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Doctoral Thesis

Navigating the Health Seas: Experiences of accessing freely available PrEP on the National Health Service

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Thesis Abstract	297	-	297
Literature Review	7952	7802	15754
Empirical Paper	7972	8172	16144
Critical Appraisal	3876	1340	5216
Ethics	1706	6325	8031
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Thesis Abstract

This thesis presents three papers exploring different aspects of Pre-Exposure Prophylaxis (PrEP) in the United Kingdom. This includes a systematic scoping review on knowledge, perceptions, and attitudes towards PrEP; a qualitative study exploring experiences of accessing PrEP on the National Health Service (NHS) and a critical appraisal.

Section one reports a systematic scoping review of UK-based literature, which aims to map various aspects of knowledge, perceptions, and attitudes towards PrEP. Forty-seven studies met the requirements for inclusion. Results present a diverse methodological landscape that is rapidly growing in scope. Knowledge and awareness of PrEP were variable across different populations. Underrepresentation in research and media campaigns continues to perpetuate bias towards gay, bisexual, and other men who have sex with men (GBMSM) as being the main proponents of PrEP. Lack of representation and poor awareness of PrEP candidacy impacted the acceptability of PrEP in several groups who experience inequitable PrEP uptake. Self-perceived HIV risk was highlighted as an important factor in PrEP uptake and adherence. Stigma towards PrEP was often associated with moralising views of sex and promiscuity.

The empirical section of this project presents a reflexive thematic analysis (RTA) of eight individuals' experiences of accessing freely available PrEP on the National Health Service (NHS). Three main themes were derived from the data. (1) Choosing PrEP: risk analysis at every turn; (2) To be, is to be perceived: the importance of feeling seen, heard and cared for by services; and (3) Added benefits: lifting the weight of risk and freedom to explore pleasure.

The final section offers a critical appraisal of the project as a whole including an overview of both papers, bringing together the results and suggesting clinical implications

and future research. In keeping with reflexive qualitative methods, positionality, subjectivity and personal reflections will also be discussed.

Declaration

This thesis presents research undertaken between April 2023 and May 2024 as a requirement of the Doctorate in Clinical Psychology at Lancaster University. The work presented here is my own, except where due reference is made. This thesis has not been submitted for the award of any higher degree elsewhere.

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I would like to thank those who chose to participate in this study. You were all so generous with your time and experiences. I hope you feel your accounts have been honoured and that sharing these findings will benefit others. Similarly, I received some incredible support from local organisations and advocates in the community who shared my recruitment and consulted on this project.

I would also like to thank my thesis supervisors, Dr Katy Bourne and Dr Sarah Rutter. This thesis charts a journey for participants, but I feel we have been on a journey of our own, too. Thank you for weathering this process alongside me and offering your wisdom and knowledge whenever I needed it. You have been so kind, and your insights have been invaluable.

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A note on language

This research was conducted to provide novel and useful insights into experiences accessing PrEP in the UK. However, it involved speaking with and about populations that are often subject to stigmatising language and discrimination.

The People First Charter, launched in July 2021, promotes the use of person-first language in health research. This approach emphasises recognising individuals as people first, not merely by their health conditions.

Throughout this study, all efforts were made to use person-first language whenever possible. Nevertheless, language is not universal, and there may be instances where this choice does not fully meet everyone's preferences. For example, some individuals feel that person-first language separates them from their condition, which they may view as an integral part of their identity, as seen in the deaf or autistic communities. The People First Charter also advises against abbreviations, but within this research, they are sometimes necessary for readability and word count limits.

Most importantly, this research is written in the spirit of trying to ensure that all people living with or at risk of HIV and sexually transmitted infections (STIs) are treated with dignity and deserve to enjoy the highest attainable standards of health, as is their fundamental human right.

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Section One: Systematic Scoping Literature Review

Knowledge, Perceptions, and Attitudes towards Pre-Exposure Prophylaxis (PrEP) in the United Kingdom: A Scoping Review

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Abstract

In their goal to reduce HIV transmission to zero by 2030 (Public Health England, 2019), the UK made pre-exposure prophylaxis (PrEP) freely available through the National Health Service (NHS) in 2020. PrEP is a biomedical technology that has been shown to be highly effective in reducing the likelihood of HIV transmission. However, PrEP uptake has been inequitable, with not all communities equally benefiting (National AIDs Trust, 2022). A scoping review was conducted to identify key themes and omissions across this developing interdisciplinary field to help researchers contextualise their findings and inform priorities for future research. Online databases were used to systematically identify sources of evidence published between 2012 and 2024. 47 UK-based publications that explored some aspect of knowledge, perceptions, or attitudes towards PrEP met the criteria for inclusion in the review. Findings revealed that opinions on publicly funded, and easily available PrEP are varied. Lack of representation and poor awareness of PrEP candidacy impacted the acceptability of PrEP in several groups who experience inequitable PrEP uptake. Underrepresentation in research and media campaigns continues to perpetuate bias towards gay, bisexual and other men-who-have-sex-with-men (GBMSM) as being the main proponents of PrEP. Large gaps continue to persist regarding research and policy for women and persons who inject drugs (PWID). Stigma towards PrEP was variable but was often associated with moralising views of sex and promiscuity. Future research should focus on theoretically informed explorations of population-specific factors that situate their findings in a robust understanding of structural, societal and cultural barriers. Results also suggest that the psychosocial benefits of PrEP warrant further investigation outside of clinical trial contexts.

Keywords: scoping review, Pre-exposure Prophylaxis, PrEP, knowledge, attitudes, perceptions

Introduction

It is estimated that 38.4 million people are living with human immunodeficiency virus (HIV), with 95,900 people estimated to be living with HIV in the United Kingdom (UK) (UK Health Security Agency, 2022). Left untreated, HIV can cause serious harm, but with early treatment, prognosis is significantly improved and many live long, healthy lives. Studies have shown that for those on effective treatment resulting in an undetectable viral load, there is no risk of transmission (Okoli et al., 2021).

Research has continued to explore opportunities for improved HIV prevention strategies, such as those which combine multiple intervention types (for example, biomedical, structural or behavioural) targeted towards key populations (Puro et al., 2013; Padian et al., 2011). Recently, the use of pre-exposure prophylaxis (PrEP) has offered an additional opportunity for the UK to meet its target to reduce HIV transmission to zero by 2030. PrEP is a biomedical technology, that has been shown to be highly effective in reducing the likelihood of HIV transmission. Some studies have suggested that with consistent daily use, PrEP can be up to 99% effective in reducing sexually transmitted HIV (Grant et al., 2010). Most individuals accessing PrEP take one dose daily, though some people may use “event-based” regimens, whereby they only take a dose prior to and after an event which has the potential to expose them to HIV.

The UK has had a turbulent and fast-moving journey toward successfully implementing PrEP. The introduction of PrEP was met with some controversy, especially over its cost, disparities in availability and access, and fears of PrEP leading to increased promiscuity and sexual risk-taking (Mowlabocus, 2020; Young et al., 2021; Jaspal & Nerlich, 2016). Access to PrEP in the UK has been uneven. Scotland was described as a leader in HIV prevention (Terrance Higgins Trust, 2023) by making PrEP available through the National

Health Service (NHS) in July 2017, with Wales following in mid-2018. Within Ireland, PrEP became available free of charge in 2019. In contrast, NHS England was widely criticised for declaring that it was not able to fund PrEP (Strudwick, 2016; The Guardian, 2016) and that access would only be through the IMPACT (Sullivan et al., 2023) or PROUD trials (McCormack et al., 2016). Following legal challenge by the National AIDS Trust Charity, it was announced that PrEP would be free on the NHS in 2020.

PrEP has already had an impact on HIV rates in the UK following being made freely available. Public Health England declaring that, alongside other HIV combination prevention interventions, PrEP has played a part in reducing HIV transmission, particularly among GBMSM, where new HIV diagnoses fell by two-thirds between 2015 and 2020 (Alcorn & Pebody, 2023; UK Health Security Agency, 2023).

As part of this introduction, the NHS suggests that PrEP can be used by “anyone from a community or group that is most at risk of HIV, or people who have sex with people from those networks” (NHS, 2023). Specifically: men without HIV having condomless sex with other men, those with a partner living with HIV or who do not know their HIV status, trans or non-binary people regularly having condomless sex, or those who engage in sex work or inject drugs.

Demand and public acceptability of PrEP have been high in the UK, particularly among GBMSM (Frankis et al., 2016a; Gilson et al., 2018). Awareness has continued to rise since its introduction, encouraged by the vocal engagement of HIV activists, researchers and sexual health clinicians, along with controversy in the media about NHS England’s funding stance (Frankis et al., 2016a).

Despite this, access to PrEP has been noticeably inequitable (National AIDs Trust, 2022). One study found that since PrEP became available through the NHS, inequities have widened, particularly across gender, ethnicity, and region of residence (Coukan et al., 2024). Some systematic reviews have explored the potential barriers and facilitators to successful PrEP uptake; however, these are typically based in the United States (US) within the context of a private healthcare system (Hannaford et al., 2018; Mayer et al., 2020; Baldwin et al., 2021; Rutstein & Muessig, 2024) or focus solely on service provision (Kamitani et al., 2023; Vanhamel et al., 2020; Li et al., 2014) or only explore specific populations in the UK (Whelan et al., 2023; Cernasev et al., 2023).

One recent systematic review that explored PrEP delivery in the UK suggested that barriers and facilitators to PrEP uptake occur across a number of levels: individual, provider and system. The review highlighted that the factors identified in most papers were situated on the individual level. These included awareness of PrEP, personal perception of HIV risk, PrEP willingness, and HIV stigma (Coukan et al., 2023). HIV stigma specifically is often understood as separate but related to PrEP stigma, as they are both conceptualised within wider social processes that involve labelling, stereotyping, separation, status loss, and discrimination (Link & Phelan, 2001). HIV stigma is more attuned to Goffman's original theory of stigma, which refers to a socially devalued "mark", in this case HIV, which signifies a "tarnished character" (Goffman, 1963 as cited in Earnshaw & Chaudoir, 2009). In contrast, PrEP stigma differs as it is socially discrediting because of its association with HIV and its behavioural assumptions (for example, multiple sexual partners).

Importantly, lack of PrEP knowledge and awareness were the two most reported barriers to PrEP use, with some studies suggesting that of those individuals who declined PrEP, nearly half did so because they wanted more information (Wong et al., 2021).

However, the paper also concluded that more research was needed to explore provider and system-level factors, to inform national interventions or awareness programmes (Coukan et al., 2023; Nunn et al., 2017). Provider and system-level factors may include service provision, socioeconomic disparities, healthcare inequalities, prevailing cultural norms and public perceptions (Ayala et al., 2013; Jaspal et al., 2019; Melo, 2021).

International research on barriers and facilitators to PrEP offer similar conclusions, with individual-level factors such as attitudes, beliefs and perceptions (i.e. perception of PrEP candidacy, HIV risk perception, fear of side effects) being important in conceptualising PrEP uptake, but do not offer the full picture (Muhumuza et al., 2021; Calabrese, 2020; Antonini et al., 2023; Mayer et al., 2020).

This is further complicated by the impact of media in shaping attitudes and perceptions towards HIV and preventative medicine (Niedt, 2020; An et al., 2014; Coelho et al., 2024). Media narratives have been shown to impact public perceptions of HIV risk, attitudes towards PrEP provision, as well as values and preferences related to PrEP use in the UK (Jaspal & Nerlich, 2016; Mowlabocus, 2020; Young et al., 2021).

Overall, the introduction of PrEP in the UK has been highly politicised, and research continues to be disparate and heterogeneous. To continue to improve access to and uptake of PrEP, with the long-term plan of meeting the UNAIDS goal of no new transmission of HIV by 2030 (Public Health England, 2019; Brizzi et al., 2021; UNAIDS, 2016), it is important to explore the interplay between individuals, service providers, the healthcare system, and associated policies within which they operate (Rutstein & Muessig, 2024).

This review aims to map what we have learned thus far by asking the question: What are people's knowledge, attitudes, and perceptions of PrEP in the UK?

Method

A scoping review was identified as the most appropriate methodology as the aim was to map what is known across this research area from a wide range of sources, rather than attempt to answer a narrowly defined question. Furthermore, it enabled this review to provide an overview of the size and scope of the current evidence body and highlight knowledge gaps or areas that would benefit from further review. Research that is novel and diverse in scope and methodology is best suited to be synthesised through a scoping review methodology (Peters et al. 2015). The Joanna Briggs Institute (JBI) (Peters et al., 2015; Peters et al., 2020) has developed a systematic protocol to provide methodological guidance for conducting a scoping review.

The five-stage scoping framework designed by Arksey and O'Malley (2005), later developed by Levac et al. (2010), was used. It was completed in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) extension for Scoping Reviews (Appendix 1-E)

Stage one: Identifying the research question

Broad research question: What is the current state of knowledge, perceptions, and attitudes towards PrEP in the UK?

The study has two goals. First, to systematically identify research across this area to date, and to provide an overview of the extent and type of research undertaken on knowledge, attitudes, and perceptions towards PrEP in the UK. This includes a summary of the leading research questions posed by these studies, the most common methods used, the settings in which studies are conducted, and their target populations.

Second, to identify key themes that have emerged from research on knowledge, attitudes, and perceptions towards PrEP in the UK. In keeping with the principles of this methodology, this review is not intended to be a systematic review and evaluation of all

available evidence on this topic; instead, the aim is to identify common themes and omissions across a developing interdisciplinary field to help researchers contextualise their research findings and inform priorities for future research.

Stage two: Identifying relevant studies

Information sources

This review aimed to include all original research articles published in peer-reviewed journals and grey literature addressing the above-stated research question. Systematic searches of relevant articles were performed using electronic databases such as PubMed (+MEDLINE), CINAHL, PsychInfo and EMBASE. Further literature was also sought from reference lists, government reports, policy documents, doctoral thesis, and position papers from relevant organisations. A number of sources were searched for grey literature.

Identification of studies was accomplished by searching published literature in English between 2012 and January 2024. These dates were based on when PrEP became available in the UK. Search terms were defined following an extensive search of relevant literature and consultation with an academic librarian (Pollock et al., 2021). These included ‘Awareness’, ‘Attitude’, ‘Perception’, ‘PrEP’, ‘United Kingdom’. Boolean terms such as ‘OR’ and ‘AND’ were used to separate the search keywords. Medical Subject Headings (MeSH) terms were also included in the search (Appendix 1-B).

Stage three: Study Selection

Eligibility criteria

Inclusion criteria were original research articles of any design conducted in the UK, published in English since 2012 specifically exploring knowledge of, or attitudes and perceptions towards PrEP in any population.

Exclusion criteria included papers that didn’t directly explore knowledge, attitudes, and perceptions of PrEP, articles conducted outside of the UK, conference abstracts, and

articles not published in English. Global articles were excluded. To avoid double reporting, systematic reviews and research protocol were also excluded, but searched for applicable references. Lack of empirical data was also a reason for exclusion.

Selection of Sources of Evidence

Prior to the formal screening process, a calibration exercise was conducted with two reviewers (KB, SR) on a subset of articles, to ensure that the main reviewer (HS) was applying the screening criteria as consistently as possible. After this, the initial title and abstract sift was completed by one reviewer (HS). For the remaining papers, the full-text versions were obtained and read to determine whether the studies met eligibility criteria to be included in the final review.

Stage four: Charting the data

Data charting process

Data from the identified studies were extracted using a charting framework developed a priori. The full process required review and discussion within the core research team (HS, KB, and SR) to resolve any uncertainties.

Data extraction

Data extraction included: Type of evidence, author/s, year, location research conducted, study population (sample size), aims/purpose and method.

[Table 1 Extraction Table]

Data management and software

Microsoft Excel was used for charting and completion of frequency analysis. Rayyan (Ouzzani et al., 2016), a web-based software, was used to support articles' screening and initial deduplication. Endnote V21 (Endnote, 2013) was used to collate all screened references.

Stage five: Collating, summarising, and reporting the results

Summary tables were used to complete descriptive numerical summary analysis based on updated scoping review guidance from Levac et al. (2010).

Due to the variety of studies included, it was deemed that a narrative synthesis would be the most appropriate way to synthesise the literature further. This process was guided by Rodgers et al. (2009) narrative synthesis framework and involved utilising several strategies to develop a preliminary synthesis, explore the relationships between the studies, and assess the robustness of the synthesis.

