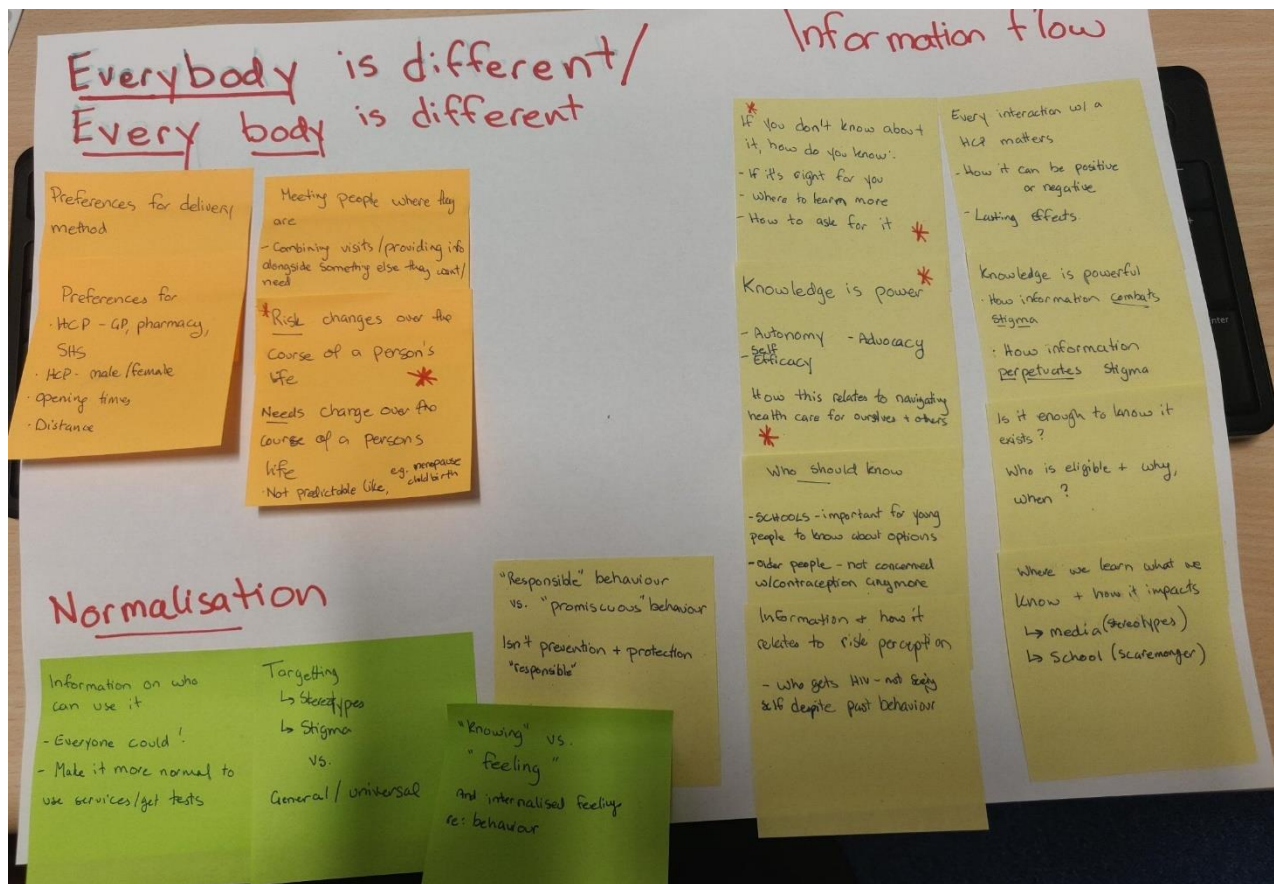


Figure 16: Concept map used in the early stages of theme generation

Appendix 16: Tables of themes and supporting quotes

Table 21: Themes and subthemes with illustrative quotes

Theme	Subtheme	Topic	Illustrative quote
Information gaps: HIV, HIV prevention and PrEP	HIV knowledge	General HIV knowledge	P18: Yeah. Yeah, and I believe that it – if not all, most of it is not – there's no complete cure for it yet, or is it a different disease? (24, Asian, London)
			P12: I think it's a – I'm not sure, like something to do with your blood, and it also weakens your immune system. It's something that you have for life. I don't think it can be treated. I don't know – I'm not sure in this day and age of the treatment of HIV. But yeah, that's all I know, really. (37, White, South East)
		Beliefs and perceptions around HIV acquisition	P15: I know that if you get it, you can now live because you can have – it's no longer a death sentence because you can have medication which can keep you pretty healthy, really. (61, White, East of England)
			P14: Yeah, I think – and I think that there was, particularly as this was in the '80s and there was very much an attitude that HIV kind of was only happening to gay men, so like it's not going to happen to a nice, young, straight girl like you (50, White, London)
	HIV testing and prevention engagement	Where HIV knowledge and perceptions were acquired and shaped	P09: Like, I don't know exactly where I learnt it but I think I've watched some soaps, like storylines on soaps of, like... I don't know. I've definitely watched one or two where it's been the focus, and that's probably changed my view of HIV. (24, White, South West)
			P16: I don't want to come off as sounding biased, but to me it's always been, from the media and stuff, especially from back in the day, as something that's more of a health concern in the LGBTQ+ population. (25, White, North West)
		Engaging with testing	P04: So I feel like if it is what it is, if that's what you need to do to prevent, I don't see the problem with having a test. (37, black British, London)
			P13: Yeah, right, OK, yeah, because I was just thinking, yes, yes, when I was pregnant, they did, yeah. (52, White, East of England)
	PrEP awareness and knowledge	Reasons for not testing	Interviewer: But you haven't had an HIV test ever?
			P02: No, I never, yeah. I would like to do it. (25, Asian, London)
		General PrEP knowledge	P08: I was quite, or I'm still quite confident about my health issues and then in terms of sexual health because I have regular partners and, not at the moment, but like previously. So I was quite confident that I would not get HIV in any times, like in different channels in my life so I've never thought that I should get one. (29, Chinese, West Midlands)
			P13: I've recently gone to a sexual health clinic and sat in the reception with my daughter while she was having an appointment, but I don't really remember there being much – it being that widely advertised. I don't know how much general population or people that would know about it. (52, White, East of England)
			P01: When I, I would consider myself reasonably well informed and I do take onus on my own health. But I do think it's quite odd that I'm not that familiar with it. (41, White, London)

Theme	Subtheme	Topic	Illustrative quote
Information gaps: HIV, HIV prevention and PrEP	PrEP Perceptions	Concerns	P12: Because, just because it's available, doesn't mean that people should abuse the drug (...) cause people to take more risks because they have a drug to fall back on. (37, White, South East)
			P03: And how long has this been in process for? Do they know if there's any side effects of having to take this drug all the time? (37, White, London)
		Relevance to current circumstances	P02: I think it's useful to know, but I don't think it's something that I will use myself. (25, Asian, London)
			Interviewer: OK. So I was wondering, so you mentioned that you took PrEP for a period of time. Why did you decide to stop taking it?
			P10: I don't know. I personally didn't feel like I was at any high risk. I am now in quite a stable, one partnered relationship. (30, black African, London)
		Perceptions of who could benefit from PrEP	P01: I would say under 30s, that was the first thing that popped into my head because that would be the target group who are probably, for lack of a better word, sleeping around more. (41, White, London)
			P13: Anybody that's sexually active, I suppose, really. I mean, this feels like the kind of – it feels like ... years and – decades ago, it feels like the stigma has been kind of taken out of it by having – some of the stigma has been taken out of it by having something like this. (52, White, East of England)
		Perceptions of who should have information about PrEP	P07: Everyone should know about PrEP because I want to believe everyone wants to have safe sex, so if everyone, so if the information is available to everyone that can be good. That information should be available to everyone without discrimination of any type. (23, black British, Yorkshire and the Humber, living with HIV)
			P15: Everybody. If you're going to offer people health style choices, then obviously they need to know everything that's available to them. (61, White, East of England)