[Figure 2 Diagram of Synthesis Process]

The tools selected for each stage were informed by the review's research questions and intention to present the resulting data usefully. Due to the heterogeneity in research methodology, textual descriptions were a helpful way of summarising results from qualitative and quantitative studies, and then themes from these summaries explored.

Results

Initial database searches identified 811 records, with a further 15 identified through hand-searching reference lists. Searches for grey literature revealed three unpublished thesis and one electronic research article from a relevant website. After removing duplicates 543 records remained, reduced to 86 after the title and abstract sift. After full-text screening, 47 records were identified that met the inclusion criteria.

[Figure 1 PRISMA]

Characteristics of sources of evidence

Of the 47 studies included, 28 used qualitative methodology (59.6%), 16 were quantitative studies (34%), and three used mixed methods (6.4%).

Of the qualitative papers, seventeen used semi-structured interviews, three used qualitative content analysis of UK Newspapers, three used focus groups, and five papers used some combination of the above. Participant numbers ranged from 10 to 117.

The quantitative papers largely utilised questionnaire methodologies, with 13 cross-sectional survey designs and one article using a survey design coupled with a HIV antibody test.

One paper utilised an experimental 2x2x2 design and one used a prospective cohort study design. Participant numbers ranged from 67 to 2280, with one outlier paper exploring 426,149 users of a regional online testing service.

All three mixed method papers used survey design and semi-structured interviews.

The majority of studies focussed mostly or exclusively on GBMSM (n=31, 66%). Of these, two focussed specifically on young men-who-have-sex-with-men (MSM) and three included transpersons in their samples. While a number of studies included women within their sample (n=16, 34%), only one of these sought to directly focus on women as participants. Preliminary analysis suggests that only 5.74% of all participants across all papers were listed as women. However, this must be interpreted with caution as papers were inconsistent in reporting whether this included cis-gendered women only. Furthermore, some papers reported on the same sample (Young & Valiotis, 2020; Young & Boydell, 2023) or reported including transwomen in an MSM sample (Hayes et al., 2023).

Two papers described participants, including GBMSM and Men & Women from Migrant African Communities, but on further examination, were different analyses from the same study (Young et al., 2015; Young et al., 2014). Six studies in total explored PrEP within the context of Black African or Black Caribbean men and women. Two studies drew a pool of participants from the wider PROUD trial (Arnold-Forster et al., 2022; Hayes et al., 2023),

and only one study explored PrEP within the context of people who inject drugs (PWID). Seven studies in total focussed on service providers or HIV experts (Hillis et al., 2021; Smith et al., 2021; Young & Valiotis, 2020; Flowers et al., 2022; Young & Boydell, 2023; Khan et al., 2023) and two further studies from the same sample reported focusing on the general population (Hildebrandt et al., 2019; Hildebrandt et al., 2020). Three papers explored PrEP within the context of the British press (Young et al., 2021; Jaspal & Nerlich, 2016; Mowlabocus et al., 2020).

This paper was limited to studies completed and based on/in the UK. 34% (n=16) of articles described their setting as “Great Britain” or the “United Kingdom” but did not specify further.

The majority of papers (44.7%, n=21) described their setting as England, with most of these being set in London (23.4%, n=11), and the rest in various locations across England (17%, n=8), Bristol (2.1%, n=1), or Leicester (2.1%, n=1)

Eight papers (17%) reported their setting as Scotland, though only one of these described a specific city (Glasgow, n=1). One paper listed their setting as Wales (Gillespie et al., 2022) and one paper described their setting as the Celtic nations (Scotland, Wales, Northern Ireland and The Republic of Ireland; Frankis et al., 2016b).

Most papers were dated after 2019 (n=34, 72.3%), just as PrEP was becoming freely available on the NHS. A number of papers were published in 2016 (n=6, 12.8%), which may allude to the increase in public discussion around PrEP following the debate over funding responsibility.

[Figure 3 Year of Publication Graph]

In summary, the majority of studies focused on service users and those impacted by PrEP. Participants were mainly from GBMSM populations, and studies were mostly

conducted in England, particularly in London. Lastly, the majority of research has been published since 2019 when PrEP was becoming available on the NHS.

Research Aims and Objectives

Most studies could be surmised as aiming to explore the barriers and facilitators of PrEP uptake, adherence, and access. As part of these larger aims, most research was situated within the context of groups considered to be disproportionately affected by HIV such as GBMSM, PWID or Black African communities.

Fourteen papers focussed on PrEP awareness, with a minority hoping to identify specific barriers and facilitators (Flowers et al., 2022; Nakasone et al. 2020). Eleven studies described hoping to isolate barriers and facilitators to PrEP uptake and adherence, with a further four exploring these within specific populations (Witzel et al., 2019; Young et al., 2014; Nakasone et al. 2020; Di Giuseppe et al., 2019). Exploring perceptions and attitudes towards PrEP was also a popular research aim, though only one paper explored this directly within heterosexual Black African Men (Ameny et al., 2021). Only one paper intended to explore healthcare providers' knowledge and attitudes towards PrEP (Desai et al., 2016). Ten papers hoped to explore direct experiences of using PrEP. However, only one recent paper reported exploring the psychosocial impact of PrEP on participants (Hayes et al., 2023).

While most papers align with these overarching themes, outliers include a few studies focusing on broader societal attitudes through media analysis (Young et al., 2021; Jaspal & Nerlich, 2016; Mowlabocus, 2020).

Narrative summary of findings

The main findings around the current state of knowledge, perceptions, and attitudes towards PrEP in the United Kingdom are summarised below.

Knowledge and awareness

Studies focusing on the GBMSM population showed variable levels of awareness and knowledge of PrEP, with percentages ranging from 29% to 84.9%. It is likely that this is due to the changes that occurred in PrEP availability across the timeframe. For example, in one of the earlier studies exploring PrEP use in MSM communities in London, it was found that only 2.2% reported having used PrEP (Aghaizu et al., 2013). In comparison, a study examining MSM attending sexual health clinics in London and Brighton found that PrEP use increased from 0% in 2013 to 43% in 2018 (Hanum et al., 2020).

More recent research from 2019 indicated that 84.9% of MSM recruited in London were aware of PrEP (Goedel, et al. 2019). Research suggested that participants typically sought out information on PrEP from their peers (Witzel et al., 2019; Maxwell et al., 2022; Flowers et al., 2022), physical and digital media (Frankis et al., 2016), dating apps (Flowers et al., 2022), and online community resources such as “I Want PrEP Now” or “PrEPster” (Paparini et al., 2018).

Studies indicated that there are lower levels of awareness in Black African Communities, especially in heterosexual populations (Ameny, 2021). In some cases, this was associated with evidence of distrust in PrEP, either regarding PrEP not aligning with their own safer sex narratives (Nakasone et al., 2020) or PrEP being connected with HIV positivity, promiscuity, and sexual risk-taking (Di Giuseppe et al., 2019).

Witzel et al. (2019) found that in a sample of Black MSM, who have higher HIV incidence and prevalence when compared with other MSM populations, PrEP awareness and acceptability were negatively impacted by being part of multiple minoritised social groups. Living with heterogenous social groups, in terms of sexual orientation and ethnicity, tended to limit discussions about sexual health to their gay male friends. Furthermore, this limiting effect was compounded by the lack of representation of BMSM in gay male spaces, and

stereotypical understandings of PrEP use intersected with racist ideals of BMSM's sexuality. Together, these factors presented a complex set of circumstances for BMSM to navigate PrEP.

Only one study explored PrEP within the context of PWID (Smith et al., 2021), and one study explored GBMSM who engage in chemsex (Maxwell et al., 2022). They found low awareness in PWID, variable awareness in service providers working with these populations, but all GBMSM included in the study were aware of and using PrEP.

Little research focused on exploring knowledge of PrEP in healthcare workers in HIV services. This may be because it is expected that knowledge would be high, or possibly because some HIV teams work only with people living with HIV, who therefore have no need for PrEP. One study looked at healthcare provider knowledge, and as expected, 80% reported "medium" or "high" levels of knowledge, though 25% of participants were involved in the PROUD trial (Desai et al., 2016).

[Figure 4 Research setting by location Chart]

The only study that directly explored women's knowledge and awareness of PrEP was Nakasone et al's 2020 study into Black African and Black Caribbean women in the UK. It found that despite nearly all participants displaying good levels of knowledge about HIV and previous prevention strategies, few knew of PrEP. Interestingly, it was also found that once the participants had PrEP explained to them, they expressed that PrEP was a positive development for 'women they knew', but it did not fit into their own personal safer sex narratives; they did not see PrEP as something they themselves would use.

This relationship between high levels of HIV awareness and low levels of PrEP awareness in Black African and Black Caribbean women is important to consider within the context of the rest of the literature. Poor HIV literacy was commonly cited as a barrier to

PrEP awareness in a number of populations (Di Giuseppe et al., 2019; Frankis et al., 2016; Young et al., 2015; Young & Valiotis, 2020), or similarly, proximity to HIV was shown to positively affect PrEP awareness (Aghaizu, et al., 2013). It may be that the provision of information relating to HIV and PrEP is not sufficient in isolation to have an impact on PrEP awareness. Instead, for staff to be truly well informed, they must be able to tailor this information to different social or cultural groups (Young & Valiotis, 2020).

Factors affecting acceptability and willingness

Within the literature body, the terms willingness, acceptability, and likelihood of use are often used interchangeably without full operationalisation. However, for the purposes of this article, it is necessary to clarify how these concepts will be conceptualised. Acceptability refers to the belief that PrEP should be available to the public (i.e., Should PrEP be available at all?). Willingness refers to the personal likelihood of using PrEP (i.e., Would you use PrEP?).

Within GBMSM populations, percentages of participants' willingness to use PrEP were high and relatively consistent across locations and time, ranging from 54.3% to 64% (Aghaizul et al., 2013; Bull et al., 2018; Frankis et al., 2016; Goedel et al., 2019; Young et al., 2013).

Nutland (2016) attempts to explain personal PrEP willingness, suggesting three overarching characteristics: personal acceptability (side effects; HIV vulnerability; adherence); inter-personal acceptability (navigating sex; stigma or discrimination); and community or social concepts of acceptability (financial burden and concepts of increased 'community risk').

Age and educational attainment were also highlighted as important factors in GBMSM populations in regard to acceptability and willingness, though findings were

inconsistent (Hanum et al., 2020; Ogaz et al., 2022; Jaspal et al., 2019; Jolley & Jaspal, 2020; Young et al., 2013). In contrast, side effects were found to impact acceptance and willingness (Ameny, 2021; Arnold-Forster et al., 2022; Goedel et al., 2019; Papparini et al., 2018; Williamson et al., 2019; Young et al., 2014).

Research into Black African populations demonstrated the potential for high acceptability, but this was tempered by lack of knowledge (about PrEP or HIV vulnerability) or fears of side effects, poor effectiveness, and limited availability (Ameny, 2021; Young, et al., 2014). Ultimately, Black African participants rarely identified themselves as someone who would need to use PrEP. For Black MSM this may be even more complex, with individuals having to navigate the intersection of their sexual, ethnic, cultural, and religious identities (Witzel, et al., 2019).

In the one study that explored PrEP within the context of PWID, willingness was also found to be high. This was despite low awareness of PrEP (Smith et al., 2021). Although participants were unlikely to know of PrEP, when they were informed as part of the study, they showed enthusiasm. Regardless, both service users and providers highlighted barriers to PrEP implementation within the wider PWID population. Barriers included individual level factors, such as perception of personal HIV risk and self-worth and systematic level issues, such as stigma and being an underserved population (Smith et al., 2021).

Perceptions and attitudes

Perception of risk and PrEP use

A clear link between PrEP and perceptions of risk is present within the literature sources, manifesting in several ways. Many sources discuss the perception of personal risk of HIV acquisition being a key reason for PrEP uptake or adherence (Arnold-Forster et al., 2022; Bull et al., 2017; Caoimhe et al., 2024; Flowers et al., 2022; Gillespie et al., 2022; Goedel et al., 2019; Haggipavlou & Hamshaw, 2023; Lorenc et al., 2021; Maxwell et al.,

2022; Nakasone et al., 2020; Papparini et al., 2018; Witzel et al., 2019; Young et al., 2014; Young et al., 2015). The perception of the risk of HIV transmission appears to be related to individuals' beliefs about PrEP candidacy.

Within the MSM population, perceived personal risk of HIV was a dominant reason to take PrEP or not. Those who did not think they were at risk of acquiring HIV reported they were unlikely to take PrEP (Gillespie et al., 2022; Goedel et al., 2019; Haggipavlou & Hamshaw, 2023; Lorenc et al., 2021; Young et al., 2013); in contrast individuals who were concerned they were at risk reported it as a main motivator for taking PrEP (Harrington et al., 2020).

There were a number of factors that influenced GBMSM individuals' perception of risk, such as condom use, specific social scenarios, sexual risk-taking, engaging in chemsex, or belonging to a specific group that is labelled as high risk for acquiring HIV (e.g. being gay or from a particular ethnic group) (Lorenc et al., 2021; Frankis, et al. 2016b; Harrington, et al., 2020; Maxwell et al., 2022).

PrEP Morality and Stigma

Within the literature, moralising narratives were apparent regarding the role of PrEP in sexual behaviour. In some cases, it appeared that the public perceived PrEP negatively, as they believed it potentially encouraged sexual risk-taking. However, some papers reported more complicated perceptions of PrEP and its impact on the MSM community. For example, some believed that PrEP encouraged men to abandon other preventative methods, such as condoms, resulting in a potential rise in STIs (Madhani & Finlay, 2022). Young et al. (2014) found that some men saw STIs as unavoidable for MSM due to their high prevalence and believe "STIs come with the territory" of gay sex.

Williamson et al. (2019) found inconsistencies in how the gay community perceived those using PrEP. Some men suggested that PrEP was more appropriate in specific contexts (such as serodifferent couples in long-term relationships or young gay men "to allow them a period of not worrying about HIV") but also offered a more 'moralising' narrative that 'certain sorts of gay men' would be using PrEP who had a low likelihood of adherence. Arnold-Forster et al. (2022) found there was little concern around stigma or negative perceptions of PrEP users in MSM, but one participant did share that he wouldn't use PrEP because they feared other men would perceive him as promiscuous and said he would have this perception of PrEP users himself. Jaspal and Daramilas (2016) reported a significant difference in participants' HIV status and their perceptions of PrEP. They found that people not living with HIV generally perceived PrEP as a risk-laden solution for "high-risk" individuals. In contrast, people living with HIV regarded it as potentially enhancing interpersonal relations between serodifferent partners.

Young et al.'s (2021) paper exploring PrEP in the UK newsprint demonstrated that public perceptions of PrEP showed a similar paradoxical view. It was suggested that newspapers described PrEP as a significant tool with which to combat the HIV epidemic, but only when used correctly. Articles queried the capacity of individuals to use PrEP appropriately, drawing on well-rehearsed stereotypes to suggest that irresponsible sexual practice would threaten the effectiveness of the intervention. This suggests a locating of responsibility in the individual.

Jaspal and Nerlich (2016) echo this narrative, suggesting two competing social representations of PrEP in the UK press. In the first instance, PrEP as a vehicle for hope in the 'battle' against HIV, but simultaneously has the potential to "do more harm than good" by leading to increased sexual risk-taking in certain groups. Mowlabocus (2020) also discussed PrEP within Britain, highlighting a changing narrative between 2012 and 2016 whereby PrEP

moved from being a 'wonder drug' that benefited the health of the general population to a 'promiscuity pill' that threatened the lives of the most vulnerable.

As discussed previously, PrEP had low awareness in Black African communities, with research suggesting that this may be due to stigma and perceptions of PrEP candidacy (Young & Valiotis, 2020). Di Giuseppe et al., 2019, reported that participants felt that HIV was not a risk for African communities in the UK but rather a reflection of the epidemic in Africa, divorced from the British context. Similarly, Black women were also found to struggle to incorporate PrEP into their safer sex routines because they did not see themselves as at risk of HIV and did not understand how PrEP could address their specific safer sex needs (Nakasone et al., 2020). Service providers also recognised cultural differences in PrEP candidacy. One research paper exploring service providers working with gay and bisexual men and African communities found that participants were faced with implicit whiteness and gendered images of PrEP users (Young & Boydell, 2023).

Black MSM shared a complex picture suggesting harmful beliefs and stereotypes of Black men intersected with those of PrEP users, limiting feelings of PrEP candidacy and, therefore, PrEP acceptability. Participants shared that taking PrEP meant taking on the additional stigmatising label of "promiscuous" in combination with already established racialised stereotypes of hypersexuality (Witzel et al., 2019).