Theme	Subtheme	Topic	Illustrative quote
Information Flow	Barriers to information access	Gender bias	P11: I think women are quite overlooked, at least in my experience in the UK HIV response (27, white, South West)
			P01: And also because it's about women and it's about women's health and to me that's such – everything seems to be done based on male bodies and male point of view, so for me that's really important. (41, white, London)
		HIV-related stigma	P06: Not everybody is usually confident enough to open up to their parents or to the doctors. They normally feel like they are going to receive a lot of judgement from the doctors and friends and maybe their parents. (24, Mixed, West Midlands, living with HIV)
			P07: I've undergone a lot of stigmatisation living with HIV. Because it's not easy telling your friends or even your maybe partner about your status because people tend to judge you harshly. Despite it not being easily transmittable to the next person, they tend to outcast you. So it has not been an easy experience (23, black British, Yorkshire and the Humber, living with HIV)
		PrEP awareness as a pre-requisite to seeking out information	P05: I think to be honest, hmm, the only thing I would say is I think the education on it, which I think I've touched on, having knowledge of certain things sometimes can be limited because you just don't know. And I think knowing is the greatest thing and if you don't know, you just don't know. (40, black Caribbean, London)
			P17: They might, because it's really common, and I feel like if I was in that situation, and I didn't know about it, and then I read up on it, it's something that's come, like, maybe I'd think about it later on because now I know about it, and then if I'm talking to the GP then I might mention it. But of course if I didn't have that information, then I don't think I would even think about it. (25, Bangladeshi, London)
		Individual and cultural factors	P16: Definitely ethnicity as well, because there are disparities on ethnic groups, as much as society tends to try and decline, it's something that is an issue. It is very much still an issue. (25, white, North West)
			P05: The pandemic has hit now very, very – pandemic has hit now, but if we look like now, for example, and a lot of people would like to access, you know, they've lost their jobs. Mental health has kicked in, things are harder. Some people have large families, some people have medium. So for them, the things what they might need is not great because health wise they can't afford doing what they would like to do. So what they can do they're just living heads, just above water, above the waters, to carry on. (40, London, black Caribbean)

Theme	Subtheme	Topic	Illustrative quote
Information Flow	Information sources	Internet and social media	P06: Social media. I think social media because everyone uses social media. (26, Mixed, West Midlands, living with HIV)
			P12: Maybe the internet like forums, Facebook groups, maybe that sort of thing, or advertise – because obviously I know that with Facebook algorithms and things, you can set adverts to target certain audiences on Facebook – I think that'd be a good idea, something like that. (37, white, South East)
		Relationship and sex education (RSE) in schools	P16: I think at school at the earliest standpoint, but I think it needs to be something that's routine because for example, my understanding of the sexual education I was given is different from people even in my year group at school who went to the same school. (25, white, North West)
			P15: I mean, I go to my granddaughter's high school when she's in performances and things, and there's lots of information leaflets around the place, which I noticed, but I didn't – there was one for FGM, but I didn't see one for HIV. But I don't know whether they had them somewhere else. I was only in the main entrance area. (61, white, East of England)
		Signposting and conversations in healthcare settings	P17: Like, you know when you're in the waiting room and there's a lot of posters and leaflets, like just having it available there, sometimes you're sitting there for a long time, so why not? At that point, everyone's thinking about all of these things and where they are sitting, the place, where medication is offered or where you're getting treatments for – not life threatening illnesses, but you're at a situation where, yes, you do think about these things, so it's good to have it at a place where you're waiting, and then you can read the information and absorb it, and then because you're there, maybe you might actually then go to talk to a doctor, and you might actually mention it or something, just because you've read it. (25, Bangladeshi, London)
			P05: I mean also you have like little leaflets and it's placing these like, yeah, having like these leaflets because people look around. I mean when you go to the GP, when you go to a Health Centre, these things are like, whether it's digitally displayed or whether it's on a rack with information there, people I'm sure, but have it in peoples' view because like when you go to your GP or you go to – chemist is another place you can actually, people go to the chemist to pick a prescription up. Have a display board, however, you know, whether they – however, it's getting it across. (40, London, black Caribbean)

Theme	Subtheme	Topic	Illustrative quote
Information Flow	Information sources	The role of healthcare providers	P14: So I think your age definitely makes a difference, because I think maybe my experience, when I rang up the sexual health clinic recently, perhaps I was just putting this into it, that it didn't exist, but I felt like she was sort of saying, "What, you want to have some free – like, you want to have some free condoms are your age?" kind of thing. That's what it felt like, a bit, and I was thinking, "Well, yeah, I am. Is that an issue?" And it shouldn't be, because you don't know who I – what I'm doing or anything like that, so yeah. And just, that made me think, not me personally, but I've worked with women who have been involved in sex work because of a pimp or because of a controlling partner, and then it might be really hard for them to access services because of that, yeah. (50, white, London)
			P04: My doctor – like before I was doing my vaccine, my doctor said ... he goes, "Why haven't you taken the vaccine?" ... But it was like that and he kind of prompted me and he spoke to me about it, he spoke to me about you know the reason why and he spoke about yellow fever. And then I said about my arm and he said, "OK, what about your thigh?" And then from there I got my injection in my thigh, you know, because we were talking about it and I, you know, he kind of prompted it and made me. So then any questions that I had, if he had not done that, it would have taken me a long time to be like, "Oh I'm going to call a GP and ask questions, I'm going to call him and ask questions." It wouldn't have happened, so him intervening was a great touch. ((37, black British, London))
	Information campaign contents	Importance of language	P13: Yeah. It's not saying – it's saying genders, but it's not saying about anyone's sexuality, or this is for so and so, or this is for ... But yeah, it's not saying that, so it feels more inclusive because it's not narrowing it down to certain sexualities. (52, white, East of England)
			P15: It's not just to marginalise it to certain high risk groups, but to take it on board as it being part of our national healthcare prevention plans, like we immunise – I mean, Saturday I'm having my COVID boosters, the following Saturday, I'm having my flu jab. We need this kind of information, and people knowing the accessibility, to be just part of our normal health prevention policies and plans of the whole nation, really. (61, white, East of England)
		Eligibility criteria	P08: I guess might be get a checklist or anything on the website so that when people they are reading those kind of information they can also fill in the checklist by themselves to assess the risk of getting HIV and then make them aware that they're probably more high risk than others, I guess it might make them more likely to get PrEP (29, Chinese, West Midlands)

Theme	Subtheme	Topic	Illustrative quote
Information Flow	Information networks	Engaging with others about PrEP	P03: I feel its good information to have, it may not ever be relevant to me but I have four nieces and nephews that are all in their 20s, well one just hit 30 yesterday. So it's information I can pass on if I ever feel that, you know they talk to me about things and what they're up to. (37, white, London)
			P02: And yeah, in terms of support networks, yeah, I feel – my social circle are quite, like, well-educated when it comes to sexual health, so yeah. They will tell me certain things and I learn a lot from them, in terms of protection. So yeah, if they recommend going for PrEP, I might be more inclined to go for it. (25, Asian, London)
Meeting people where they are	Perceived barriers to PrEP access	Stigma of attending SHS	P10: A lot of people, again, are going to feel some level of stigma just going to the sexual health clinic to ask for that (30, black African, London)
			P14: I think again, as much as we try not to, it's still a bit of a stigma, and again, if you live in a place like mine that's really small, then you might be thinking about who else might see you going in there, and why they think you're going in there, and all that kind of thing. I think that can really have an impact, yeah, on people wanting to do it, I think. (50, white, London)
		Difficulties attending SHS	P11: But I feel like there's another layer to that, so there's almost like a – there's a layer that's like physically I cannot go, and then there's almost like a, sort of like an efficacy in advocacy side of things, is that you also have to sort of be able to escape the confines of the world of judgement around you to go and do that, and that ties more into things that aren't like, "Do I have enough money for the bus?" and more like, "Is it culturally acceptable for me to be going out on my own to some random place? Will people notice? Will people be like, "Where have you gone?" All that sort of stuff is its own little layer that isn't, "I physically cannot afford this." (27, white, South West)
			P16: And where they live, I suppose if you're in a very rural – yeah, rural area, I suppose that would, because to me, cities, there are sexual health clinics that are very accessible, they're out and about, but if you're in a rural area, especially a close-knit rural area where everyone knows everyone's business, it's probably going to be difficult, especially if you feel like you'll be judged or stigmatised. (25, white, North West)
			P10: Yeah, and it's like, "This is something that's commonly happening. You need to think about HIV as another risk that you could have, not just pregnancy." And yeah, when I was younger, again, pregnancy was a big motivator to go to clinics and go to pharmacies. (30, black African, London)

Theme	Subtheme	Topic	Illustrative quote
Meeting people where they are	Opportunities to embed HIV prevention and PrEP into usual care	Embedding HIV prevention into other scenarios	P09: Yeah. So, like, for example, if I was already having my blood taken and tested for something and if they offered that then I might as well, because it's, like, no extra effort on my part. I've already had the blood taken, so yeah, they might as well. Yeah. (24, white, South West)
			P10: Yeah, and it's like, "This is something that's commonly happening. You need to think about HIV as another risk that you could have, not just pregnancy." And yeah, when I was younger, again, pregnancy was a big motivator to go to clinics and go to pharmacies. (30, black African, London)
			P11: I imagine that women are more likely to access some kind of sexual health than men are, just in general, although I think different from men who have sex with men, but that maybe the services that – of those who do access services, I'd imagine that more men go to specific sexual health services, whereas more women end up at other providers, probably in part because of the fact they're in contact with other providers for other reasons as well. (27, white, South West)
		Other places women go for sexual health care	P13: Well, I mean, I suppose in theory it could be available from pharmacists and GPs. I don't know if they have the more in-depth knowledge to prescribe it or whether it'd be more of a specialist thing, but in theory, yes, to make it more accessible. (52, white, East of England)

Theme	Subtheme	Topic	Illustrative quote
Meeting people where they are	Expanding PrEP provision settings	Preferences for PrEP access	P02: If it's only sexual health clinics, then probably yes, because some people might not be as educated about sexual health. But almost everybody will have to go to their GP at one point in their lives, so it would be a good way for people to be exposed to this preventative method. (25, Asian, London)
			P04: Probably someone that works in sexual health. I think that when it comes to a GP, they're a general practitioner, even when you've got, you know, a condition, they can only give you so much and most of the stuff they give you, it's what on the internet. So like they can only do so much, they're there, they can, you know, give you medication and blah, blah, blah, but I think they can only do so much. I think that when it comes to certain things, it's better you go to the specialist who that's their job. And you can get information firsthand and more intense. That's what I think on that one. (37, black British, London)
	Preferences for PrEP modality	Preferences for who to discuss PrEP with	P03: Participant: But I wouldn't mind it being with the nurse practitioners because they deal with other issues that are similar, and they just don't seem as intimidating when you've got things like your knickers down round your ankles. (37, white, London)
		Individual preferences	P09: I mean, no. It's just, like, what your preference is, I guess. Like with contraception, there's different methods and it's just what your preference is. I feel like it's the same with this. Like, different people want different things, so... (24, white, South West) P04: Because some people are very crap on the Pill and that causes people a lot of pregnancies, unwanted pregnancies and things like that because people were like not equipped if they miss the pill for 12 hours, are you supposed to go on to the next one, miss one? So I think that the injection will make it so much easier. ((37, black British, London))

Appendix 17: Example social media advertisements for the quantitative study



Want to help us improve women's health?

Researchers at UCL are studying women's views of, and experiences with, HIV prevention options and sexual health

If you're **18 years or over**, **living in England**, and **identify as a woman or non-binary**, take part in our anonymous survey



Please note: The information you give and results from the study will be kept confidential and anonymous. No one will be able to link your name with your information and no names will be used in the final report. All data will be collected and stored in accordance with the UK Data Protection Act 2018.

This study is being conducted as part of Melissa Cabecinha's PhD research and has been approved by the UCL Research Ethics Committee (UCL Ethics Project ID number: 20443/002)

Figure 17: Twitter (now X) quantitative study advertisement

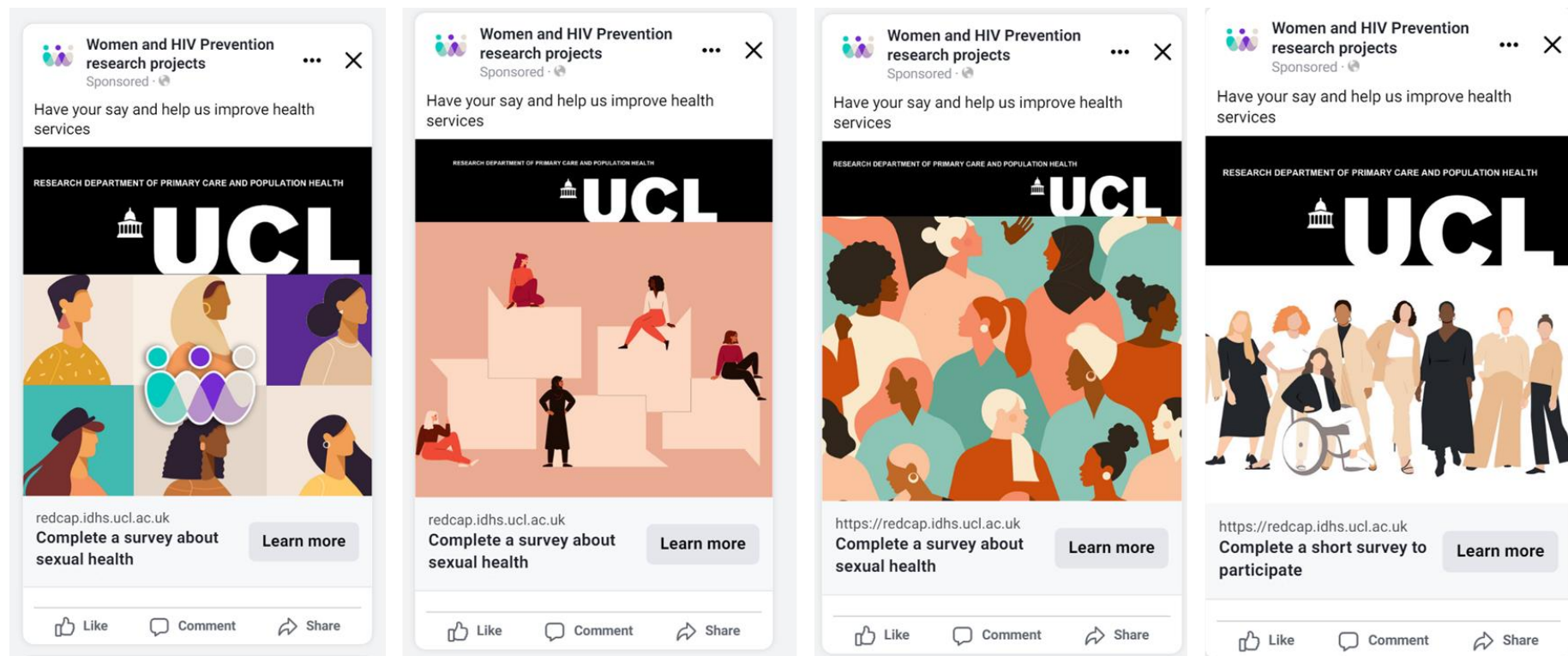


Figure 18: Example Meta platform quantitative study advertisements

Appendix 18. Quantitative survey

1	[record_id]	Record ID	text																																																												
2	[consent]	Please read the statements below carefully and tick the appropriate box to indicate whether you agree to participate in this survey	radio, Required <table border="1"> <tr> <td>1</td> <td>I have read and understood the information above and I agree to participate in the survey</td> </tr> <tr> <td>0</td> <td>I do not want to take part in this survey</td> </tr> </table> Stop actions on 0	1	I have read and understood the information above and I agree to participate in the survey	0	I do not want to take part in this survey																																																								
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3	[agecheck]	Are you aged 18 years or over?	radio, Required <table border="1"> <tr> <td>1</td> <td>I am aged 18 or over</td> </tr> <tr> <td>0</td> <td>I am aged under 18</td> </tr> </table> Stop actions on 0	1	I am aged 18 or over	0	I am aged under 18																																																								
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4	[englandcheck]	Are you currently living in England?	yesno, Required <table border="1"> <tr> <td>1</td> <td>Yes</td> </tr> <tr> <td>0</td> <td>No</td> </tr> </table> Stop actions on 0	1	Yes	0	No																																																								
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5	[age]	Section Header: <i>This set of questions are on your demographics and general health</i> How old are you?	dropdown (autocomplete), Required <table border="1"> <tr><td>18</td><td>18</td></tr> <tr><td>19</td><td>19</td></tr> <tr><td>20</td><td>20</td></tr> <tr><td>21</td><td>21</td></tr> <tr><td>22</td><td>22</td></tr> <tr><td>23</td><td>23</td></tr> <tr><td>24</td><td>24</td></tr> <tr><td>25</td><td>25</td></tr> <tr><td>26</td><td>26</td></tr> <tr><td>27</td><td>27</td></tr> <tr><td>28</td><td>28</td></tr> <tr><td>29</td><td>29</td></tr> <tr><td>30</td><td>30</td></tr> <tr><td>31</td><td>31</td></tr> <tr><td>32</td><td>32</td></tr> <tr><td>33</td><td>33</td></tr> <tr><td>34</td><td>34</td></tr> <tr><td>35</td><td>35</td></tr> <tr><td>36</td><td>36</td></tr> <tr><td>37</td><td>37</td></tr> <tr><td>38</td><td>38</td></tr> <tr><td>39</td><td>39</td></tr> <tr><td>40</td><td>40</td></tr> <tr><td>41</td><td>41</td></tr> <tr><td>42</td><td>42</td></tr> <tr><td>43</td><td>43</td></tr> <tr><td>44</td><td>44</td></tr> <tr><td>45</td><td>45</td></tr> <tr><td>46</td><td>46</td></tr> <tr><td>47</td><td>47</td></tr> </table>	18	18	19	19	20	20	21	21	22	22	23	23	24	24	25	25	26	26	27	27	28	28	29	29	30	30	31	31	32	32	33	33	34	34	35	35	36	36	37	37	38	38	39	39	40	40	41	41	42	42	43	43	44	44	45	45	46	46	47	47
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6	[gender]	How would you describe your gender identity?	radio 1 Woman (including trans-woman) 2 Man (including trans-man) 3 Non-binary 4 Prefer to self describe (please describe below)
7	[genderoth] Show the field ONLY if: [gender] = '4'	How would you describe your gender identity?	text
8	[sex]	Is the gender you identify with the same as your sex registered at birth?	radio 1 Yes 0 No 99 Prefer not to say
9	[sexassigned] Show the field ONLY if: [sex] = 0	What sex were you assigned at birth?	radio 1 Female 2 Male 3 Intersex 99 Prefer not to say
10	[sexid]	Which of the following options best describes how you think of yourself?	radio 1 Heterosexual or straight 2 Gay or Lesbian 3 Bisexual 4 Other (please describe) 99 Prefer not to say
11	[sexidoth] Show the field ONLY if: [sexid] = '4'	How would you describe your sexual identity?	text
12	[ethnicity]	How would you describe your ethnicity?	radio 1 Arab 2 Asian/Asian British - Indian 3 Asian/Asian British - Pakistani 4 Asian/Asian British - Bangladeshi 5 Asian/Asian British - Chinese 6 Asian/Asian British - Any other Asian background 7 Black or Black British - African 8 Black or Black British - Caribbean 9 Black or Black British - Any other black background 10 Hispanic/Latino 11 Mixed/multiple ethnic groups - White and Black Caribbean 12 Mixed/multiple ethnic groups - White and Black African 13 Mixed/multiple ethnic groups - White and Asian 14 Mixed/multiple ethnic groups - Any other mixed background 15 Other ethnic groups - Any other ethnic group 16 White - British 17 White - Irish 18 White - Any other White background 99 Prefer not to say
13	[ethoth] Show the field ONLY if: [ethnicity] = '5' or [ethnicity] = '8' or [ethnicity] = '15' or [ethnicity] = '18'	How would you describe your ethnicity?	text