Experiences of PrEP (Psychosocial impact)

Several papers explored the lived experiences of those taking PrEP (n=14, 29.8%); however, this sometimes included only speaking with one regular PrEP user (Williamson et al., 2019), only describing the impact of PrEP on sexual behaviours (Lorenc et al., 2021; Maine, 2019; Hillis et al., 2021), only exploring the practicalities of PrEP adherence (Arnold-Forster et al., 2022), or only describing the experiences of accessing PrEP online privately (Paparini et al., 2018).

Despite this, there was collective evidence that suggested PrEP might have psychosocial benefits beyond the medical implications of reduced risk of HIV acquisition. Harrington et al., (2020) suggested all MSM participants reported having suffered from HIV related anxiety, but for most this was substantially or completely reduced after using PrEP. Several papers echoed this message, reporting that participants found PrEP to have a positive impact on intimacy or pleasure during sex due to the reduced anxiety (Nutland, 2016; McCormack, 2021; Weil et al., 2024; Harrington et al., 2020). This was, in part, due to feeling able to engage in activities which may have been considered too high risk previously (Nutland, 2016; Harrington et al., 2020).

HIV anxiety and HIV-related anxiety as concept terms were used interchangeably between papers but were experienced by nearly all participants who have taken PrEP at some point, and also those who had not taken PrEP but were at risk for HIV acquisition through injecting drug use (Smith, 2021). When discussing how this changed following PrEP use, words like ‘peace of mind’, ‘reassurance’, ‘safety’ and ‘protection’ were regularly used (Hayes, 2023; McCormack, 2021; Nutland 2016). It was theorised this reduction in HIV anxiety might be a result of challenged internalised stigmatised beliefs about gay sex and disease or weaken the association between gay sex and HIV (McCormack, 2021). Only GBMSM were included in these samples, so it is not clear if this is representative of the whole population of people who may consider or be offered PrEP.

Discussion

This review's purpose was to provide an overview of the extent and type of research undertaken on knowledge, attitudes, and perceptions towards PrEP in the UK to date. 47 papers were identified that matched the inclusion criteria and were published since 2012. This area has seen dramatic growth, with over 70% of papers being published after 2019.

Papers largely focussed on PrEP awareness, barriers and facilitators of PrEP uptake or adherence to PrEP, which is consistent with several global reviews mapping the PrEP literature (Kamitani et al., 2019; Zhou & Assanangkornchai, 2022). Analysis revealed a diverse methodological landscape despite the limited populations studied. Predominantly, research focused on GBMSM, often within clinical trials, but evidence from other minority groups is beginning to emerge. Notably, some studies are beginning to explore PrEP within Black African or Black Caribbean populations, but limited attention continues to be dedicated to women-specific perspectives. The most recent UK statistics suggest that GBMSM still represent the group in which most new diagnoses are made each year. However, they are also the group that has demonstrated the highest-ever uptake of HIV testing, with new diagnoses continuing to fall year on year. Conversely, HIV diagnoses have risen in heterosexual adults, particularly in women and ethnic minority groups (UK Health Security Agency, 2023). This suggests that the literature does not represent the current HIV landscape in the UK.

Generally, high levels of awareness were seen in MSM populations, with evidence suggesting that over time awareness and knowledge have increased (Aghaizu, et al., 2013, Goedel, et al., 2019; Nutland 2016). This is perhaps linked to PrEP becoming licensed and more freely available in the UK.

Importantly, populations who are similarly disproportionately affected by HIV, such as Black African populations, demonstrated low awareness, but the reasons behind this were complex and varied. Studies in heterosexual Black African communities suggested barriers to PrEP awareness involved HIV stigma and inaccurate perceptions of PrEP candidacy (Di Giuseppe et al., 2019; Young & Valiotis, 2020), whereas studies with Black MSM individuals suggested harmful beliefs and stereotypes of Black men intersected with those of PrEP users (Witzel et al., 2019). This suggests that increasing awareness in these communities requires addressing culturally specific biases in the perception of HIV risk as well as tackling societal-

level messages of explicit and implicit whiteness and gendered images of PrEP users (Young & Boydell, 2023).

Ultimately, the results from this review suggest that there is a wide disparity in knowledge among potential PrEP users in the UK. Groups with low awareness were often also the groups least represented in PrEP media and awareness campaigns. Participants did not see themselves as someone who would benefit from PrEP, and therefore did not seek out information, resulting in stereotypes regarding PrEP being only for GBMSM being perpetuated. Additional efforts are needed to raise awareness about the benefits of PrEP and ensure that campaigns are tailored and informed by the specific needs of different populations. Different groups require different methods to address barriers to awareness and knowledge of PrEP that utilise macrosocial, mesosocial, and microsocial factors (Flowers et al., 2022). The UK Department of Health and Social Care (2024) recently published its roadmap for meeting the PrEP needs of those at significant risk of HIV and similarly suggested that any national or local campaigns promoting PrEP awareness should be co-designed with those using PrEP and evaluated by target populations.

One important element that was consistent among groups was the importance of their self-perceived HIV risk. Perceived HIV risk, or lack thereof, was participants' main reason for taking or not taking PrEP (Gillespie et al., 2022; Goedel et al., 2019; Haggipavlou & Hamshaw, 2023; Lorenc et al., 2021; Young et al., 2013). Participants described using PrEP within a “jigsaw of risk reduction strategies” in their attempt to reduce their HIV risk and, at times, allowed participants to feel able to engage in condomless anal sex due to the reduced fear of HIV transmission (Lorenc et al., 2021). Perception of risk was often weighed up against the perception of potential side effects from PrEP. This weighing up of pros and cons was considered an important factor in acceptability (Ameny, 2021; Young et al., 2015) and willingness (Arnold-Forster et al., 2022; Goedel et al., 2019; Young et al., 2014).

Stigma continues to persist, evident at all levels, from early to recent studies; particularly in public narratives of PrEP within the British Press. The overarching story of PrEP, the transition from a mechanism of hope in the “battle against HIV” to a driver of promiscuity and sexual risk-taking, was shaped by political motives and corresponding activist retaliation (Jaspal & Nerlich, 2016). This representation echoes the narrative that surrounded the contraceptive pill in the 1960s and was at times used as a familiar anchor to compare it against (Jaspal & Nerlich, 2016; Pawson & Grov, 2018). It seems that PrEP, like the pill, was ultimately framed within a moralising view as a medical advance that has the potential to encourage sexual promiscuity (Hildebrandt et al., 2020).

Furthermore, the evidence was clear that for GBMSM, PrEP may have psychosocial impacts beyond the health benefits of reduced risk of HIV acquisition. It may be that this decline in HIV anxiety could refute internalised notions about homosexuality and disease or lessen the historical relationship between the two that was established during the 1980s HIV/AIDS epidemic.

Drawing the findings together, it seems that opinions on offering HIV prevention within the context of a pill that is publicly funded and easily available are varied. Lack of representation and poor awareness of PrEP candidacy impacted the acceptability of PrEP in several groups who experience inequitable PrEP uptake. Underrepresentation in research and media campaigns continues to perpetuate bias towards GBMSM as being the main proponents of PrEP. There is some progress towards increasing research focussed on Black African communities. Nonetheless, this should continue until more equitable access is achieved, and success will depend on multilayer approaches that address societal and cultural barriers. Large gaps continue to persist regarding research and policy for women and PWID. Stigma towards PrEP was variable but was often associated with moralising views of sex and promiscuity.

Clinical Implications

This is a rapidly growing field made up of diverse and multidisciplinary research. The findings highlight how an understanding of multiple interrelated factors might impact successful PrEP implementation and uptake. Despite this, most research included in this review focused on individual-level elements of PrEP uptake or adherence rather than on a “whole picture” approach. This is especially important for interventions targeted at raising PrEP awareness in underrepresented groups. Results from this study reaffirmed the wide disparity in PrEP knowledge in the UK, and interventions hoping to address this will need to consider the varying societal and cultural perspectives amongst different populations.

Similarly, results from this review highlighted the role of self-perceived HIV risk in PrEP uptake and acceptability. While some research has begun to explore this concept at an individual level, for this to be fully understood this will need to be contextualised with a sufficient understanding of social, cultural and societal norms. For example, unhelpful societal narratives of HIV (and by association, PrEP) being largely a concern for GBMSM combined with poor representation in PrEP media, may prevent women from recognising their own PrEP candidacy. Interventions should focus on recognising and tackling these multilayer barriers to effectively address unequal PrEP uptake.

Furthermore, HIV prevention is typically understood within a biomedical model of health, and clinical psychologists may be best placed to offer insight into different approaches to conceptualising the multilayer factors impacting PrEP uptake. Self-determination theory (SDT) might be one helpful way of contextualising why self-perceived HIV risk was such an important factor in PrEP uptake and adherence. SDT is a theoretical model of human behaviour and personality development, focusing on social-contextual factors and how these interact with individuals' motivation and satisfaction (Ryan, 2017; p3).

SDT suggests health behaviours can be more successfully achieved by social environments supporting three basic human psychological needs: autonomy, competence, and relatedness (Ryan et al., 2008). Healthcare environments that promote autonomy may support individuals to take control of their sexual health on their own terms. It is clear that some groups, such as Black African populations, often do not see PrEP as aligning with their personal safer sex narratives, indicating a lack of perceived autonomy in making the choice to use PrEP.

Moreover, the ecological systems theory (Bronfenbrenner, 1979) highlights the role of various environmental systems on an individual's development. In this case, the ecological systems theory may be helpful as it offers a transdisciplinary approach that goes beyond the individual-level factors that might impact PrEP uptake and adherence. For example, results from the present study suggest that awareness of PrEP in the UK is impacted by both the microsystem and mesosystem. This includes peer networks and community interactions. GBMSM showed variable levels of awareness, with peer discussions and digital media being common sources of information.

Further research

Over half of the studies (66%) included in this review reported mostly or exclusively focussing on MSM or GBMSM, and reports from local authorities would suggest this group has the highest usage of PrEP (National Aids Trust, 2022; p.4). Therefore, it is clear those populations who are struggling most to access PrEP through services (such as Black African populations, women or PWID) are also the most underrepresented in the literature. Further research should focus on collecting more evidence in these underrepresented groups.

Additionally, given the understanding that further research and interventions will need to seek to address structural, societal and cultural barriers to improve PrEP uptake, there may be a role for research to explore which approaches work best for specific groups. For

example, systematic review into barriers and facilitators of PrEP awareness in ethnicity and gender minorities in the UK that utilises a theoretical approach to situate findings within the individual, structural, societal and provider norms of the population (for example, Bronfenbrenner's systems theory, Bronfenbrenner, 1979; Socioecological model, D'Angelo et al., 2021; or the PrEP Care Continuum, Nunn et al., 2017; Parsons et al., 2017; Burns et al., 2023).

Finally, research should also further explore the psychosocial impact of PrEP. Papers included in this review exploring the psychosocial impact of PrEP were often situated within clinical trials or exclusively used GBMSM. These potential benefits may offer new insights into motivators for PrEP use, but due to limited research, it is unknown if this impact differs between groups or within a real-world setting.

Strengths and Limitations

One limitation of this research is that the literature included was not reviewed with respect to the risk of bias. While this is a common limitation for scoping review methodologies more generally, there is ongoing deliberation regarding whether this constitutes best practice. Arksey and O'Malley (2005) have acknowledged although quality assessment is not critical to the scoping review methodology, the omission could be considered a limitation (Pham et al., 2014).

In this case no formal quality assessment was conducted. This resulted in a limited ability to make definitive recommendations and conclusions for policy and practice. Furthermore, it would be inappropriate for this review to suggest necessary methodological research be completed as this has not been explicitly measured. This review is, therefore, limited to suggestions of strengths in the current evidence body and unexplored areas that would benefit from more research. (Brien et al., 2010). [Additionally, this study was limited to](#)

one reviewer during the final screening stage. While three researchers did complete a calibration exercise to establish consistency when screening at the title and abstract stage, this was not done during the full-text read stage. This increases the potential for inconsistent or biased application of inclusion and exclusion criteria. Automation tools that tracked the review process, such as Rayyan (Ouzzani et al., 2016) somewhat mitigated this.

However, any research in this area should also focus on critically evaluating the research quality of included studies if they are to provide the basis for changes to policy and practice (Grant & Booth, 2009).

Despite this, a strength of this review was the broad scoping approach which allowed a varied range of research designs and outcomes to be included. This was especially important given the ever-changing and diverse nature of the topic area.

Conclusion

This scoping review found several research gaps within the UK based research on knowledge, attitudes and perceptions of PrEP, despite the drastic increase in publications in recent years. It is clear that certain populations continue to be understudied, most noticeably Black African populations, PWID and women. Therefore, it is important that continued attention be paid to better understanding the cultural narratives that may present a barrier to beliefs of PrEP candidacy, as well as media narratives that minimise the voices of these groups when designing health promotion material.

Multiple opposing attitudes towards PrEP are present in the UK, with political, social and cultural norms adding further complexity. In this regard UK specific contexts should continue to be a defining feature of ongoing research. Stigma continues to permeate at all levels, informing individuals' knowledge, attitudes, and perceptions of PrEP. This has wide-reaching implications for health intervention programs aimed at introducing PrEP to

underserved populations or increasing the use of PrEP in groups who are at increased risk of acquiring HIV.

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Tables and Figures

Table 1: Extraction Table for Included Papers

Type of evidence	Author/s	Year	Location Research Conducted	Study Population (sample size)	Aims/purpose (code)	Method [analysis]
Journal Article	Di Giuseppe et al.	2019	UK - East London and Hertfordshire	Black African Men and Women (n= 247 quantitative sample, n=18 qualitative sample)	Barriers and facilitators to PrEP uptake. Barriers and facilitators to PrEP adherence. (within context of Black African communities)	Mixed Methods (Cross-sectional Survey and Focus Groups) [Textual analysis]
Journal Article	Young et al.	2014	UK - Scotland	GBMSM (n=42), Men and Women from Migrant African Communities (n=25)	Barriers to PrEP uptake. (within context of communities most affected by HIV)	Mixed Qualitative Methods (Focus Groups and Semi-Structured Interviews) [Thematic analysis]
Journal Article	Frankis et al.	2016a	UK - Scotland	MSM (n=67)	PrEP awareness. PrEP acceptability.	Mixed Methods (Quantitative Survey and Semi-Structured Interviews) [Thematic analysis]
Journal Article	Lorenc et al.	2021	UK - Bristol	MSM, Transpersons who have sex with men (n=617)	PrEP awareness. PrEP acceptability. PrEP accessibility.	Mixed (Survey and Semi-Structured Interviews) [Thematic analysis]
Journal Article	Arnold-Forster et al.	2022	UK - London, Sheffield, Manchester or Brighton	MSM and Transwomen (PROUD) (n=41)	Barriers and facilitators to PrEP adherence. Experiences of PrEP.	Qualitative (Semi-Structured Interviews) [Framework analysis]
Journal Article	Hillis et al.	2021	UK - Northern and Central England	MSM (n=20) and Service Providers (n=25)	Service provision of PrEP. PrEP accessibility. Perceptions and attitudes towards PrEP.	Qualitative (Semi-Structured Interviews) [Interpretive Phenomenological Analysis]
Journal Article	Hayes et al.	2023	UK - London, Sheffield, Manchester and Brighton	GBMSM (PROUD) (n=41)	Psychosocial impact of PrEP. Perceptions and attitudes towards PrEP.	Qualitative (Semi-Structured Interviews) [Thematic analysis]