16	[postcode]	What is your postcode? Please note: This survey is anonymous and confidential. We will not use your postcode to identify you. It will be used to understand health and services in different areas of England. We would like to remind you that your participation is strictly voluntary and that your responses are used for research purposes only. The answers that you provide will be presented in aggregate form and none of them will be linked back to you in any way.	text, Identifier												
17	[housing]	In the past year, have you experienced any sort of housing difficulties? Housing difficulties could include staying with family or friends temporarily, sleeping rough or sleeping in public places, staying in a place not intended as a permanent home, or staying in emergency or other temporary accommodation.	radio <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> <tr><td>98</td><td>Unsure</td></tr> <tr><td>99</td><td>Prefer not to say</td></tr> </table>	1	Yes	0	No	98	Unsure	99	Prefer not to say				
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18	[disability]	Do you consider yourself to have a disability? A disability is defined as a physical or mental impairment that has a "substantial" and "long-term" negative effect on your ability to do normal daily activities.	radio <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> <tr><td>98</td><td>Don't know/unsure</td></tr> <tr><td>99</td><td>Prefer not to say</td></tr> </table>	1	Yes	0	No	98	Don't know/unsure	99	Prefer not to say				
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19	[interest]	Section Header: <i>Over the last two weeks, how often have you been bothered by the following problems?</i> Little interest or pleasure in doing things	radio (Matrix) <table border="1"> <tr><td>1</td><td>Not at all</td></tr> <tr><td>2</td><td>Several days</td></tr> <tr><td>3</td><td>More than half the days</td></tr> <tr><td>4</td><td>Nearly every day</td></tr> </table>	1	Not at all	2	Several days	3	More than half the days	4	Nearly every day				
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20	[depressed]	Feeling down, depressed, or hopeless	radio (Matrix) <table border="1"> <tr><td>1</td><td>Not at all</td></tr> <tr><td>2</td><td>Several days</td></tr> <tr><td>3</td><td>More than half the days</td></tr> <tr><td>4</td><td>Nearly every day</td></tr> </table>	1	Not at all	2	Several days	3	More than half the days	4	Nearly every day				
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21	[nervous]	Feeling nervous, anxious, or on edge	radio (Matrix) <table border="1"> <tr><td>1</td><td>Not at all</td></tr> <tr><td>2</td><td>Several days</td></tr> <tr><td>3</td><td>More than half the days</td></tr> <tr><td>4</td><td>Nearly every day</td></tr> </table>	1	Not at all	2	Several days	3	More than half the days	4	Nearly every day				
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22	[worrying]	Not being able to stop or control worrying	radio (Matrix) <table border="1"> <tr><td>1</td><td>Not at all</td></tr> <tr><td>2</td><td>Several days</td></tr> <tr><td>3</td><td>More than half the days</td></tr> <tr><td>4</td><td>Nearly every day</td></tr> </table>	1	Not at all	2	Several days	3	More than half the days	4	Nearly every day				
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23	[honeypot1]	For this question, please select "All of the time" as your response option	radio (Matrix) <table border="1"> <tr><td>1</td><td>Not applicable</td></tr> <tr><td>2</td><td>Never</td></tr> <tr><td>3</td><td>Once or twice</td></tr> <tr><td>4</td><td>Several times</td></tr> <tr><td>5</td><td>Most of the time</td></tr> <tr><td>6</td><td>All of the time</td></tr> </table>	1	Not applicable	2	Never	3	Once or twice	4	Several times	5	Most of the time	6	All of the time
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3	Once or twice														
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24	[shc]	Section Header: <i>The next set of questions are on your experiences accessing sexual health and HIV prevention services. HIV (Human Immunodeficiency Virus) is a virus which attacks the immune system. HIV stays in the body for life, but treatment can keep the virus under control and the immune system healthy. HIV can be passed from one person to another through sex without a condom, but only if that person is not on effective treatment. STIs (sexually transmitted infections) are infections that can be passed from one person to another through sexual contact.</i> Have you ever visited a sexual health clinic?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No								
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25	[whyshc] Show the field ONLY if: [shc] = 1	What was your reason for attending a sexual health clinic? (Please tick all that apply) If you have attended a sexual health clinic more than once, please think about your reason for your most recent visit	checkbox <table border="1"> <tr><td>1</td><td>whyshc__1</td><td>I wanted a general check-up of my sexual health</td></tr> <tr><td>2</td><td>whyshc__2</td><td>To get contraception (e.g., condoms, the birth control pill, an intrauterine device (IUD))</td></tr> <tr><td>3</td><td>whyshc__3</td><td>I had no symptoms, but I was worried I might have an STI or HIV</td></tr> <tr><td>4</td><td>whyshc__4</td><td>I had symptoms</td></tr> <tr><td>5</td><td>whyshc__5</td><td>A sexual partner had symptoms</td></tr> <tr><td>6</td><td>whyshc__6</td><td>A sexual partner was diagnosed with an STI</td></tr> <tr><td>7</td><td>whyshc__7</td><td>Treatment after a previous positive test</td></tr> <tr><td>8</td><td>whyshc__8</td><td>Check-up after a previous positive test</td></tr> <tr><td>9</td><td>whyshc__9</td><td>As follow-up to an online test</td></tr> <tr><td>10</td><td>whyshc__10</td><td>Ongoing HIV care and treatment</td></tr> <tr><td>11</td><td>whyshc__11</td><td>To get PEP to prevent HIV</td></tr> <tr><td>12</td><td>whyshc__12</td><td>To get PrEP to prevent HIV</td></tr> <tr><td>13</td><td>whyshc__13</td><td>Following sexual assault</td></tr> <tr><td>14</td><td>whyshc__14</td><td>Following domestic violence</td></tr> <tr><td>15</td><td>whyshc__15</td><td>I was told to attend by my GP/family doctor or another healthcare professional</td></tr> <tr><td>16</td><td>whyshc__16</td><td>I needed a vaccination</td></tr> <tr><td>17</td><td>whyshc__17</td><td>For another reason</td></tr> </table>	1	whyshc__1	I wanted a general check-up of my sexual health	2	whyshc__2	To get contraception (e.g., condoms, the birth control pill, an intrauterine device (IUD))	3	whyshc__3	I had no symptoms, but I was worried I might have an STI or HIV	4	whyshc__4	I had symptoms	5	whyshc__5	A sexual partner had symptoms	6	whyshc__6	A sexual partner was diagnosed with an STI	7	whyshc__7	Treatment after a previous positive test	8	whyshc__8	Check-up after a previous positive test	9	whyshc__9	As follow-up to an online test	10	whyshc__10	Ongoing HIV care and treatment	11	whyshc__11	To get PEP to prevent HIV	12	whyshc__12	To get PrEP to prevent HIV	13	whyshc__13	Following sexual assault	14	whyshc__14	Following domestic violence	15	whyshc__15	I was told to attend by my GP/family doctor or another healthcare professional	16	whyshc__16	I needed a vaccination	17	whyshc__17	For another reason
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16	whyshc__16	I needed a vaccination																																																				
17	whyshc__17	For another reason																																																				
26	[hivtest]	Have you ever received an HIV test result?	radio <table border="1"> <tr><td>0</td><td>No, I have never received an HIV test result</td></tr> <tr><td>1</td><td>Yes, my last test was negative (I did not have HIV at the time of the test)</td></tr> <tr><td>2</td><td>Yes, I have tested positive (I am living with HIV)</td></tr> </table>	0	No, I have never received an HIV test result	1	Yes, my last test was negative (I did not have HIV at the time of the test)	2	Yes, I have tested positive (I am living with HIV)																																													
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27	[whenhivtest] Show the field ONLY if: [hivtest] != 0	When did you have your last HIV test?	radio <table border="1"> <tr><td>1</td><td>In the last 3 months</td></tr> <tr><td>2</td><td>Between 3 months and 12 months ago</td></tr> <tr><td>3</td><td>Between 1 year and 5 years ago</td></tr> <tr><td>4</td><td>More than 5 years ago</td></tr> </table>	1	In the last 3 months	2	Between 3 months and 12 months ago	3	Between 1 year and 5 years ago	4	More than 5 years ago																																											
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28	[wherehivtest] Show the field ONLY if: [hivtest] != 0	Where did you have your last HIV test?	radio <table border="1"> <tr><td>1</td><td>Sexual health clinic</td></tr> <tr><td>2</td><td>GP surgery/clinic</td></tr> <tr><td>3</td><td>Self-sampling service (sent sample to lab)</td></tr> <tr><td>4</td><td>Self-testing (immediate result)</td></tr> <tr><td>5</td><td>Screening during pregnancy</td></tr> <tr><td>6</td><td>Other (please describe)</td></tr> </table>	1	Sexual health clinic	2	GP surgery/clinic	3	Self-sampling service (sent sample to lab)	4	Self-testing (immediate result)	5	Screening during pregnancy	6	Other (please describe)																																							
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6	Other (please describe)																																																					
29	[wheretestother] Show the field ONLY if: [wherehivtest] = 6	Where did you have your last HIV test?	notes																																																			
30	[stitest]	Have you ever had a test for other sexually transmitted infections (STIs) - e.g., chlamydia, gonorrhoea, syphilis?	radio <table border="1"> <tr><td>0</td><td>No, I have never had an STI test</td></tr> <tr><td>1</td><td>Yes, in the last 3 months</td></tr> <tr><td>2</td><td>Yes, between 3 and 12 months ago</td></tr> <tr><td>3</td><td>Yes, between 1 year and 5 years ago</td></tr> <tr><td>4</td><td>Yes, more than 5 years ago</td></tr> </table>	0	No, I have never had an STI test	1	Yes, in the last 3 months	2	Yes, between 3 and 12 months ago	3	Yes, between 1 year and 5 years ago	4	Yes, more than 5 years ago																																									
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4	Yes, more than 5 years ago																																																					