					Experiences of PrEP.	
Journal Article	Harrington et al.	2020	UK - London	MSM (n=13)	Barriers and facilitators to PrEP uptake. Barriers and facilitators to PrEP adherence. Perceptions and attitudes towards PrEP.	Qualitative (Semi-Structured Interviews) [Thematic analysis]
Journal Article	Smith et al.	2021	UK - Glasgow	Service Providers (n=11) and PWID (person who inject drugs) (n=21)	Service provision of PrEP. PrEP accessibility. (within the context of PWID) Perceptions and attitudes towards PrEP.	Qualitative (Semi-Structured Interviews) [Thematic analysis]
Journal Article	Young & Valiotis	2020	UK - Scotland	Service Providers working with gay and bisexual men and African communities (n=32)	Service provision of PrEP. PrEP accessibility.	Mixed Qualitative Methods (Focus Groups and Semi-Structured Interviews) [Systematic data analysis]
Journal Article	Madhani & Finlay	2022	UK	MSM (n=13)	Barriers and facilitators to PrEP uptake.	Qualitative (Semi-Structured Interviews) [Thematic analysis]
Journal Article	Jaspal & Daramilas	2016	UK - East Midlands & West London	MSM (n=20)	Perceptions and attitudes towards PrEP.	Qualitative (Semi-Structured Interviews) [Thematic analysis]
Journal Article	Williamson et al.	2019	UK - West Midlands/Leicester	MSM (n=18)	Perceptions and attitudes towards PrEP. Experiences of PrEP.	Qualitative (Focus Group) [Thematic analysis]
Journal Article	Young et al.	2021	UK	UK Newspapers (16 newspapers)	Societal attitudes towards PrEP (press).	Qualitative Content Analysis [Thematic analysis]
Journal Article	Haggipavlou & Hamshaw	2023	UK	Young MSM (n=10)	Barriers and facilitators to PrEP uptake.	Qualitative (Semi-Structured Interviews) [Thematic analysis]
Thesis	Nutland	2016	UK - London	MSM (including Transmen)	PrEP awareness.	Qualitative (Semi-Structured Interviews)

				(n=20)	PrEP acceptability. Experiences of PrEP.	[Thematic analysis]
Journal Article	Jaspal & Nerlich	2016	UK	UK Newspapers (59 articles)	Societal attitudes towards PrEP (press).	Qualitative Content Analysis [Thematic analysis]
Journal Article	Gillespie et al.	2022	UK - Wales	MSM (n=21)	Barriers and facilitators to PrEP uptake. Barriers and facilitators to PrEP adherence. Experiences of PrEP.	Qualitative (Semi-Structured Interviews) [Thematic analysis]
Journal Article	Khan et al.	2023	UK	HIV experts (n=14)	Societal attitudes towards PrEP.	Qualitative (Semi-Structured Interviews) [Thematic analysis]
Journal Article	Maine	2019	UK	GBMSM (n=20)	Societal attitudes towards PrEP.	Qualitative (Semi-Structured Interviews) [Narrative analysis]
Journal Article	Mowlabocus	2020	UK (press)	UK Newspapers (125 articles)	Societal attitudes towards PrEP (press).	Qualitative Content Analysis [Critical Discourse Analysis]
Journal Article	Flowers et al.	2022	UK - Scotland	Clinic attendees, Service Providers, Community Based Organisation (CBO) Service Users, CBO Staff (n=117)	Barriers and facilitators to PrEP awareness. PrEP accessibility.	Mixed Qualitative Methods (Focus Groups and Semi-Structured Interviews) [Thematic analysis]
Journal Article	Nakasone et al.	2020	UK - London or Glasgow	Black African/Black Caribbean Women (n=32)	Barriers and facilitators to PrEP awareness. Barriers and facilitators to PrEP uptake. (within the context of Black African/Black Caribbean Women) Service provision of PrEP.	Qualitative (Semi-Structured Interviews) [Thematic analysis]

Journal Article	Witzel et al.	2019	UK	Black MSM (n=25)	Barriers and facilitators to PrEP uptake. (within the context of Black MSM)	Qualitative (Semi-Structured Interviews) [Thematic analysis]
Journal Article	Young et al.	2015	UK - Scotland	GBMSM, Men and Women from Migrant African Communities (n=34)	PrEP accessibility.	Mixed Qualitative Methods (Focus Groups and Semi-Structured Interviews) [Thematic analysis]
Thesis	Ameny	2021	UK - London	Heterosexual Black African Men (n=8)	PrEP awareness. Perceptions and attitudes towards PrEP. (within the context of Heterosexual Black African Men)	Qualitative (Semi-Structured Interviews) [Thematic analysis]
Journal Article	Paparini et al.	2018	UK - London	MSM (n=20)	Experiences of PrEP. Service provision of PrEP.	Focus Group [Thematic analysis]
Thesis	McCormack	2021	UK - London	GBMSM (n=10)	Experiences of PrEP. Perceptions and attitudes towards PrEP.	Qualitative (Semi-Structured Interviews) [Thematic analysis]
Journal Article	Young & Boydell	2023	UK - Scotland	Service Providers working with gay and bisexual men and African communities (n=32)	Service provision of PrEP. Barriers and facilitators to PrEP uptake.	Mixed Qualitative Methods (Focus Groups and Semi-Structured Interviews) [undefined qualitative analysis]
Journal Article	Maxwell et al.	2022	UK	GBMSM (n=19)	Barriers and facilitators to PrEP uptake. Barriers and facilitators to PrEP adherence. Experiences of PrEP.	Qualitative (Semi-Structured Interviews) Mixed Qualitative Methods (Focus Groups and Semi-Structured Interviews) [Thematic analysis]
Electronic article	Weil et al.	2024	UK - London	Young MSM (n=18)	Service provision of PrEP. Experiences of PrEP.	Qualitative (Focus Group) [not disclosed]

					Perceptions and attitudes towards PrEP.	
Journal Article	Desai et al.	2016	UK	Service Providers (n=328)	PrEP awareness. Perceptions and attitudes towards PrEP. (within the context of service providers)	Cross-sectional study [Statistical]
Journal Article	Jaspal et al.	2019	UK - Leicester	MSM (n=191)	PrEP acceptability.	Cross-sectional study [Statistical]
Journal Article	Bull et al.	2018	UK - London	MSM (n=839)	PrEP awareness. Perceptions and attitudes towards PrEP.	Cross-sectional study [Statistical]
Journal Article	Gilson et al.	2018	UK	MSM (n=377)	Perceptions and attitudes towards PrEP. PrEP awareness.	Cross-sectional study [Statistical]
Journal Article	Young et al.	2013	UK - Scotland	GBMSM (n=1393)	PrEP awareness. PrEP acceptability. Perceptions and attitudes towards PrEP.	Cross-sectional study [Statistical]
Journal Article	Jolley & Jaspal	2020	UK	MSM (n=244)	PrEP acceptability. Perceptions and attitudes towards PrEP.	Cross-sectional study [Statistical]
Journal Article	Aghaizu et al.	2013	UK - London	MSM (n=842)	Perceptions and attitudes towards PrEP. PrEP awareness.	Cross-sectional study [Statistical]
Journal Article	Frankis et al.	2016b	UK - Scotland, Wales, Northern Ireland and The Republic of Ireland (Celtic nations)	MSM (n=2280)	Perceptions and attitudes towards PrEP. PrEP awareness. PrEP acceptability. Barriers and facilitators of PrEP uptake.	Cross-sectional study [Statistical]
Journal Article	Taylor et al.	2024	UK - London	GBMSM (n=67)	Barriers and facilitators of PrEP adherence. Experiences of PrEP.	Cross-sectional study [Statistical]

Journal Article	Ogaz et al.	2022	UK - London	MSM (n=1408)	Perceptions and attitudes towards PrEP. PrEP awareness. PrEP acceptability. Barriers and facilitators of PrEP uptake.	Survey and HIV testing [Statistical]
Journal Article	Hildebrandt et al.	2019	UK - Britain	General Population (n=738)	Societal attitudes towards PrEP.	Cross-sectional study [Statistical]
Journal Article	Goedel et al.	2019	UK - London	MSM (n=179)	PrEP awareness. PrEP acceptability. Perceptions and attitudes towards PrEP.	Cross-sectional study [Statistical]
Journal Article	Jaspal et al.	2020	UK	Undergraduate Students (n=222)	Societal attitudes towards PrEP.	Experimental 2x2x2 [Statistical]
Journal Article	Hanum et al.	2020	UK - London or Brighton	MSM (AURAH2) (n=1162)	PrEP awareness. Barriers and facilitators of PrEP uptake. Service provision of PrEP.	Prospective Cohort Study [Statistical]
Journal Article	Hildebrandt et al.	2020	UK - England	General Population (n=738)	Societal attitudes towards PrEP.	Cross-sectional study [Statistical]
Journal Article	Caoimhe et al.	2024	UK	Clinic attendees (Sexual Health London - SHL) (n=426,149)	Barriers and facilitators of PrEP uptake. PrEP awareness. Perceptions and attitudes towards PrEP.	Cross-sectional study [Statistical]

Table 2: Sample of free-text search terms applied to database

Sample of Search Strategy				
	Knowledge, Perceptions, Attitudes	United Kingdom	PrEP	Additional limiters
PsychInfo Subject Headings	(MM “Attitudes” OR MM “Public Opinion” OR DE “Stigma”) OR (DE “Public Opinion”) OR willingness to use OR willingness to take OR utilization OR utilisation OR acceptance OR acceptability OR adoption OR uptake OR awareness OR adherence OR knowledge OR attitude OR perce* OR feasibility OR patient attitudes OR public opinion OR social attitudes OR barrie* OR facilitato*)	PL (United Kingdom OR UK OR England OR English OR Britain OR wales OR Scotland OR “northern Ireland”)	(DE “Pre-Exposure Prophylaxis”) OR Tenofovir+ OR “pre-exposure prophylaxis” OR “PrEP” OR “HIV pre-exposure prophylaxis” OR “HIV preexposure prophylaxis” OR “pre-exposure antiretroviral prophylaxis” OR “preexposure antiretroviral prophylaxis” OR “pre-exposure chemoprophylaxis” OR “preexposure chemoprophylaxis” OR “anti-HIV prophylaxis” OR Truvada OR tenofovir OR emtricitabine OR tenofovir disoproxil fumarate	Publication Year: 2012: 2024

Figure 1: PRISMA

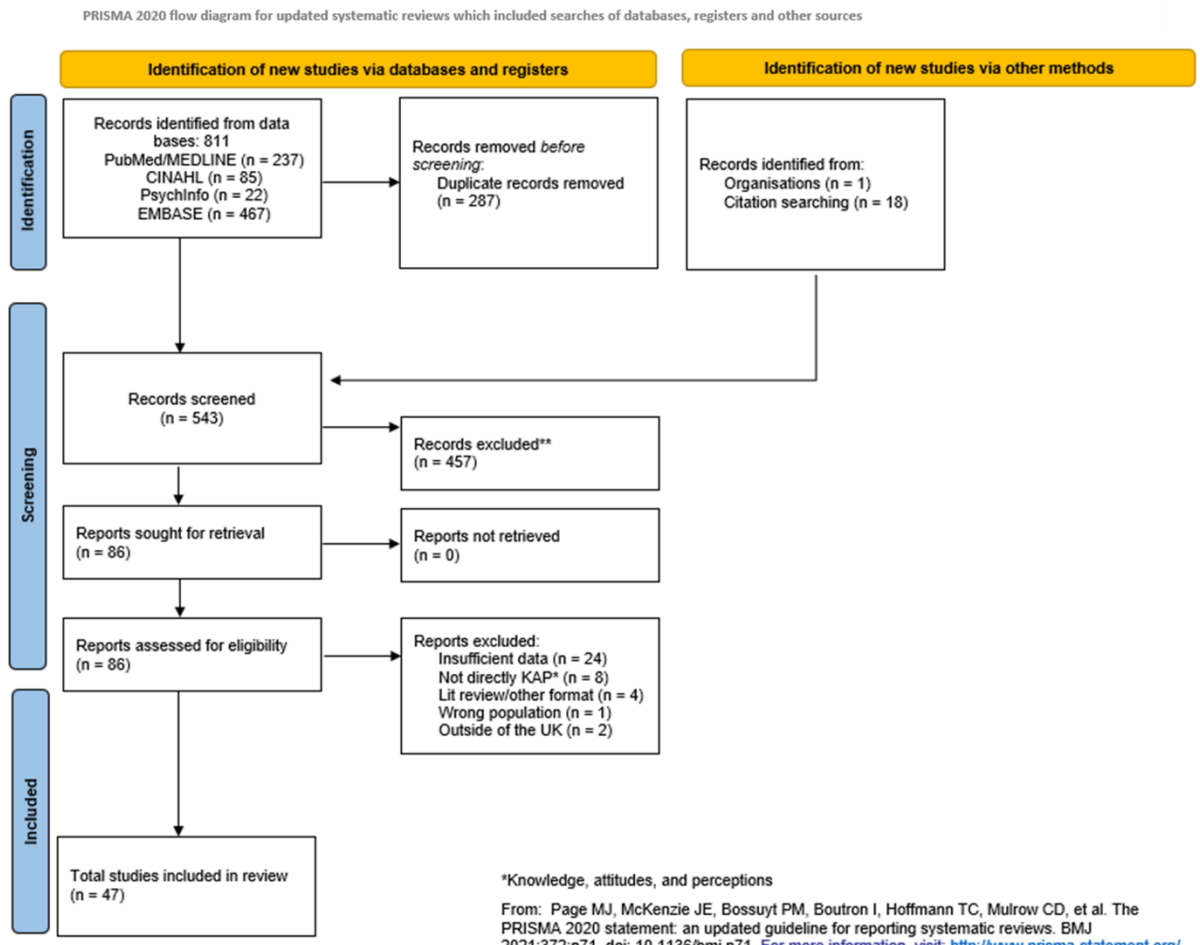


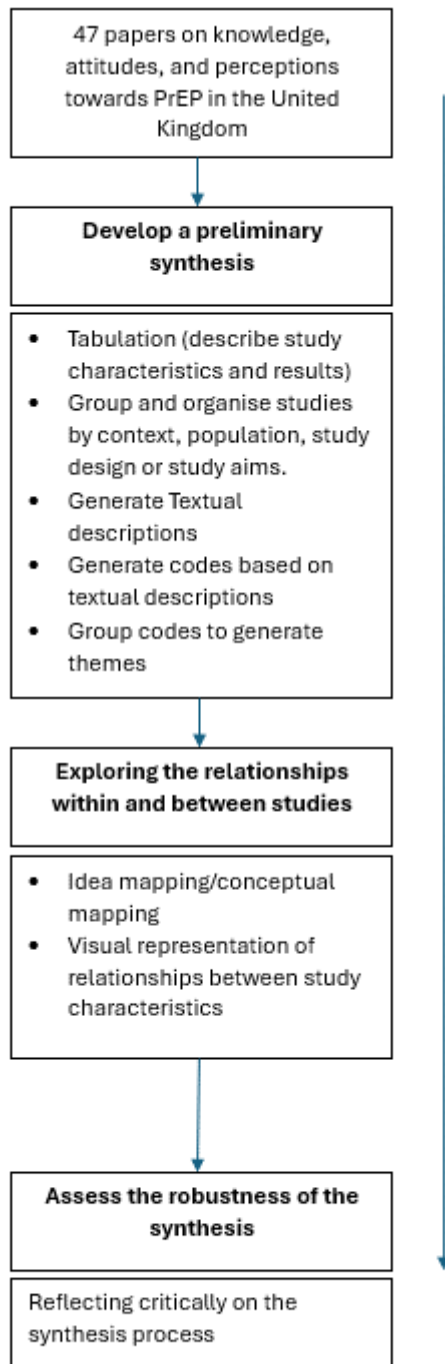
Figure 2: Diagram of Synthesis Process

Figure 3: Year of publication

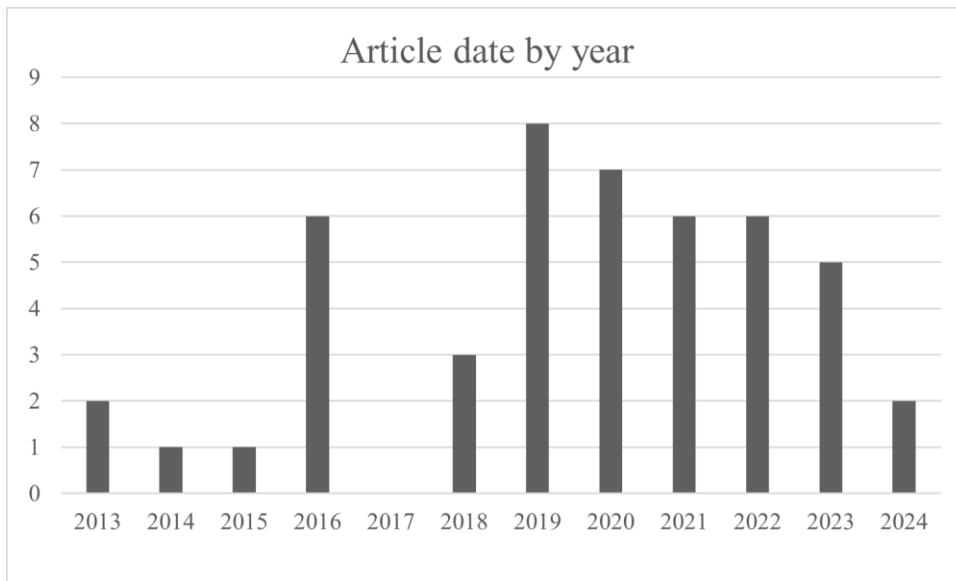
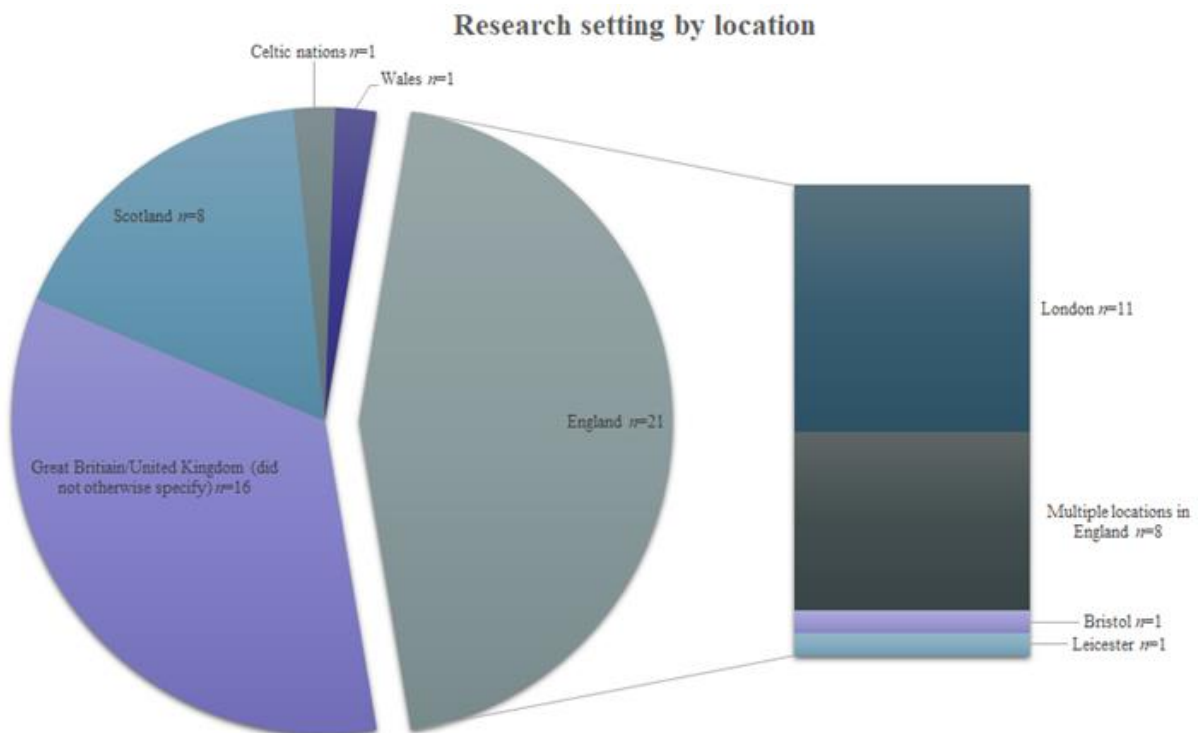


Figure 4: Research setting by location (pie chart)



Appendices

Appendix 1-A - Guidance for journal submission/ Manual Submission Guidelines

[🏠 AIDS Care](#)

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Aims and scope

AIDS Care is an international peer-reviewed journal publishing multi-disciplinary research related to HIV/AIDS including the planning of services, prevention and the social and psychological aspects of care and treatment.

HIV and AIDS infection affects many echelons of society ranging from individuals, couples and families through to institutions and communities. The condition clusters and overlaps with several co-infections, individual and societal risks demanding a broad base for understanding and comprehensive reaction. *AIDS Care* aims to publish work emanating from many centers and in so doing to address the global impact of HIV/AIDS.

The journal covers topics that originate from multiple disciplines, including psychology, sociology, epidemiology, social work and anthropology, social aspects of medicine, nursing, education, health education, law, administration and counselling.

AIDS Care accepts original research articles, reviews and short reports as well as Methodological papers for our online-only Methodological Issue.

The journal operates a double-anonymized peer review policy. Authors can [choose to publish gold open access](#) in this journal.

Read the [Instructions for Authors](#) for information on how to submit your article.

Preparing Your Paper

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Word Limits

Please include a word count for your paper.

The maximum word count for the journal is 7000 words, excluding tables, figures, references, and endnotes.

Style Guidelines

Please refer to these [quick style guidelines](#) when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript.

Please use double quotation marks, except where "a quotation is 'within' a quotation". Please note that long quotations should be indented without quotation marks.

Font

Use Times New Roman font in size 12 with double-line spacing.

Margins

Margins should be at least 2.5cm (1 inch).

Title

Use bold for your article title, with an initial capital letter for any proper nouns.

Abstract

Indicate the abstract paragraph with a heading or by reducing the font size.

The instructions for authors for each journal will give specific guidelines on what's required here, including whether it should be a structured abstract or graphical abstract, and any word limits.

If you need further guidance, [learn more on how to write an effective abstract and title](#). 

What is an abstract in a research paper?

This is your opportunity to 'pitch' your article to the journal editors, and later, its readers. Your abstract should focus on what your research is about, what methods have been used, and what you found out.

Keywords

Keywords help readers find your article, so are vital for discoverability. If the journal instructions for authors don't give a set number of keywords to provide, aim for five or six.

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This will show you the different levels of the heading section in your article:

- 1 First-level headings (e.g. Introduction, Conclusion) should be in bold, with an initial capital letter for any proper nouns.
- 2 Second-level headings should be in bold italics, with an initial capital letter for any proper nouns.
- 3 Third-level headings should be in italics, with an initial capital letter for any proper nouns.
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- Asian languages (such as Sanskrit, Korean, Chinese, or Japanese): choose Arial Unicode font from the dropdown menu in the "insert symbol" window and insert the character you require.
- Transliterated Arabic: choose either Times New Roman or Arial Unicode (unless the instructions for authors specify a particular font). For ayns and hamzas, choose Arial Unicode font from the dropdown menu in the "insert symbol" window. Type the Unicode hexes directly into the "Character code" box, using 02BF for ayn, and 02BE for hamza.

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This reference guide details methods for citing and formatting reference entries in accordance with principles established by the *Publication Manual of the American Psychological Association, Seventh Edition* (2020). For more information about APA style, visit <https://apastyle.apa.org/> and <https://apastyle.apa.org/blog>

If you have access to the software, a corresponding EndNote output style can be downloaded from <http://endnote.com/downloads/style/tf-standard-apa> by searching for the style named TF-Standard APA.

Version 3.1

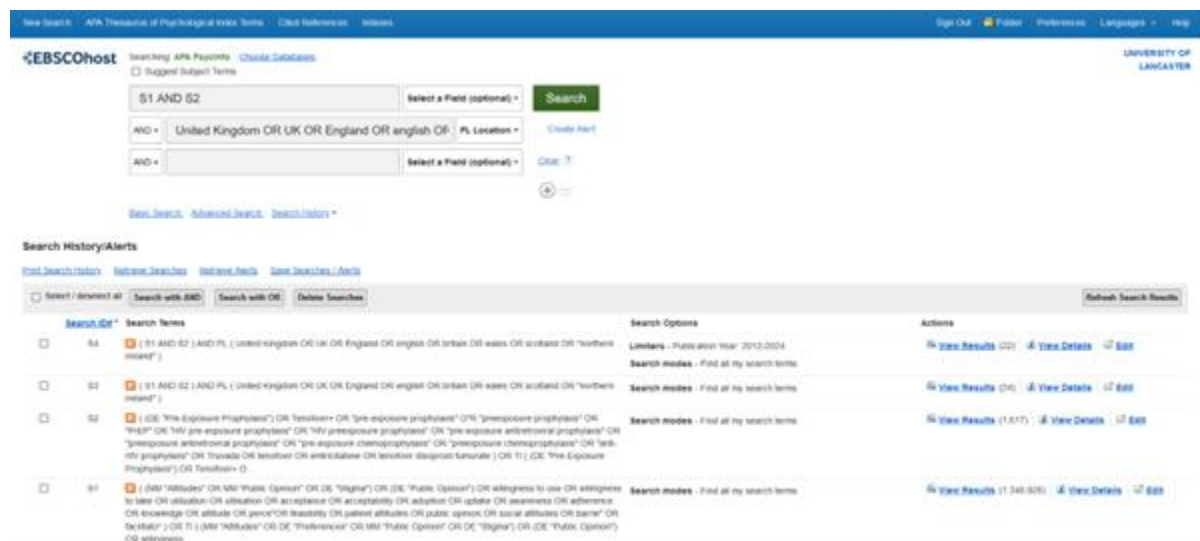
Date of original release: 5 December 2014

Date of current version's release: 28 September 2021

Updated to include new models for

1. FORCE11-compliant software reference entry (with version number)
2. FORCE11-compliant software reference entry (without version number)

Appendix 1-B - Audit for PsycINFO Database



Appendix 1-C - Excerpt of Research Aims and Objective coding and frequency counts

Author (year)	In paper quote:	Code
Madhani & Finlay (2022)	<i>“Objectives: Using the COM-B model, this study aimed to characterize barriers and facilitators to pre-exposure prophylaxis (PrEP) uptake amongst men who have sex with men (MSM).”</i>	<ul style="list-style-type: none"> Barriers and facilitators to PrEP uptake.
Young et al. (2021)	<i>“In this paper, we examine how UK newsprint media reported PrEP as a public health intervention prior to the NHS England decision. While the media coverage of PrEP after March 2016 was steeped in questions around sexuality, responsibility and entitlement, we ask how PrEP was configured in newsprint media as a public health intervention up until this point and consider how this may have shaped subsequent public PrEP debates.”</i>	<ul style="list-style-type: none"> Societal attitudes towards PrEP (press).
Flowers et al. (2022)	<i>“Objectives: HIV Pre-Exposure Prophylaxis (PrEP) is a highly effective biomedical intervention for HIV prevention and is key to HIV transmission elimination. However, implementation is challenging. We identified barriers and facilitators to PrEP awareness and access during the roll out of Scotland’s national PrEP programme to develop recommendations for future provision.”</i>	<ul style="list-style-type: none"> Barriers and facilitators to PrEP awareness. PrEP accessibility.

Research aims and Objectives (code)	Frequency count
Barriers and facilitators to PrEP awareness.	2
PrEP awareness.	14
Barriers and facilitators to PrEP adherence.	5
Barriers and facilitators to PrEP adherence (within context of Black African communities).	1
Barriers and facilitators of PrEP uptake.	11*
Barriers and facilitators to PrEP uptake (within the context of Black MSM).	1
Barriers to PrEP uptake (within context of communities most affected by HIV).	1
Barriers and facilitators to PrEP uptake (within the context of Black African/Black Caribbean Women).	1
Experiences of PrEP.	10
Psychosocial impact of PrEP.	1
Perception and attitudes towards PrEP.	17*
Perceptions and attitudes towards PrEP (within the context of service providers).	1
Perceptions and attitudes towards PrEP (within the context of Heterosexual Black African Men).	1
PrEP acceptability.	9
PrEP accessibility.	5
PrEP accessibility (within the context of PWID).	1
Service provision of PrEP.	8
Societal attitudes towards PrEP.	5
Societal attitudes towards PrEP (press).	3

Appendix 1-D - An excerpt of textual descriptions used in the synthesis

Study	Textual description	Codes	Wider theme
Lorenc et al. 2021	<p>Study: Mixed method study which used an online anonymous survey (617) and semi-structured interviews (24) to explore knowledge, attitudes and perceptions of sexual health risk.</p> <p>Participants: Participants were all TPMSM or MSM using a sexual health clinic in Bristol.</p>	<p>High awareness in MSM</p> <p>PrEP associated with increase in condomless anal sex</p>	<p>Awareness and knowledge</p>

	<p>Method: Interviews were analysed thematically and integrated with survey data.</p> <p>Results: The PrEP awareness was high, but purchase cost limited access. PrEP may increase condomless anal intercourse, but interviewees used PrEP as one of many risk-reduction tools. Reduced fear of HIV transmission and testing was highly valued.</p>	<p>PrEP used as one of many protection tools</p> <p>Reduced HIV-anxiety</p> <p>Increased testing highly valued</p>	<p>Experiences of PrEP</p> <p>Perceptions of PrEP</p>
<p>Hillis et al. 2021</p>	<p>Study: Qualitative study which used semi-structured interviews to explore men who have sex with men (MSM) and service provider (SP) perspectives on provision and accessibility of PrEP in Northern and Central England</p> <p>Participants: MSM (20) and Service Providers (25)</p> <p>Method: Interviews were analysed using Interpretive Phenomenological Analysis (IPA).</p> <p>Results: Three key themes emerged: "Self-sourcing PrEP"; "Service delivery learnings"; and "Impact of using PrEP". Problems with equity of access and accessibility were noted, and recommendations for the future of PrEP programming and equitable service delivery were also presented. The study highlighted divergence in PrEP service experience from patients and providers, with results informing policy, practice and professional training.</p>	<p>Perspectives on service provision</p> <p>Accessibility</p> <p>Impact of using PrEP</p> <p>Experiences of PrEP service delivery</p> <p>Experiences of PrEP</p>	<p>Experiences of PrEP</p> <p>Attitudes and perspectives</p>
<p>Williamson et al. 2019</p>	<p>Study: Qualitative study which used focus group data to explore how an ethnically and socio-economically diverse group of GSM felt about PrEP and to explore their views, experiences, representations and intentions.</p> <p>Participants: 18 GBMSM (both HIV+ and HIV-)</p> <p>Method: Interviews were analysed using thematic analysis (TA).</p> <p>Results: The first theme 'I can't get my head around people like that': Representations of PrEP users within and beyond gay communities explores how PrEP users are vilified by some GSM and the wider media. The second theme,</p>	<p>Experiences of PrEP</p> <p>Experience of PrEP service delivery</p> <p>Perspectives of people using PrEP</p> <p>PrEP stigma</p>	<p>Attitudes and perspectives</p> <p>Experiences of PrEP</p>

	<p>'There's a culture of anti-trust': PrEP, stigma and the interpersonal politics of HIV disclosure discusses how PrEP influences HIV disclosure and sexual decision-making in casual serodifferent sexual encounters in a context where seropositive men experienced pervasive HIV stigma and HIV- men were suspicious of HIV+ sexual partners. In the final theme, 'I'm still suspicious': Discourses of doubt and distrust participants voiced concern over the safety of PrEP and the motives of drug companies, healthcare agencies and PrEP activists. We consider these findings through a critical lens of wider theorising around the relationship between public health agencies and GSM communities and consider the impact of these perspectives on likely engagement with PrEP in an English context.</p>	<p>Impact on sexual decision making</p> <p>HIV stigma</p> <p>Perspectives of PrEP safety</p>	<p>Attitudes and perspectives</p>
<p>Haggipavlou & Hamshaw. 2023</p>	<p>Study: Qualitative study which used semi-structured interviews to explore barriers to PrEP uptake in U.K in young MSM. Participants: 10 YMSM Method: Interviews were analysed using reflexive thematic analysis (RTA). Results: Analysis highlighted three principal barriers to PrEP uptake: lack of perceived necessity, lack of knowledge, and perceived acquisition discomfort. YMSM experience unique barriers to PrEP uptake. Recommendations for tackling barriers included implementation of an online application, alongside educational measures.</p>	<p>Barriers to PrEP uptake</p> <p>Self-perception of HIV risk</p> <p>Lack of PrEP awareness</p> <p>Barriers to uptake</p> <p>Experiences of PrEP service provision</p>	<p>Awareness and knowledge</p> <p>Experiences of PrEP</p> <p>Perceptions of PrEP</p>

Appendix 1-E - PRISMA-ScR Checklist

Section	Item	PRISMA-ScR Checklist Item
Title	1	Identify the report as a scoping review.
Abstract		
Structured summary	2	Provide a structured summary that includes (as applicable) background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.
Introduction		
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.
Methods		
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).
Summary measures	13	Not applicable for scoping reviews.
Synthesis of results	14	Describe the methods of handling and summarizing the data that were charted.
Risk of bias across studies	15	Not applicable for scoping reviews.
Additional analyses	16	Not applicable for scoping reviews.
Results		
Selection of sources of evidence	17	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.
Characteristics of sources of evidence	18	For each source of evidence, present characteristics for which data were charted and provide the citations.
Critical appraisal within sources of evidence	19	If done, present data on critical appraisal of included sources of evidence (see item 12).
Results of individual sources of evidence	20	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.
Synthesis of results	21	Summarize and/or present the charting results as they relate to the review questions and objectives.
Risk of bias across studies	22	Not applicable for scoping reviews.
Additional analyses	23	Not applicable for scoping reviews.
Discussion		
Summary of evidence	24	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.
Limitations	25	Discuss the limitations of the scoping review process.
Conclusions	26	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.
Funding	27	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.