31	[wherestitest] Show the field ONLY if: [stitest] != 0	Where did you have your last STI test?	radio <table border="1"> <tr><td>1</td><td>Sexual health clinic</td></tr> <tr><td>2</td><td>GP surgery/clinic</td></tr> <tr><td>3</td><td>Self-sampling service (sent sample to lab)</td></tr> <tr><td>4</td><td>Other (please describe)</td></tr> </table>	1	Sexual health clinic	2	GP surgery/clinic	3	Self-sampling service (sent sample to lab)	4	Other (please describe)		
1	Sexual health clinic												
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3	Self-sampling service (sent sample to lab)												
4	Other (please describe)												
32	[wherestitestother] Show the field ONLY if: [wherestitest] = '4'	Where did you have your last STI test?	notes										
33	[stipos] Show the field ONLY if: [stitest] = '1' OR [stitest] = '2'	In the last 12 months (from today) have you been diagnosed with an STI?	radio <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> <tr><td>2</td><td>Don't know</td></tr> <tr><td>99</td><td>Prefer not to say</td></tr> </table>	1	Yes	0	No	2	Don't know	99	Prefer not to say		
1	Yes												
0	No												
2	Don't know												
99	Prefer not to say												
34	[worryhiv] Show the field ONLY if: [hivtest] !=2	Section Header: Please read each statement carefully and choose the answer that is closest to your viewpoint I worry about getting HIV	radio (Matrix) <table border="1"> <tr><td>1</td><td>Strongly agree</td></tr> <tr><td>2</td><td>Tend to agree</td></tr> <tr><td>3</td><td>Neutral/uncertain</td></tr> <tr><td>4</td><td>Tend to disagree</td></tr> <tr><td>5</td><td>Strongly disagree</td></tr> </table>	1	Strongly agree	2	Tend to agree	3	Neutral/uncertain	4	Tend to disagree	5	Strongly disagree
1	Strongly agree												
2	Tend to agree												
3	Neutral/uncertain												
4	Tend to disagree												
5	Strongly disagree												
35	[hivtestconf] Show the field ONLY if: [hivtest] !=2	I am confident that I know where I can get an HIV test	radio (Matrix) <table border="1"> <tr><td>1</td><td>Strongly agree</td></tr> <tr><td>2</td><td>Tend to agree</td></tr> <tr><td>3</td><td>Neutral/uncertain</td></tr> <tr><td>4</td><td>Tend to disagree</td></tr> <tr><td>5</td><td>Strongly disagree</td></tr> </table>	1	Strongly agree	2	Tend to agree	3	Neutral/uncertain	4	Tend to disagree	5	Strongly disagree
1	Strongly agree												
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4	Tend to disagree												
5	Strongly disagree												
36	[worrysti]	I worry about getting an STI	radio (Matrix) <table border="1"> <tr><td>1</td><td>Strongly agree</td></tr> <tr><td>2</td><td>Tend to agree</td></tr> <tr><td>3</td><td>Neutral/uncertain</td></tr> <tr><td>4</td><td>Tend to disagree</td></tr> <tr><td>5</td><td>Strongly disagree</td></tr> </table>	1	Strongly agree	2	Tend to agree	3	Neutral/uncertain	4	Tend to disagree	5	Strongly disagree
1	Strongly agree												
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4	Tend to disagree												
5	Strongly disagree												
37	[stitestconf]	I am confident that I know where I can get an STI test	radio (Matrix) <table border="1"> <tr><td>1</td><td>Strongly agree</td></tr> <tr><td>2</td><td>Tend to agree</td></tr> <tr><td>3</td><td>Neutral/uncertain</td></tr> <tr><td>4</td><td>Tend to disagree</td></tr> <tr><td>5</td><td>Strongly disagree</td></tr> </table>	1	Strongly agree	2	Tend to agree	3	Neutral/uncertain	4	Tend to disagree	5	Strongly disagree
1	Strongly agree												
2	Tend to agree												
3	Neutral/uncertain												
4	Tend to disagree												
5	Strongly disagree												
38	[hivrisk] Show the field ONLY if: [hivtest] !=2	There are different opinions about how many people are perceived as at risk of acquiring HIV. We would like to know what you think about the risks to you, personally, with your present sexual lifestyle?	radio (Matrix) <table border="1"> <tr><td>1</td><td>Greatly at risk</td></tr> <tr><td>2</td><td>Quite a lot</td></tr> <tr><td>3</td><td>Not very much</td></tr> <tr><td>4</td><td>Not at all at risk</td></tr> <tr><td>5</td><td>Don't know</td></tr> </table>	1	Greatly at risk	2	Quite a lot	3	Not very much	4	Not at all at risk	5	Don't know
1	Greatly at risk												
2	Quite a lot												
3	Not very much												
4	Not at all at risk												
5	Don't know												
39	[stirisk]	What do you think about the risks to you, personally, with your present lifestyle, of getting an STI that is not HIV	radio (Matrix) <table border="1"> <tr><td>1</td><td>Greatly at risk</td></tr> <tr><td>2</td><td>Quite a lot</td></tr> <tr><td>3</td><td>Not very much</td></tr> <tr><td>4</td><td>Not at all at risk</td></tr> <tr><td>5</td><td>Don't know</td></tr> </table>	1	Greatly at risk	2	Quite a lot	3	Not very much	4	Not at all at risk	5	Don't know
1	Greatly at risk												
2	Quite a lot												
3	Not very much												
4	Not at all at risk												
5	Don't know												
40	[prepaware]	Section Header: The next set of questions are on PrEP (HIV Pre-exposure prophylaxis). PrEP is a medication that can be taken by HIV-Negative people that reduces the risk of getting HIV. It involves taking a pill daily, on an ongoing basis (starting before a person is exposed to HIV and continuing for as long as the person is at risk). It is one of the many safer sex tools that can be used for HIV prevention. Before taking part in this study, had you ever heard of PrEP?	radio <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> <tr><td>98</td><td>Unsure</td></tr> </table>	1	Yes	0	No	98	Unsure				
1	Yes												
0	No												
98	Unsure												