JB1 = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where sources of evidence (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with information sources (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy documents).

Section Two: Research Paper

Navigating the Health Seas: Experiences of accessing freely available PrEP on the National Health Service

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Abstract

Objectives: The aim of this study was to explore the experiences of individuals accessing PrEP through the NHS in the UK. Specifically, the research aimed to understand how having access to PrEP impacts individuals' health and psychological well-being, including the role of individuals' interpersonal experiences within healthcare services.

Design: Eight individuals participated in semi-structured interviews.

Methods: The data were analysed using an inductive approach to Reflexive Thematic Analysis (RTA).

Results: Three main themes were derived from the data. The first theme related to choosing PrEP and the risk analysis that takes place at a number of key decision points in individuals' lives. The second theme revealed the value participants placed on feeling seen, heard and cared for (or not) by services when using PrEP. The third theme detailed the additional positive psychological impact that accessing PrEP had on participants.

Conclusion: Those who are interested in accessing PrEP through the NHS face a tricky process, which involves navigating a deeply personal understanding of one's own vulnerability to HIV, as well as circumnavigating a complex, under-resourced national health service peppered with systematic barriers. However, if individuals are successful, PrEP offers both protection from HIV and, for some, psychological benefits.

KEYWORDS: Pre-Exposure Prophylaxis, PrEP, United Kingdom, National Health Service, NHS, psychological, wellbeing

Introduction

Human immunodeficiency virus (HIV) is a blood-borne virus which attacks the body's immune system. While those on effective treatment, which protects their immune system and keeps their viral load 'undetectable', have equivalent life expectancy to people not living with HIV, left untreated HIV progresses to late-stage HIV or AIDS (Pebody, 2019; Terrance Higgins Trust, 2022).

PrEP (pre-exposure prophylaxis) is a medication that can reduce the risk of acquiring HIV through the use of antiretroviral medications that block HIV from entering the body and replicating. Clinical trials have shown that when taken as prescribed, PrEP is almost 100% effective (Chou et al., 2019; Donnell et al., 2014; Grant et al., 2010; Molina et al., 2017).

Between 2014 and 2021, the UK saw a significant reduction in new HIV diagnoses, particularly among gay, bisexual, and males-who-have-sex-with-males (GBMSM) (Health Security Agency, 2023). Whilst it is difficult to fully explain what is driving this decline, there is evidence to suggest that it may be the combination of high levels of viral suppression in people living with HIV, investment in HIV testing and the introduction of PrEP (Eisinger et al., 2019; The Lancet HIV, 2017).

PrEP is currently available across the UK as part of the National Health Service (NHS), specifically through sexual health services. NHS-funded PrEP has been controversial, with the NHS initially declining and suggesting it was local authorities' responsibility to fund (NHS England, 2016). Routine access was officially granted in 2021 as part of the government's aim to end HIV transmission by 2030 (Health and Social Care, 2019; Health and Social Care; 2020), though this varied across Scotland (April 2017), Wales (July 2017) and Northern Ireland (2018/2021). Due to the disparity in access over time, many individuals reported accessing PrEP privately through unregulated online purchases.

PrEP can be taken by anyone once a day, known as Daily Dosing, or for specific groups PrEP can be taken on demand, in anticipation of a sexual event, also known as Event-Based Dosing (Buchbinder, 2018; Terrence Higgins Trust, 2020). For those accessing PrEP through sexual health clinics, individuals must have regular testing for sexually transmitted infection (STI), renal function and HIV.

Despite PrEP offering another key opportunity for HIV prevention in the UK, routine provision is not meeting its potential. The Terrence Higgins Trust reported receiving repeated requests regarding PrEP initiation, refills and routine monitoring (National Aids Trust, 2022).

Furthermore, PrEP effectiveness can be critically affected by poor adherence (Dimitrov et al., 2016; Grant et al., 2014; et al., 2013; Sousa et al., 2023). PrEP adherence is complex as it can be influenced by individual factors (such as awareness, attitudes, perceptions and acceptability) as well as structural factors (such as healthcare accessibility, service provision and staff bias). This can be further complicated by overarching societal facts such as (stigma, public perceptions and cultural norms).

There is growing evidence that bias within healthcare services is a contributing factor to poor PrEP uptake and adherence (Young & Boydell, 2023). In particular for groups who might be more vulnerable to HIV and also face systematic disadvantages, such as people who: inject drugs, engage in sex work, experience homelessness, experience coercive behaviour or intimate partner violence, and Black African communities and transgender individuals (Delpech, 2022; Fox et al., 2006; Platt et al., 2011; Pyett & Warr, 1997; Shaw, 2004; Walker et al., 2023). These groups experience an intersection of minority identities and the way society, and at times NHS services, treats those people further marginalises them; leaving them vulnerable to acquiring HIV (Jaspal & Bayley, 2019; Scott et al., 2017). Individuals continue to report routine institutional stigma and racism, this is particularly

salient in this context as healthcare professionals are the gatekeepers of PrEP (Nakasone et al., 2020). Research has suggested that historical systemic medical mistreatment of racial groups have resulted in greater cynicism towards HIV-related care (Eaton et al., 2017). In turn, this results in reduced engagement and greater barriers to access services, further perpetuating disadvantages.

Typically, GBMSM have been disproportionately affected by HIV (Kohli et al., 2024) and therefore PrEP initiatives and research have heavily focused on this population (McCormack et al., 2016). The Impact trial reported men who have sex with men (MSM) made up 96% of participants (Sullivan et al., 2021). The Scottish and Welsh PrEP programmes also reported a similar MSM majority in their participants (Fina et al., 2019; Health Protection Scotland, 2019). Typically, GBMSM are also at greater risk for psychosocial stressors (such as stigma, homophobia, HIV-related anxiety) and therefore significant mental health inequalities (Mercer et al., 2016).

Additionally, emerging papers have demonstrated improved mental health outcomes after taking PrEP (Harrington et al., 2020; Hayes, 2023; Nutland, 2016; McCormack, 2021; Weil et al., 2024), which highlight the relationship between sexual wellbeing, mental health and physical health. Participants often described PrEP as providing a sense of “safety” or “protection” in their sexual experiences, which translated into increased feelings of confidence, self-assuredness, and efficacy in navigating their sexual health and, therefore, their physical health.

The aim of this study, therefore, was to explore the experiences of individuals accessing PrEP through the NHS in the UK. Specifically, the research aimed to understand how having access to PrEP impacts individuals’ health and psychological well-being, including the role of individuals’ interpersonal experiences within healthcare services. It is

hoped that this research will provide a deeper knowledge of the benefits of PrEP beyond protection from HIV and inform clinical practice as to how to promote good practice and remove barriers to care.

Method

Design

Qualitative research was thought suitable as it allows for flexibility in exploring human experiences and processes (Harper & Thompson, 2012), within a specific context (Cypress, 2015). A semi-structured interview method was employed, to generate rich exploratory data on individuals' experience of choosing and adhering to a PrEP regime provided by the NHS in the UK.

Participants

Individuals who had accessed PrEP using the NHS at any point were invited to participate. Posters were placed in PrEP clinic waiting rooms, as well as adverts on various social media platforms (Ethics Section 4, Appendix 4-E)

Once participants had made initial contact, they were provided with a participant information form, informed of the purpose and intention of the research and asked for further details to confirm eligibility. Eligible participants were asked to provide consent via a digital consent form (Ethics Section 4, Appendix 4-C).

Inclusion criteria included being aged 18 or more, being able to be interviewed in English and having accessed PrEP via the NHS in the UK at some point (outside of clinical trials). Due to the low number of individuals accessing PrEP in the UK, the relatively small number of sexual health clinics, and the possibility of interested parties reading this research – minimal participant demographics will be reported for the sake of anonymity.

29 individuals requested further details, 18 were eligible and offered a consent form, 10 returned the consent form, and eight attended their interview.

Ethical considerations

Ethical approval was granted by Lancaster University's Faculty of Health and Medicine Research Ethics Committee.

Wellbeing of participants and debrief

Due to the sensitive nature of the topic, all participants were given a Debrief Support and Information Sheet, which included details for PrEP-specific services. A local HIV charity also provided consultation on relevant details and guidance on language. A distress protocol was developed prevent or minimise harm and respond if necessary.

Data collection

Interviews were conducted remotely using Microsoft Teams at a time and place convenient to the participant to reduce participation barriers. Interviews ranged from 25 to 64 minutes ($M = 43.5$) and took place between July and December 2023. [The researcher did not possess any formal qualitative interviewer training.](#)

Development of Interview schedule

The interview schedule was developed based on an initial literature search and further consultation with relevant stakeholders (Ethics Section 4, Appendix 4-F). The interview schedule was consulted on by a number of different stakeholders, including a local sexual health charity, a local LGBTQ+ peer support charity, two clinical psychologists working in HIV services, and a medical doctor actively prescribing PrEP. Feedback from these stakeholders resulted in several adjustments in the phrasing of the interview schedule. No formal pilot testing was completed.

Analysis

Reflexive Thematic Analysis (RTA) offered a conceptually coherent fit that supported the research aims, as it explores the intersection of the participants' contextually situated experiences, perspectives, behaviours, and the subjectivity of the researcher (Braun & Clarke, 2021, p.98). Furthermore, it is suited to describing the lived experiences of socially marginalised groups (Braun et al., 2019).

Epistemological and Ontological Position

The study aimed to gain knowledge of what is 'really' going on in the world but acknowledges that the data gathered may not provide direct access to this reality. Critical Realism (CR) combines ontological realism (the belief in an independent reality) with a relativistic epistemology (different people will come to know different things in different ways) (Stutchbury, 2021). In research, this manifests as an assumption that data might indicate the true reality but does not provide a clear picture; it is clouded by participants' perception of their reality, shaped by and embedded within their specific social context (Braun & Clarke, 2022, p.171). Researchers must seek to interpret this data, but with acknowledgement and critical engagement with their own personal lens.

CR allows for the exploration of the experiences of individuals accessing PrEP, and considers these real and true to them, while recognising the impact of social context that they exist in (Maxwell, 2012; Stutchbury, 2022). The analysis is an interpretation made by the researcher who in turn constructs the findings based on their own context, (Fryer, 2022).

The method of qualitative analysis needs to be compatible with the epistemological position (Willig, 2013). Reflexive Thematic Analysis (RTA) is a method of "developing, analysing and interpreting patterns across a qualitative data set" (Braun & Clarke, 2022, p.4). Crucially to this research, CR was coherent with the RTA qualitative position of a subjective

researcher who does not exist outside of the social constructs that impact the reality they want to explore (Pilgrim, 2014).

Reflexivity

As discussed, it is accepted within this research project that the researcher's experiences, attitudes, assumptions, and beliefs will influence how they relate to, understand, and interpret data (Clarke & Braun, 2013). Transparency and self-reflexivity on researchers' positionality regarding the topic matter are essential to this methodology (Braun & Clarke, 2022), and contributes to the credibility of the research process (Willig, 2013).

Statement of position by the researcher

The researcher is a trainee clinical psychologist with experience working in a sexual health context. They identify as a white, cis-gendered bisexual woman but are currently engaged in a heterosexual relationship. Relating to the subject area, that brings a sense of “one foot in and one foot out”, with regards to the LGBTQI+ community. Although the researcher identifies as being part of this community, there is distance and privilege that comes with being in a heteronormative relationship. PrEP can, of course, be used by anyone regardless of sexual orientation. However, it is recognised that the LGBTQI+ community have been disproportionately impacted by both the HIV/AIDs epidemic and PrEP implementation. Research subjectivity is further complicated by the nature of the researcher's role in the NHS. In this regard, the researcher occupies several positions with different levels of power and influence.

Throughout the analysis, it was important for the researcher to revisit these positions (and possible accompanying assumptions) for possible blind spots or areas of interest. A reflexive journal was also kept throughout data collection and analysis (Appendix 2-F).

Process of Coding and Developing Themes

Coding and analysis of interviews were guided by Braun and Clarke's practical guide to reflexive thematic analysis (Braun & Clarke, 2022), which involves six phases as described below. Reflexive Thematic Analysis (RTA) differs from other versions of Thematic Analysis (TA) due to the importance it places on reflexivity, the process of critically interrogating "what we do, how and why we do it, and the impacts and influences of this on research" (Braun & Clarke, 2022. p.5). RTA is fundamentally different because it values and accepts the subjective and situated position of the researcher. This is particularly important when researching socially minoritised groups and when researchers may be more socially powerful and privileged outsiders (Braun & Clarke, 2022b)

Phase one, familiarisation, involved three practices: developing a deep and intimate knowledge of the data set, immersion and critical engagement (Braun & Clarke, 2013). In this project, this involved reading (and re-reading) individual interview transcripts as well as making textual and visual notes. Reflecting at this stage was important to identify things that might have shocked the researcher and challenged any assumptions held.

Phase two, the coding process, involved systematically tagging segments of participants' interview transcripts with code labels, starting to capture repetitions of meaning (Appendix 2-C).

A largely inductive orientation to the data guided the coding process, as this research was concerned with participants' experiences and perspectives (Braun & Clarke, 2013). Coding initially began from a semantic stance, coding transcripts explicitly to clearly express what participants said, however as this process continued, coding moved towards a more latent approach. Latent coding relied more heavily on the researcher's subjectivity to consider less obviously evident patterns, such as those influenced by social context.

Phase three, generating initial themes, required an initial clustering of codes where there is a similarity of meaning (Appendix 2-D).

Stage four necessitated further developing and reviewing themes. In practice, this involved a recursive process of revisiting potential themes and exploring their validity and richness (Braun & Clarke, 2022).

Stages five and six required additional precision to refine, define, and name themes and to begin the writing of the analysis presented in this report.

Quality Assurance

RTA does not have specific guidelines which should be applied rigidly and often looks significantly different between papers. Furthermore, Braun and Clarke have highlighted their opposition to the ‘proceduralism’ (Braun & Clarke, 2022; King & Brooks, 2017) or enforcement of strict methodological criteria in thematic analysis.

However, in recognition of the need to support researchers in evaluating quality thematic analysis, Braun and Clarke have published a twenty-question evaluation tool (Braun & Clarke; RTARG). Questions largely focus on whether a paper provides an adequate justification and explanation of the methods, methodology applied and conceptual coherence. These, and other methodological writings on TA (Braun & Clarke 2006; Braun & Clarke, 2020; Smith, 2017), were used in the design and construction of the methods used in this paper. A quality appraisal of the current study can be found in Appendix 2-B.

Results

Eight participants took part; six reported currently using daily PrEP as opposed to event-based. Six described themselves as gay men who have sex with other men. Two participants described themselves as transgender, of these, one participant requested he/him

pronouns and one participant requested they/them pronouns. Participants' ages ranged from 21-58 years. Three main themes were derived through analysis of the interview transcripts.

[Table 1: Participant Demographics]

Choosing PrEP: risk analysis at every turn

Participants described a regular process of risk analysis at key decision points in their journey with PrEP. This appeared to be a constant process that required thought and consideration for their personal circumstances, such as their sexual practices (visiting sexual premises, engaging in chemsex, sex work or frequency of sex, etc), relationship status or location. This ongoing analytical process began even before individuals approached NHS services, assessing whether they should approach services regarding PrEP or whether they would prefer to access this privately at a cost. Many participants reported having high levels of awareness before they approached NHS services in the first instance, researching prescription criteria, potential side effects or effectiveness. Some participants had accessed PrEP through clinical trials or paid it for themselves privately. In all instances, participants reported actively seeking out lived experiences from their peers or local community. Social media was also used to compare their circumstances and perceived risk of acquiring HIV to the prescribing criteria before they ever spoke with a medical professional.

Participant 3 “Alright, I was single and I was living in [redacted location] which I knew had a high prevalence of HIV and not just people living with HIV, but sort of undiagnosed and uncontrolled or untreated and I felt it was a sensible thing”

Once individuals determined PrEP was something they wanted to pursue, the next risk analysis came by weighing up the potential for side effects, often concerning the impact PrEP might have on their kidneys, with the value of feeling protected from HIV. Many participants reported a notion that they felt unprotected sex would inevitably result in HIV,

which resulted in persistent anxiety around HIV before, during and after sex. It seemed that this fear overshadowed any potential worry about side effects or health implications of PrEP.