41	[prephear] Show the field ONLY if: [prepaware] = "1"	To the best of your memory, where did you first learn about PrEP?	radio <table border="1"> <tr><td>1</td><td>At a sexual health clinic</td></tr> <tr><td>2</td><td>From a sexual partner</td></tr> <tr><td>3</td><td>From a friend</td></tr> <tr><td>4</td><td>In the news or on the internet</td></tr> <tr><td>5</td><td>Other (please describe)</td></tr> </table>	1	At a sexual health clinic	2	From a sexual partner	3	From a friend	4	In the news or on the internet	5	Other (please describe)											
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4	In the news or on the internet																							
5	Other (please describe)																							
42	[prephearother] Show the field ONLY if: [prephear] = '5'	Please describe where you first learned about PrEP	notes																					
43	[prepuse] Show the field ONLY if: [prepaware] = '1'	Have you ever taken PrEP?	yesno <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> </table>	1	Yes	0	No																	
1	Yes																							
0	No																							
44	[preplearn] Show the field ONLY if: [hivtest] !=2	Section Header: Please read each statement carefully and choose the answer that is closest to your viewpoint I would be interested in learning more about PrEP	radio (Matrix) <table border="1"> <tr><td>1</td><td>Strongly agree</td></tr> <tr><td>2</td><td>Agree</td></tr> <tr><td>3</td><td>Neutral/uncertain</td></tr> <tr><td>4</td><td>Disagree</td></tr> <tr><td>5</td><td>Strongly disagree</td></tr> </table>	1	Strongly agree	2	Agree	3	Neutral/uncertain	4	Disagree	5	Strongly disagree											
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3	Neutral/uncertain																							
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5	Strongly disagree																							
45	[prepinterest] Show the field ONLY if: [hivtest] !=2	I would be interested in taking PrEP	radio (Matrix) <table border="1"> <tr><td>1</td><td>Strongly agree</td></tr> <tr><td>2</td><td>Agree</td></tr> <tr><td>3</td><td>Neutral/uncertain</td></tr> <tr><td>4</td><td>Disagree</td></tr> <tr><td>5</td><td>Strongly disagree</td></tr> </table>	1	Strongly agree	2	Agree	3	Neutral/uncertain	4	Disagree	5	Strongly disagree											
1	Strongly agree																							
2	Agree																							
3	Neutral/uncertain																							
4	Disagree																							
5	Strongly disagree																							
46	[preptype] Show the field ONLY if: [hivtest] !=2 AND ([preplearn] <=2 OR [prepinterest]<=2)	New forms of PrEP are currently under development. If all of these options were available and equally effective in preventing HIV, which of these would you want to use? (Please tick all that apply)	checkbox <table border="1"> <tr><td>1</td><td>preptype__1</td><td>Daily pill</td></tr> <tr><td>2</td><td>preptype__2</td><td>Event-based pill or "on-demand" pill (a pill taken a few days before and a few days after you have sex)</td></tr> <tr><td>3</td><td>preptype__3</td><td>Long-acting injectable (a jab every 2-3 months given by a clinician)</td></tr> <tr><td>4</td><td>preptype__4</td><td>Removable implant (an implant underneath your skin inserted by a clinician)</td></tr> <tr><td>5</td><td>preptype__5</td><td>Other (please describe)</td></tr> <tr><td>6</td><td>preptype__6</td><td>I would not want to use any of these</td></tr> </table>	1	preptype__1	Daily pill	2	preptype__2	Event-based pill or "on-demand" pill (a pill taken a few days before and a few days after you have sex)	3	preptype__3	Long-acting injectable (a jab every 2-3 months given by a clinician)	4	preptype__4	Removable implant (an implant underneath your skin inserted by a clinician)	5	preptype__5	Other (please describe)	6	preptype__6	I would not want to use any of these			
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5	preptype__5	Other (please describe)																						
6	preptype__6	I would not want to use any of these																						
47	[preptypeinfo] Show the field ONLY if: [preptype(5)] = 1	What form of PrEP would you want to use?	text																					
48	[whereprep] Show the field ONLY if: [hivtest] !=2 AND ([preplearn] <=2 OR [prepinterest]<=2)	New ways of delivering PrEP are currently under discussion. Some of the options below are already available. If all of these options were available, which of these would you want to use to get PrEP? (Please tick all that apply)	checkbox <table border="1"> <tr><td>1</td><td>whereprep__1</td><td>Sexual health clinic</td></tr> <tr><td>2</td><td>whereprep__2</td><td>GP Surgery</td></tr> <tr><td>3</td><td>whereprep__3</td><td>Pharmacy/pharmacist</td></tr> <tr><td>4</td><td>whereprep__4</td><td>The internet</td></tr> <tr><td>5</td><td>whereprep__5</td><td>A private clinic</td></tr> <tr><td>6</td><td>whereprep__6</td><td>Other (please describe)</td></tr> <tr><td>7</td><td>whereprep__7</td><td>I would not want to use any of these services to get PrEP</td></tr> </table>	1	whereprep__1	Sexual health clinic	2	whereprep__2	GP Surgery	3	whereprep__3	Pharmacy/pharmacist	4	whereprep__4	The internet	5	whereprep__5	A private clinic	6	whereprep__6	Other (please describe)	7	whereprep__7	I would not want to use any of these services to get PrEP
1	whereprep__1	Sexual health clinic																						
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6	whereprep__6	Other (please describe)																						
7	whereprep__7	I would not want to use any of these services to get PrEP																						
49	[whereprepothor] Show the field ONLY if: [whereprep(6)] = 1	Please describe where you would prefer to get PrEP from	notes																					