Participant 8 “So you do wonder what's important, what's available if you do react badly to it or something like that, you know and but no, it was just a risk analysis against the dangers of HIV to me, which far outstripped any other argument in the end... I thought, you know, there's a reasonable chance that if I carried on without PrEP, I probably become infected at some point, you know?”

Similar processes were reported with regard to when participants had to decide whether to use condoms during their sexual encounters in combination with PrEP. There was a sense that PrEP facilitated condomless sex in a safe way and although there might be an increased likelihood of STIs, these were perceived as less serious than HIV. The value of increased pleasure and intimacy through condomless sex was appraised as higher than the potential for STIs because PrEP drastically reduced the chances of acquiring HIV.

Participant 6 “but I think that there was this feeling that...Since we're not getting HIV and we have antibiotics or treatment for all the rest of them, then OK, let's go for it...”

Some participants reported considering the potential of STIs and side effects within the context of the three-monthly visits typically required by sexual health clinics prescribing PrEP. For them, if any potential STIs would be picked up by the required sexual health screening and any side effects or detrimental impact on their kidneys would be monitored at their next appointment, this swayed their analysis in favour of PrEP. To some degree, the three-monthly visits were seen as an additional benefit of their journey with PrEP as they felt it would likely identify and prevent the unidentified spread of STI's within their community.

Participant 8 “And I think the three-monthly things useful because you know, if you do have anything else, you tend to find out early and are unlikely then to have that jig, that geometric progression from people that are simply unaware cause you can be asymptomatic with any number of them.”

Participant 2 “And you started to test regularly and understood the impact, you know, understood the fact that you know, if you then had picked something up, it was being picked up quicker and could be treated. So, therefore, you weren't passing something on over a longer period of time, so you know that was the other good thing about PrEP. It meant people getting tested more often.”

Dosing was also assessed in a similar fashion, with individuals weighing up how their personal circumstances may benefit from, or counter-indicate different dosing styles. For example, two participants discussed a recent neurodevelopmental diagnosis that impacted their memory and swayed them towards either daily or event-based PrEP. Other participants considered how they engaged in sex, what they valued in their sexual experiences and the comfort they found in feeling “protected” and “safe” in order to choose a dosing regimen.

Participant 1 “Daily, I would say, is safe for me, cause um...I'm not really one to plan out...sexual interactions and not really one to plan out who and when, what, why, how. And it comes more naturally than that. And it just means that I am always protected against HIV AIDS”

When exploring discontinuing PrEP, participants often cited a change in their personal circumstances that would swing their analysis the other way. For example, suddenly experiencing side effects might make PrEP no longer “worth it”, or they felt their likelihood of acquiring HIV reduced because they entered a monogamous relationship.

Participant 5 “It's my kidneys or whatever. If they started playing up then. Yeah, of course. I'd understand changing my meds. And it needs to be even changing my lifestyle as much as I can. But It's unless there's a reason like that. Then I'm trying to take it.”

The perpetual risk analysis described by participants was a uniquely individual process that required an honest assessment of one's personal life within the context of HIV risk. However, in reality, individuals' values heavily influenced this process. It appears service design can have a significant impact on how able services are to fully appreciate and support service users with this process.

To be, is to be perceived: the importance of feeling seen, heard and cared for by services

Participants had variable experiences of engaging with NHS services, however, a common pattern was evident within the interviews. Services that allowed for flexibility, easy access and were welcoming of all circumstances that led individuals to consider PrEP were experienced as judgment-free, supportive and unmedicalised. Individuals who described positive experiences seemed to experience being recognised as someone who might benefit from PrEP as affirming.

Participant 1 “The medical staff were all completely judgement free, and they're brilliant in fact...the fact you have to go with them to something that's quite taboo in society and even when they were helping me get the PrEP, they were very good. They told me the criterion they were like, you do fit these. It's okay don't worry about it. And they were very-just relaxed about it, which helps me like gain just a relaxed way of dealing with it”

Services that prioritised rigid, high volume, impersonalised appointments seemed to result in poor experiences that left participants feeling dismissed and unseen by services. One participant described approaching NHS services regarding PrEP after

previously accessing it privately, but feeling as if he needed to justify his need for PrEP strictly by the prescribing criteria rather than his own perception of PrEP eligibility.

Participant 3 “when I first started accessing it on the NHS, as opposed to accessing it privately, know that at my first appointment, I almost felt I had to justify my need to take it, and there was a....You have to like make sure you met the criteria”

Another participant recalled a similar feeling, whereby he felt he had to utilise his previous experience of working within the healthcare system to navigate the service and advocate for his PrEP eligibility.

Participant 4 “But I suspect had I been less health literate, that interaction with that clinician wouldn't have ended in a prescription for me, I suspect.”

Correspondingly, one participant described feeling as a trans person, they were not recognised as having a PrEP need, as they do not fit healthcare staff's perception of what PrEP eligibility looks like.

Participant 5 “But we don't get offered PrEP. We don't get offered the same sort of checking up and coming in, and you should do this like we're not part of campaigns.”

Participants also discussed not feeling attuned with or at odds with the criteria for discontinuation of PrEP within the NHS. Some participants acknowledged fear they might not be provided with PrEP any longer if they didn't strictly meet prescribing criteria.

Participant 1 “I don't think I would personally stop, choose stop taking it, but I know friends who have been kicked off for getting it for free because they haven't had as many sexual partners, which is a real shame to me cause I feel like it shouldn't. It's almost like anti slut shaming of people shouldn't have to have a certain amount of partners to feel safe in those relationships.”

This left participants with fear that if they did not *appear* to fit healthcare services' idea of what someone with a high likelihood of HIV acquisition looked like (or were not engaging in behaviour deemed "high risk"), they would not be able to access a medication that they felt immensely benefited their lives.

Participant 2 "I mean, I understand why, but it's playing with people's lives a little bit in terms of...just because they [healthcare services] think ohh that's low risk or no risk- doesn't mean to say that it is actually low risk or no risk"

Participants reiterated this experience of not feeling seen by services on a structural level, highlighting that PrEP was not treated the same as other medication by services. Six of the eight participants acknowledged the contraceptive pill as an example of how PrEP was treated differently from other preventative medicines. Specifically, this example seemed to highlight how services were ignoring participants' needs in regard to PrEP provision and failing to structure services in a way that supports equitable access to PrEP.

Participant 3: "Let's take the contraceptive pill versus PrEP. They're both are preventive medicine to prevent them...-well they're not directly comparable at full, but the ease of access is so considerably different-the barriers that need to be gone through and that kind of thing.....There's a difference and I understand why there are differences in some aspects, but societally there is a very different approach to it. And but they involve sex and we think there is still some stigma towards queer sex or and I say this from a man who has sex with men, whereas there are lots of other people who take PrEP."

It appears that individuals who do not fit the service perception of a person who uses PrEP may face additional barriers to accessing PrEP, which have the potential to collide with already present minority group stressors and systemic biases within services. However, when services utilise the routine monitoring currently recommended for PrEP, they can be used to

build relationships between those taking PrEP and hopefully challenge historical narratives that perpetuate inequitable access to health services.

Added Benefits: lifting the weight of risk and freedom to explore pleasure

PrEP was overwhelmingly considered as positive by participants in a number of facets, but this seemed especially apparent in the psychological impact. Participants reported reduced HIV anxiety, explaining that PrEP offered a sense of “safety”, “protection” and “peace of mind”. The relief felt by participants was particularly noticeable before and after sex and a desire for a “safety net” was often cited as a main motivator for initiating PrEP.

Participant 2 “Yeah, I mean it's peace of mind, isn't it? It takes away that little bit of anxiety. ... I mean, certainly the beginning. There were still some anxiety, but not to the same level.”

Although nearly all participants shared that PrEP had not directly changed their sexual behaviour, they were clear that the sense of safety provided by PrEP allowed them to experience greater sexual freedom.

Participant 1 “knowing that I now have this drug that keeps me safe from that makes that part like exploring my sexuality, being open a bit so much more freeing, I don't have to be weighed down by that worry.”

Furthermore, participants' view of self and others also seemed impacted by PrEP, reporting increased confidence in themselves and sexual encounters. Some participants perceived accessing PrEP as a marker that they care about their sexual health.

Participant 4 “It's a confidence thing. I feel like actually if I go into a sexual encounter and I can say I'm on PrEP, it's a demonstration that I take my sexual health seriously and that's, I guess... it sounds like if someone says ohh like I've got PrEP, you

know, on some level they must have engaged with the health service and have some thoughts about their sexual health just to have even got hold of it.”

This also seemed also true in regard to how participants viewed others as a source of risk. Participants valued that PrEP removed the need to trust or rely on others' accounts of their own HIV risk. This also played out in the discussions of HIV status between individuals, which might previously have been how individuals attempted to reduce their chances of acquiring HIV without PrEP while engaging in condomless sex.

Participant 8 “It used to be, you know, you'd have a conversation if you were gonna have unprotected sex with someone whose status you're unsure of. Do you know if you're HIV positive or not? And then effectively have conducted an ad hoc risk assessment you know?... But no, I mean, those conversations have ceased. I don't hear of them anymore, basically because I think there's a wider assumption out there now that everyone's on PrEP, which is possibly not true, but I kind of work on the basis that well, I am.”

It seems that PrEP offers individuals a sense of control over their sexual health, which is not dependent on partners; with PrEP, individuals feel they are in charge of their own protection. This appears to facilitate an opportunity for more fun and less stress.

Participant 1 “It gives me less anxiety after sex to be honest, because you're not scared of getting AIDS, right? Rightly or wrongly, I do know that there's a risk there, but it's a lot lower risk and it makes that experience more fun and less stressful, which it really should be [laughs].”

Ultimately, what participants described was an immensely positive benefit from PrEP in addition to biomedical HIV prevention, that reduced anxiety and increased wellbeing by facilitating health and a rewarding sex life.

Discussion

This study aimed to explore experiences of accessing PrEP through the NHS in the UK in order to have a better understanding of how having access to PrEP impacts individuals' health and psychological well-being, including the role of individuals' interpersonal experiences within healthcare services. Three main themes were identified which chart a journey that individuals must embark on if they are to access PrEP via the NHS. The continual risk formulation required to adhere to PrEP successfully requires a profound personal knowledge of one's own circumstances, which appears to go beyond the typical understanding of HIV risk within services. Participants described an internal assessment of their own context that involved their medical history, preferences for sexual interactions, actual sexual behaviour, personal tolerance for risk of (and actual) side effects, relationship status and personal tolerance for HIV anxiety. These elements of individuals' personal lives fluctuate and vary throughout their lives and, especially for minoritised groups, are unlikely to be sufficiently captured by the current clinical assessment by healthcare professionals as it is. This is inevitably complicated further by the lack of representation in PrEP-related information or within the wider healthcare system. It may be that healthcare professionals' lack of 'cultural competence' in regard to some minority groups (Betancourt et al., 2002; Quinn et al., 2019) results in individuals taking on more of the burden of the PrEP 'risk assessment', because their risk factors are not known or recognised by services (Maloney et al., 2017). Meyer's minority stress model (2003) might suggest this is an example of (proximal) minority stress processes in action, with individuals learning to internalise their 'risk assessment' due to expectations to be stigmatised due to awareness of prevailing social stigma (Douglass et al., 2019).

However, the three-monthly visits often accompanying PrEP were highly valued by participants, not just for the identification of possible renal decline and STIs but also because

it facilitated a relationship with sexual health services that was supportive of a more personalised experience. When services moved towards rigid, high-volume, impersonalised appointments, this left individuals feeling dismissed and unseen because it did not leave space for the formulation required. Previous research has suggested that PrEP delivery may benefit from being part of a holistic approach, which allows space for exploration and treatment of other health needs (Hayes et al., 2023; Sidebottom et al., 2018). Within HIV care, Warner & Rutter (2020) discuss the role of HIV teams as a ‘pseudo family’ for clients who receive ongoing (and sometimes lifelong) care. They go on to discuss how there is a benefit to understanding healthcare relationships within the context of attachment theory (Ainsworth & Bowlby, 1991; Bowlby, 1969), particularly for populations which experience a heightened risk of HIV transmission. For example, they consider how early adversity, trauma, or societal inequalities might contribute to an individual's ability to reliably manage their healthcare (Boarts et al., 2009; Hutchinson & Dhairyawan, 2017). This may support services in understanding poor PrEP adherence, and for those individuals who may struggle with adherence, services may be able to better support them by offering person-centred care “that is underpinned by understanding the attachment-based needs of service users” (Warner & Rutter, 2020 p119). Additionally, it is suggested that delivering services in a way that provides a ‘safe base’ for individuals, which might involve the consistency and tailored approach discussed by participants in this study, offers the potential for improved healthcare outcomes. While sexual health care is different from HIV care, often more transient, the results from the present study appear to be concordant with the idea that having consistent appointments with services is important and highly valued by those accessing PrEP in the UK.

In addition, participants described services positively when staff recognised them as having a PrEP need. While participants had conceptualised that they had a need for PrEP,

they felt reassured by services that listened to and affirmed their perspective. For trans participants, the reverse was also true; they felt unseen and unrecognised by services because they felt they did not fit the image of a “PrEP user” that NHS services had. It may be that ‘feeling seen’ by services requires a multilayer approach. Firstly, individuals desire to feel recognised as having a PrEP need, and therefore, justification does not become an additional barrier to overcome. This requires a wide and non-judgmental approach to what ‘PrEP need’ entails, one that accounts for the variety of individuals' lived experiences.

Similarly, in order to provide truly patient-centred care (Robinson et al., 2008), services must be culturally competent (Saha et al., 2008). Within HIV care, person-centred care is considered an essential part of service design and is used to inform how professionals should respond to individuals' needs and preferences about their care (BHIVA, 2018). Cultural competence also has been highlighted as a foundational element of providing care to those who engage in chemsex, and therefore are eligible for PrEP. The British Psychological Society (BPS) describes this explicitly, suggesting that professions should provide information that is “accurate, scientific, and culturally sensitive information and the opportunity to speak with professionals who are non-judgmental and understand the needs and experiences of GBMSM” (BPS, 2023, p.8).

Once individuals have chosen to engage with PrEP, the next challenge they are faced with is being recognised by services. Participants reported that knowledge of the NHS was helpful, if not a necessity, in navigating the healthcare system when seeking to obtain PrEP. It may be that the participants in this study, who were required to have successfully been prescribed PrEP by the NHS, were a biased sample. For example, because they had a high level of health literacy and experience of the inner workings of the NHS (either through profession or lived experience as a patient), they were able to traverse the systematic barriers that prevent many others from accessing PrEP services. This would echo narratives regarding

those living with HIV, who are required to access and maintain relationships with healthcare services in order to receive care (Watkins-Hayes, 2014). Some individuals may struggle with this type of engagement with services as a result of “intersectional stigma” (Berger, 2004). This is due to existing social disadvantages intersecting with components of identity such as race, class, gender, or sexuality, meeting social narratives surrounding HIV. The way that PrEP is currently provided also requires individuals to engage with services, which may leave those with interlocking inequalities facing more barriers to access.

Furthermore, participants reported often turning to their community for knowledge regarding PrEP. Similar themes have been identified in US-based literature reviews, particularly the role of peer communication during the earlier stages of PrEP’s availability (Sophus & Mitchell, 2019). This places an unfair knowledge burden on individuals and may facilitate barriers for those who have a different level of health literacy or limited access to knowledgeable communities. This could leave those individuals, who are likely to be those already not accessing the wider NHS, further isolated in regard to sexual health. Social-cognitive theory might suggest that interventions targeting PrEP awareness utilise peer networks to diffuse more tailored information to specific groups (Munro et al., 2007). This would engage observational learning as a method of behaviour change and could involve collaboration with trusted community-based organisations to overcome interpersonal barriers to PrEP use and promote social support (Biello et al., 2018). This might be especially relevant for those groups where PrEP acceptability is hindered by a lack of knowledge, such as Black African populations in the UK (Young et al., 2014).

However, despite the factors that prevented or facilitated PrEP access, all participants reported positive psychological impacts from PrEP. This is concordant with other research completed within clinical trial settings (Harrington et al., 2020; Hayes et al., 2023; Keen et

al., 2020) and suggests that participants experience significant benefits outside of HIV prevention.