50	[relationshipstatus]	Section Header: The next questions are about your relationships and sexual experiences. Some of these questions may feel quite personal. As a reminder, your participation is entirely voluntary and the answers people provide will be combined so that no individuals can be identified. You can skip any questions you do not want to answer by selecting 'prefer not to say'. Which statement best describes your current relationship status? (Please tick all that apply)	checkbox <table border="1"> <tr> <td>1</td> <td>relationshipstatus__1</td> <td>Married/in a civil partnership</td> </tr> <tr> <td>2</td> <td>relationshipstatus__2</td> <td>In a steady relationship and living together</td> </tr> <tr> <td>3</td> <td>relationshipstatus__3</td> <td>In a steady relationship and not living together</td> </tr> <tr> <td>4</td> <td>relationshipstatus__4</td> <td>In a new relationship</td> </tr> <tr> <td>5</td> <td>relationshipstatus__5</td> <td>In a casual relationship</td> </tr> <tr> <td>6</td> <td>relationshipstatus__6</td> <td>Single</td> </tr> <tr> <td>7</td> <td>relationshipstatus__7</td> <td>In more than one type of relationship</td> </tr> <tr> <td>8</td> <td>relationshipstatus__8</td> <td>In a polyamorous relationship</td> </tr> <tr> <td>9</td> <td>relationshipstatus__9</td> <td>Other (please describe)</td> </tr> <tr> <td>99</td> <td>relationshipstatus__99</td> <td>Prefer not to say</td> </tr> </table>	1	relationshipstatus__1	Married/in a civil partnership	2	relationshipstatus__2	In a steady relationship and living together	3	relationshipstatus__3	In a steady relationship and not living together	4	relationshipstatus__4	In a new relationship	5	relationshipstatus__5	In a casual relationship	6	relationshipstatus__6	Single	7	relationshipstatus__7	In more than one type of relationship	8	relationshipstatus__8	In a polyamorous relationship	9	relationshipstatus__9	Other (please describe)	99	relationshipstatus__99	Prefer not to say
1	relationshipstatus__1	Married/in a civil partnership																															
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9	relationshipstatus__9	Other (please describe)																															
99	relationshipstatus__99	Prefer not to say																															
51	[relationshipstatusoth] Show the field ONLY if: [relationshipstatus(9)] = 1	Please describe your relationship status	text																														
52	[lastsex]	When was the last time you had sex?	radio <table border="1"> <tr> <td>1</td> <td>In the last 4 weeks</td> </tr> <tr> <td>2</td> <td>Between 4 weeks and 3 months ago</td> </tr> <tr> <td>3</td> <td>Between 3 months and 6 months ago</td> </tr> <tr> <td>4</td> <td>Between 6 months and 1 year ago</td> </tr> <tr> <td>5</td> <td>Between 1 and 5 years ago</td> </tr> <tr> <td>6</td> <td>Longer than five years ago</td> </tr> <tr> <td>7</td> <td>N/A, I've never had sex</td> </tr> <tr> <td>99</td> <td>Prefer not to say</td> </tr> </table>	1	In the last 4 weeks	2	Between 4 weeks and 3 months ago	3	Between 3 months and 6 months ago	4	Between 6 months and 1 year ago	5	Between 1 and 5 years ago	6	Longer than five years ago	7	N/A, I've never had sex	99	Prefer not to say														
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99	Prefer not to say																																
53	[partnernum] Show the field ONLY if: [lastsex] <=3	How many sexual partners have you had in the last 6 months?	dropdown <table border="1"> <tr><td>0</td><td>0</td></tr> <tr><td>1</td><td>1</td></tr> <tr><td>2</td><td>2</td></tr> <tr><td>3</td><td>3</td></tr> <tr><td>4</td><td>4</td></tr> <tr><td>5</td><td>5</td></tr> <tr><td>6</td><td>6</td></tr> <tr><td>7</td><td>7</td></tr> <tr><td>8</td><td>8</td></tr> <tr><td>9</td><td>9</td></tr> <tr><td>10</td><td>10+</td></tr> <tr><td>99</td><td>Prefer not to say</td></tr> </table>	0	0	1	1	2	2	3	3	4	4	5	5	6	6	7	7	8	8	9	9	10	10+	99	Prefer not to say						
0	0																																
1	1																																
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9	9																																
10	10+																																
99	Prefer not to say																																
54	[partnergender] Show the field ONLY if: [lastsex] <=3	Were your sexual partners (please tick all that apply)	checkbox <table border="1"> <tr> <td>1</td> <td>partnergender__1</td> <td>Male</td> </tr> <tr> <td>2</td> <td>partnergender__2</td> <td>Female</td> </tr> <tr> <td>3</td> <td>partnergender__3</td> <td>Transgender or non-binary</td> </tr> <tr> <td>99</td> <td>partnergender__99</td> <td>Prefer not to say</td> </tr> </table>	1	partnergender__1	Male	2	partnergender__2	Female	3	partnergender__3	Transgender or non-binary	99	partnergender__99	Prefer not to say																		
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99	partnergender__99	Prefer not to say																															
55	[condomless] Show the field ONLY if: [lastsex] <=3	Have you had vaginal or anal sex without a condom with any sexual partners, in the last 6 months?	radio <table border="1"> <tr> <td>1</td> <td>Yes</td> </tr> <tr> <td>0</td> <td>No</td> </tr> <tr> <td>99</td> <td>Prefer not to say</td> </tr> </table>	1	Yes	0	No	99	Prefer not to say																								
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0	No																																
99	Prefer not to say																																

56	[whycondomless] Show the field ONLY if: [condomless] = 1	In the last 6 months, when you had vaginal or anal sex without a condom, what were the reasons for not using a condom? (Please tick all that apply)	checkbox <table border="1"> <tr> <td>1</td> <td>whycondomless__1</td> <td>Trying for pregnancy</td> </tr> <tr> <td>2</td> <td>whycondomless__2</td> <td>Other forms of contraception were used (e.g., the pill, an implant, a coil (intrauterine device, IUD))</td> </tr> <tr> <td>3</td> <td>whycondomless__3</td> <td>Didn't think about using a condom or did not have a condom</td> </tr> <tr> <td>4</td> <td>whycondomless__4</td> <td>Don't like using condoms or it's more enjoyable / close without a condom</td> </tr> <tr> <td>5</td> <td>whycondomless__5</td> <td>My partner didn't want to use a condom</td> </tr> <tr> <td>6</td> <td>whycondomless__6</td> <td>Felt unable to discuss condom use</td> </tr> <tr> <td>7</td> <td>whycondomless__7</td> <td>Got carried away</td> </tr> <tr> <td>8</td> <td>whycondomless__8</td> <td>Was under the influence of alcohol or drugs</td> </tr> <tr> <td>9</td> <td>whycondomless__9</td> <td>Difficult for partner to keep erection or ejaculate when using a condom</td> </tr> <tr> <td>10</td> <td>whycondomless__10</td> <td>For another reason (please describe)</td> </tr> <tr> <td>99</td> <td>whycondomless__99</td> <td>Prefer not to say</td> </tr> </table>	1	whycondomless__1	Trying for pregnancy	2	whycondomless__2	Other forms of contraception were used (e.g., the pill, an implant, a coil (intrauterine device, IUD))	3	whycondomless__3	Didn't think about using a condom or did not have a condom	4	whycondomless__4	Don't like using condoms or it's more enjoyable / close without a condom	5	whycondomless__5	My partner didn't want to use a condom	6	whycondomless__6	Felt unable to discuss condom use	7	whycondomless__7	Got carried away	8	whycondomless__8	Was under the influence of alcohol or drugs	9	whycondomless__9	Difficult for partner to keep erection or ejaculate when using a condom	10	whycondomless__10	For another reason (please describe)	99	whycondomless__99	Prefer not to say
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57	[whycondomlessoth] Show the field ONLY if: [whycondomless(10)] = 1	In the last 6 months, what were the reasons for not using a condom during vaginal or anal sex?	text																																	
58	[allpartnerhiv] Show the field ONLY if: [condomless] = 1	In the past 6 months when you had sex without a condom, did you know the HIV status of your partner(s)?	radio <table border="1"> <tr> <td>0</td> <td>No, I did not know the HIV status of any of my partner(s)</td> </tr> <tr> <td>1</td> <td>Yes, I knew the HIV status of all my partner(s)</td> </tr> <tr> <td>2</td> <td>Yes, I knew the HIV status of some of my partner(s)</td> </tr> <tr> <td>99</td> <td>Prefer not to say</td> </tr> </table>	0	No, I did not know the HIV status of any of my partner(s)	1	Yes, I knew the HIV status of all my partner(s)	2	Yes, I knew the HIV status of some of my partner(s)	99	Prefer not to say																									
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99	Prefer not to say																																			
59	[transactional]	In the past year, have you ever received money, drugs or goods in exchange for sexual services?	radio <table border="1"> <tr> <td>1</td> <td>Yes</td> </tr> <tr> <td>0</td> <td>No</td> </tr> <tr> <td>99</td> <td>Prefer not to say</td> </tr> </table>	1	Yes	0	No	99	Prefer not to say																											
1	Yes																																			
0	No																																			
99	Prefer not to say																																			
60	[frightened]	Section Header: <i>All relationships go through good and bad times. We would like to know whether you have experienced any of the following behaviours in relationships you have had. Please tick as many boxes per row that apply to you</i> Have you ever felt frightened of the behaviour of a partner?	checkbox <table border="1"> <tr> <td>1</td> <td>frightened__1</td> <td>Never</td> </tr> <tr> <td>2</td> <td>frightened__2</td> <td>Yes, more than 1 year ago</td> </tr> <tr> <td>3</td> <td>frightened__3</td> <td>Yes, within last year with former partner</td> </tr> <tr> <td>4</td> <td>frightened__4</td> <td>Yes within last year with current partner</td> </tr> </table>	1	frightened__1	Never	2	frightened__2	Yes, more than 1 year ago	3	frightened__3	Yes, within last year with former partner	4	frightened__4	Yes within last year with current partner																					
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4	frightened__4	Yes within last year with current partner																																		
61	[permission]	Have you ever needed to ask a partner's permission to work, go shopping, visit relatives, or visit friends (i.e., beyond the usual of being considerate to and checking with a partner)?	checkbox <table border="1"> <tr> <td>1</td> <td>permission__1</td> <td>Never</td> </tr> <tr> <td>2</td> <td>permission__2</td> <td>Yes, more than 1 year ago</td> </tr> <tr> <td>3</td> <td>permission__3</td> <td>Yes, within last year with former partner</td> </tr> <tr> <td>4</td> <td>permission__4</td> <td>Yes within last year with current partner</td> </tr> </table>	1	permission__1	Never	2	permission__2	Yes, more than 1 year ago	3	permission__3	Yes, within last year with former partner	4	permission__4	Yes within last year with current partner																					
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62	[physassault]	Have you ever been hit, slapped, kicked, or otherwise physically hurt by a partner?	checkbox <table border="1"> <tr> <td>1</td> <td>physassault__1</td> <td>Never</td> </tr> <tr> <td>2</td> <td>physassault__2</td> <td>Yes, more than 1 year ago</td> </tr> <tr> <td>3</td> <td>physassault__3</td> <td>Yes, within last year with former partner</td> </tr> <tr> <td>4</td> <td>physassault__4</td> <td>Yes within last year with current partner</td> </tr> </table>	1	physassault__1	Never	2	physassault__2	Yes, more than 1 year ago	3	physassault__3	Yes, within last year with former partner	4	physassault__4	Yes within last year with current partner												
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63	[sexassault]	Have you ever been forced to have sex or made to engage in some sexual activity when you did not want to?	checkbox <table border="1"> <tr> <td>1</td> <td>sexassault__1</td> <td>Never</td> </tr> <tr> <td>2</td> <td>sexassault__2</td> <td>Yes, more than 1 year ago</td> </tr> <tr> <td>3</td> <td>sexassault__3</td> <td>Yes, within last year with former partner</td> </tr> <tr> <td>4</td> <td>sexassault__4</td> <td>Yes within last year with current partner</td> </tr> </table>	1	sexassault__1	Never	2	sexassault__2	Yes, more than 1 year ago	3	sexassault__3	Yes, within last year with former partner	4	sexassault__4	Yes within last year with current partner												
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64	[forcedci]	Have you ever been coerced into having sex without a condom when you did not want to?	checkbox <table border="1"> <tr> <td>1</td> <td>forcedci__1</td> <td>Never</td> </tr> <tr> <td>2</td> <td>forcedci__2</td> <td>Yes, more than 1 year ago</td> </tr> <tr> <td>3</td> <td>forcedci__3</td> <td>Yes, within last year with former partner</td> </tr> <tr> <td>4</td> <td>forcedci__4</td> <td>Yes within last year with current partner</td> </tr> </table>	1	forcedci__1	Never	2	forcedci__2	Yes, more than 1 year ago	3	forcedci__3	Yes, within last year with former partner	4	forcedci__4	Yes within last year with current partner												
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4	forcedci__4	Yes within last year with current partner																									
65	[educate]	Section Header: <i>The final set of questions are about your demographics</i> What is your highest educational qualification?	radio <table border="1"> <tr> <td>1</td> <td>I have no formal educational qualifications</td> </tr> <tr> <td>2</td> <td>GCSEs/O-levels/National 5 or equivalent</td> </tr> <tr> <td>3</td> <td>A-levels/Scottish highers or equivalent</td> </tr> <tr> <td>4</td> <td>Higher education below degree level (e.g., a Higher National Certificate (HNC), a Higher National Diploma (HND))</td> </tr> <tr> <td>5</td> <td>Degree or higher (e.g., a bachelor's degree, a master's degree, a doctoral degree)</td> </tr> <tr> <td>6</td> <td>Other (text box)</td> </tr> </table>	1	I have no formal educational qualifications	2	GCSEs/O-levels/National 5 or equivalent	3	A-levels/Scottish highers or equivalent	4	Higher education below degree level (e.g., a Higher National Certificate (HNC), a Higher National Diploma (HND))	5	Degree or higher (e.g., a bachelor's degree, a master's degree, a doctoral degree)	6	Other (text box)												
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6	Other (text box)																										
66	[educateoth] Show the field ONLY if: [educate] = '6'	Please describe your educational qualifications	text																								
67	[employ]	Which of the following best describes your situation?	radio <table border="1"> <tr> <td>1</td> <td>Employed full-time</td> </tr> <tr> <td>2</td> <td>Employed part-time</td> </tr> <tr> <td>3</td> <td>Self-employed</td> </tr> <tr> <td>4</td> <td>Unemployed</td> </tr> <tr> <td>5</td> <td>Full-time student</td> </tr> <tr> <td>6</td> <td>Part-time student</td> </tr> <tr> <td>7</td> <td>Retired</td> </tr> <tr> <td>8</td> <td>In receipt of universal credit, income support, or other benefits</td> </tr> <tr> <td>9</td> <td>Unable to work (e.g., due to immigration status)</td> </tr> <tr> <td>10</td> <td>Full-time</td> </tr> <tr> <td>11</td> <td>Part-time carer</td> </tr> <tr> <td>12</td> <td>Other (Please describe)</td> </tr> </table>	1	Employed full-time	2	Employed part-time	3	Self-employed	4	Unemployed	5	Full-time student	6	Part-time student	7	Retired	8	In receipt of universal credit, income support, or other benefits	9	Unable to work (e.g., due to immigration status)	10	Full-time	11	Part-time carer	12	Other (Please describe)
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12	Other (Please describe)																										
68	[employoth] Show the field ONLY if: [employ] = '12'	Please describe your current employment situation	text																								
69	[needsmet]	Do you have enough money to cover your basic needs (e.g., food, rent, gas, electricity, water, etc.)	radio <table border="1"> <tr> <td>1</td> <td>Yes, always</td> </tr> <tr> <td>2</td> <td>Yes, most of the time</td> </tr> <tr> <td>3</td> <td>Yes, some of the time</td> </tr> <tr> <td>0</td> <td>No</td> </tr> </table>	1	Yes, always	2	Yes, most of the time	3	Yes, some of the time	0	No																
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0	No																										

70	[osss1]	How many people are so close to you that you can count on them if you have severe or significant personal problems?	radio <table border="1"> <tr><td>1</td><td>None</td></tr> <tr><td>2</td><td>1-2</td></tr> <tr><td>3</td><td>3-5</td></tr> <tr><td>4</td><td>More than 5</td></tr> </table>	1	None	2	1-2	3	3-5	4	More than 5						
1	None																
2	1-2																
3	3-5																
4	More than 5																
71	[osss2]	How much interest and concern do people show in what you do?	radio <table border="1"> <tr><td>1</td><td>None</td></tr> <tr><td>2</td><td>A little</td></tr> <tr><td>3</td><td>Uncertain/not sure</td></tr> <tr><td>4</td><td>Some</td></tr> <tr><td>5</td><td>A lot</td></tr> </table>	1	None	2	A little	3	Uncertain/not sure	4	Some	5	A lot				
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3	Uncertain/not sure																
4	Some																
5	A lot																
72	[osss3]	How easy is it to get practical help from people around you if you should need it?	radio <table border="1"> <tr><td>1</td><td>Very difficult</td></tr> <tr><td>2</td><td>Difficult</td></tr> <tr><td>3</td><td>Possible</td></tr> <tr><td>4</td><td>Easy</td></tr> <tr><td>5</td><td>Very easy</td></tr> </table>	1	Very difficult	2	Difficult	3	Possible	4	Easy	5	Very easy				
1	Very difficult																
2	Difficult																
3	Possible																
4	Easy																
5	Very easy																
73	[religious]	Do you regard yourself as belonging to any particular religion?	radio <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> <tr><td>99</td><td>Unsure/Prefer not to say</td></tr> </table> Field Annotation: From British Social attitudes survey	1	Yes	0	No	99	Unsure/Prefer not to say								
1	Yes																
0	No																
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74	[religion] Show the field ONLY if: [religious] = "1"	What is your religion?	radio <table border="1"> <tr><td>1</td><td>Christian (including Church of England, Catholic, Protestant and all other Christian denominations)</td></tr> <tr><td>2</td><td>Buddhist</td></tr> <tr><td>3</td><td>Hindu</td></tr> <tr><td>4</td><td>Jewish</td></tr> <tr><td>5</td><td>Muslim</td></tr> <tr><td>6</td><td>Sikh</td></tr> <tr><td>7</td><td>Any other religion (please describe)</td></tr> </table>	1	Christian (including Church of England, Catholic, Protestant and all other Christian denominations)	2	Buddhist	3	Hindu	4	Jewish	5	Muslim	6	Sikh	7	Any other religion (please describe)
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75	[religionother] Show the field ONLY if: [religion] = '7'	Please describe your religion	notes														
76	[religionactive] Show the field ONLY if: [religious] = "1"	Do you consider that you are actively practicing your religion? Actively practicing your religion could include engaging in worship, reading Holy books, offering prayers, or attending services	radio <table border="1"> <tr><td>1</td><td>Yes</td></tr> <tr><td>0</td><td>No</td></tr> <tr><td>98</td><td>Unsure</td></tr> </table>	1	Yes	0	No	98	Unsure								
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0	No																
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77	[honeypot2]	Please leave this question blank.	notes														
78	[all_questions_complete]	Section Header: <i>Form Status</i> Complete?	dropdown <table border="1"> <tr><td>0</td><td>Incomplete</td></tr> <tr><td>1</td><td>Unverified</td></tr> <tr><td>2</td><td>Complete</td></tr> </table>	0	Incomplete	1	Unverified	2	Complete								
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