Additional psychological benefits of PrEP have been anecdotally reported since 2016 (Hojilla et al., 2016), and more recent research has begun to further this topic. The literature that exists has mainly been in agreement that PrEP offers additional benefits in addition to biomedical HIV prevention, such as enhanced sexual self-esteem, “peace of mind”, improved sexual pleasure, reduced sexual anxiety, and increased sexual agency for those taking it (Grovet al., 2021; Harrington et al., 2020; Hayes et al., 2023; McCormack, 2021). Though the research has been primarily qualitative, there are some quantitative studies exploring reduced anxiety and fear in GBMSM that have been produced in the United States (Moellar et al., 2020; Whitfield et al., 2019) and internationally (Van Dijk et al., 2022). Scoping reviews report similar results, suggesting that engaging with PrEP provides individuals with a sense of empowerment, as well as reducing generations-long sexual anxieties (Gómez, 2023).

A number of authors note that for GBMSM, this feeling of relief may be relief from anxiety rooted in historical trauma from the HIV epidemic (McCormack, 2021; Stuart, 2019). It may be that accessing PrEP challenges some of the social moralising narratives around condomless gay sex.

Likewise, increased sexual self-efficacy may lead to an increased sense of wellbeing. Defined as “a state of physical, emotional, mental and social wellbeing in relation to sexuality, it is not merely the absence of disease, dysfunction or infirmity” sexual health is an essential element of overall health (WHO, 2006). PrEP may help lots of individuals achieve this by facilitating more autonomy in sexual decision-making and offering opportunities to actively engage in HIV risk prevention, which in turn may increase sexual esteem (Whitfield et al., 2019).

PrEP may also play a role in supporting individuals' general engagement with sexual health. Health locus of control, a psychological construct based on how much control individuals feel they have over their health status (Wallston & Wallston, 1982), has been linked with sexual behaviour (Nalukwago et al., 2021; Ogunsanwo, & Ayodele, 2014; Pharr et al., 2015; Uye et al., 2023). This concept would suggest that people with an internal health locus of control are more likely to engage in protective behaviours, in this case, protective sexual behaviours. In contrast, those with an external health locus of control might assume their sexual health status is attributed to external factors such as chance or fate and, therefore, engage in less protective behaviours (Pharr et al., 2015). It may be that PrEP offers an increased sense of agency in regard to individuals' sexual health, which is essential to support an individual's overall health and wellbeing.

These additional psychological benefits may also serve as an important motivator for continued adherence. Previous research aligns with this, suggesting that sexual pleasure (Curley et al., 2022), increased intimacy (Harrington, 2020) and reduced anxiety (Keen et al., 2020) may be potential facilitators of continued PrEP adherence. Moreover, sexual pleasure is an essential element of sexual health (Ford et al., 2019) and, therefore, is an important aspect to explore and advocate for as health researchers (Gruskin & Kismödi, 2020; Launders & Kapadia, 2020).

Overall, the analysis suggests that those who are interested in accessing PrEP through the NHS face a tricky process, which involves navigating a deeply personal understanding of one's own vulnerability to HIV, as well as circumnavigating a complex, under-resourced national health service peppered with systematic barriers. However, if individuals are successful, PrEP offers both protection from HIV and, for some, relief from the deep-seated worry that appears to accompany queer sex as a result of historical trauma from the HIV/AIDS crisis.

Limitations

This analysis may be limited by the demographics of participants. While it was intended to collect a diverse group of participants, the resulting sample was small (n=8) and largely GBMSM. Specific effort was made to reach participants who identified as cis-gendered women or heterosexual, but this was not successful. This was further complicated by the limited timeframe the research needed to be completed within.

Typically, the small sample sizes often used in qualitative research is characterised as a limitation within the context of generalisability. However, within this research, it is important to note that these results are not intended to be generalisable for all individuals accessing PrEP through the NHS. It is hoped that some of the patterns developed from the data will help in exploring how service can better support increased PrEP uptake and continued adherence.

Clinical Implications

Firstly, sexual health appointments should be viewed as an opportunity to establish rapport with individuals who could be thinking about PrEP for the first time. For clinicians to successfully become partners in this continual risk assessment, individuals require flexibility, psychological safety and time in clinic appointments. This will facilitate trust and positive patient-clinician relationships. Similarly, clinicians are required to be aware of the impact of time-limited rigid appointments on how much participants choose to share in a consultation, possibly making clinical assessments more difficult.

It may be that judgment and non-compassionate encounters create barriers to sexual health care (Heath et al., 2023). Likewise, previous traumatic experiences in healthcare where minoritised individuals have been “othered” or experienced abuse and homophobia may create more barriers to accessing services, which will only be entrenched by a “production line” approach to healthcare (Arnold et al., 2014; Crawford et al., 2013; Joy et al., 2022).

Some studies have suggested that elements of humanism may be helpful in sexual health settings, such as compassion and empathy (Gordon, 2021). Furthermore, this is especially apparent for groups minoritised by their gender and/or sexuality, where compassion is believed by some to be needed at the core of healthcare (Joy et al., 2022).

The study's results also suggest some specific recommendations for service providers prescribing PrEP. The nature of an internal risk formulation requires staff to be culturally competent and recognise the varying and multilayer factors that might be impacting different groups typically underserved in sexual health environments. This is especially true for minoritised groups. Services should be aware that some groups, such as transgender or black African communities, are likely navigating a complex intersection of identities and the various forms of oppression that accompany this (Quinn et al., 2019). These groups may face significant barriers in navigating the NHS and may present with low health literacy. It may be beneficial for services to offer community advocates (sometimes called peer navigators in the US, Pagkas-Bather et al., 2020) who can support individuals in navigating NHS services. While this might not address the root cause of continuing structural and economic inequities, it offers another route for individuals to access care that they might need.

A focus on vulnerable groups is also largely in alignment with current UK standards of care in relation to PrEP. Most notably, the need for tailored interventions to support systematically disadvantaged groups is mirrored by the British HIV Association's directive to address inequitable access to PrEP and HIV testing by providing support that is based on local prevalence and population needs (BHIVA, 2018). Similarly NICE guidance on reducing sexually transmitted infections also suggests paying particular attention to groups in which PrEP uptake is lower or are more vulnerable to acquiring HIV (NICE, 2022).

However, this study also highlights the psychological impact of PrEP, which is not proportionally represented in current guidance (NICE, 2022). Presently, UK guidelines for the use of PrEP do not emphasize the role that PrEP might play within a more holistic view of health and wellbeing. For example, the reduction of HIV-related anxiety, which this study has established can be a common side effect of PrEP, may be an important factor in someone's decision to begin, continue or cease PrEP.

Future research

Future research should aim to specifically explore the psychological benefits of PrEP in under-represented groups, with specific attention being paid to the recruitment of samples and the use of community-based organisations in research design. This will hopefully aid the misrepresentation in the academic literature and shed light on the psychological impact of PrEP in these groups in comparison to GBMSM.

In regard to clinical psychology, it is important to note that there are very few clinical psychologists roles in sexual health services, so input following this study is much more likely to fall into the remit of leadership and consultation (Rao et al., 2021). However, clinical psychologists are in a central position to lead further research into the psychological impacts of PrEP as it continues to be routinely provided through the NHS. Furthermore, clinical psychologists are also well placed to support the development of psychologically informed services that foster psychological safety and encourage robust relationships between staff and individuals who would like to use PrEP.

Conclusion

The themes developed in this paper illuminate the journey individuals must embark upon if they wish to successfully navigate the NHS and fit PrEP into their lives. This journey requires thoughtful and deeply personal formulation of one's own circumstances and their interplay with official PrEP eligibility criteria. This journey is undoubtedly influenced by the

historical and ongoing impact of the HIV/AIDS epidemic, persistent HIV stigma and moralising perspectives of normative sexual behaviour. This study also highlights the additional psychological benefits experienced by individuals accessing PrEP, which appear to have significant consequences for individuals' sexual health and general well-being.

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Tables and Figures

Table 1: Participant demographics

Participant	Pronoun	Gender	Sexual orientation	PrEP regimen	Age
1	He/Him	Male	Gay	Daily	Under 25
2	He/Him (Trans)	Transgender	Gay	Daily	26-39
3	He/Him	Male	Gay	Event- Based	40+
4	He/Him	Male	Gay	Event- Based	26-39
5	They/them (Trans)	Transgender (AFAB) Non-binary	Pansexual	Daily	26-39
6	He/Him	Male	Gay	Daily	26-39
7	He/Him	Male	Gay	Daily	40+
8	He/Him	Male	Gay	Daily	40+

Figure 1: Thematic Matrix



Appendices

Appendix 2-A - Guidance for journal submission

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If you are invited to revise your manuscript after peer review, the journal will also request the revised manuscript to be formatted according to journal requirements as described below.

2. AIMS AND SCOPE

The British Journal of Health Psychology publishes original research on all aspects of psychology related to health, health-related behaviour and illness across the lifespan including:

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Papers must make a clear potential contribution to health psychology theory, knowledge and/or practice and employ rigorous research design and methodology..

We do not typically publish cross-sectional studies or those using only student populations unless there is a strong rationale for doing so.

Papers describing intervention development (without also presenting an analysis of the outcomes of the intervention) will usually only be considered if they make a contribution to health psychology theory, knowledge and/or practice beyond the specific intervention context.

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- theoretical papers which report analyses of theories in health psychology;
- review papers, which should provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses);
- methodological papers dealing with methodological issues of particular relevance to health psychology;
- we particularly welcome papers reporting effectiveness (for example, Randomised Controlled Trials) and process evaluations of interventions in clinical and non-clinical populations.

Authors who are interested in submitting papers that do not fit into these categories are advised to contact the editors who would be very happy to discuss the potential submission.

Papers describing quantitative research (including reviews with quantitative analyses) should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative or mixed methods research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes, whether in the text or in tables, but excluding the abstract, tables, figures and references). In exceptional cases the Editor retains discretion to publish papers beyond this length where the clear and concise expression of the scientific content requires greater length (e.g., explanation of a new theory or a substantially new method). Authors must contact the Editor prior to submission in such a case.

All systematic reviews must be pre-registered and an anonymous link to the pre-registration must be provided in the main document, so that it is available to reviewers. Systematic reviews without pre-registration details will be returned to the authors at submission.

Please refer to the separate guidelines for [Registered Reports](#).

Your main document file should include:

- A short informative title containing the major key words. The title should not contain abbreviations;
- Abstract structured (intro/methods/results/conclusion);
- Up to seven keywords;
- Main body: formatted as introduction, materials & methods, results, discussion, conclusion;
- References;
- Tables (each table complete with title and footnotes);
- Figure legends: Legends should be supplied as a complete list in the text. Figures should be uploaded as separate files (see below)
- Statement of Contribution.

Supporting information should be supplied as separate files. Tables and figures can be included at the end of the main document or attached as separate files but they must be mentioned in the text.

- The main text file should not include any information that might identify the authors. Please do not mention the authors' names or affiliations and always refer to any previous work in the third person.
- The journal uses British spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

Abstract

For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found [here](#).

Keywords

Please provide appropriate keywords.

Acknowledgements

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Statement of Contribution

All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each.

References

This journal uses APA reference style; as the journal offers Free Format submission, however, this is for information only and you do not need to format the references in your article. This will instead be taken care of by the typesetter.

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

[Click here](#) for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Appendix 2-B - Reflexive Thematic Analysis Reporting Guidelines (RTARG) – Braun & Clarke 2024

<i>Reflexive Thematic Analysis Reporting Guidelines (RTARG) – Braun & Clarke 2024</i>		
Review question	Yes/ No/ Unclear	Evidence
1. Do the authors explain why they are using TA, even if only briefly?	Yes	The reason why RTA was chosen is explained briefly in the Analysis section (page 2-8) and in detail within the Epistemological and Ontological Position section (page 2-8/2-9)
2. Do the authors clearly specify and justify which <i>type</i> of TA they are using?	Yes	Reflective Thematic analysis (RTA) is clarified on page 2-8 and differentiated from thematic analysis (TA) on page 2-10
3. Is the use and justification of the specific type of TA consistent with the research questions or aims?	Yes	See page 2-8 as above. “Reflexive Thematic Analysis (RTA) offered a conceptually coherent fit that supported the research aims of this paper, as it explores the intersection of the participants’ contextually situated experiences, perspectives, behaviours, and the subjectivity of the researcher (Braun & Clarke, 2021, p.98). Furthermore, it is well suited to describing the lived experiences of socially marginalised groups (Braun et al., 2019).”
4. Is there a good ‘fit’ between the theoretical and conceptual underpinnings of the research and the specific type of TA (i.e. is there conceptual coherence)?	Yes	“The method of qualitative analysis needs to be compatible with the epistemological position (Willig, 2013). Reflexive Thematic Analysis (RTA) is a method of “developing, analysing and interpreting patterns across a qualitative data set” (Braun & Clarke, 2022, p.4). Crucially to this research, CR was coherent with the RTA qualitative position of a subjective researcher who does not exist outside of the social

		constructs that impact the reality they want to explore (Pilgrim, 2014).”
5. Is there a good ‘fit’ between the methods of data collection and the specific type of TA?	Yes	Chosen data collection method is semi-structured interview.
6. Is the specified type of TA consistently enacted throughout the paper?	Yes	RTA is used consistently throughout the paper.
7. Is there evidence of problematic assumptions about, and practices around, TA? (for examples see Braun & Clarke 2020)	No	RTA is acknowledged as having six phases but allows for theoretical flexibility within the boundaries of conceptual coherence. No evidence of combining philosophically and procedurally incompatible approaches. There is no evidence of grounded theory concepts without discussion, such as data saturation (see 3-7 for further detail).
8. Are any supplementary procedures or methods justified, and necessary, or could the same results have been achieved simply by using TA more effectively?	Yes	The use of RTA over traditional TA is justified on pages 2-11 due to its prioritisation and value of the researcher's subjective and situated position.
9. Are the theoretical underpinnings of the use of TA clearly specified (e.g. ontological, epistemological assumptions, guiding theoretical framework(s)), even when using TA inductively (inductive TA does not equate to analysis in a theoretical vacuum)?	Yes	See Epistemological and Ontological Position and Reflexivity on page 2-8/2-9
10. Do the researchers strive to ‘own their perspectives’ (even if only very briefly), their personal and social standpoint and positioning? (This is especially important when the researchers are engaged in social justice-oriented research and when representing the ‘voices’ of marginal and vulnerable	Yes	See Reflexivity and Statement of position by the researcher on page 2-10.

groups and groups to which the researcher does not belong.)		
11. Are the analytic procedures used clearly outlined, and described in terms of what the authors actually did, rather than generic procedures?	Yes	See Process of Coding and Developing Themes on page 2-10, 2-11 and 2-12 for extensive description of actual procedure conducted.
12. Is there evidence of conceptual and procedural confusion? For example, reflexive TA (e.g. Braun & Clarke, 2006) is the claimed approach but different procedures are outlined such as the use of a codebook or coding frame, multiple independent coders and consensus coding, inter-rater reliability measures, and/or themes are conceptualised as analytic inputs rather than outputs and therefore the analysis progresses from theme identification to coding (rather than coding to theme development).	No	Use of term “derived from the data” suggests awareness that themes do not “emerge” from data but are analytic outputs. No evidence of multiple independent coders. Only one researcher. No evidence of codebook TA or coding frameworks.
13. Do the authors demonstrate full and coherent understanding of their claimed approach to TA? <i>A well-developed and justified analysis</i>	Yes	See above
14. Is it clear what and where the themes are in the report? Would the manuscript benefit from some kind of overview of the analysis: listing of themes, narrative overview, table of themes, thematic map?	Yes	See abstract (2-2), results section (2-11 to 2-20) and thematic matrix (figure 1, 2-45).
15. Are the reported themes topic summaries, rather than ‘fully realised themes’ – patterns of shared meaning underpinned by a central organising concept?	No	Themes are fully realised throughout the text and the central organising concept “journey to PrEP” is further highlighted in the thematic matrix (2-45)

16. Is non-thematic contextualising information presented as a theme? (e.g. the first 'theme' is a topic summary providing contextualising information, but the rest of the themes reported are fully realised themes). If so, would the manuscript benefit from this being presented as non-thematic contextualising information?	no	
17. In applied research, do the reported themes have the potential to give rise to actionable outcomes?	Yes	See clinical implications 2-26
18. Are there conceptual clashes and confusion in the paper? (e.g. claiming a social constructionist approach while also expressing concern for positivist notions of coding reliability, or claiming a constructionist approach while treating participants' language as a transparent reflection of their experiences and behaviours)	No	See extensive discussion of conceptual positioning on page 2-8 and 2-9. Notably the role of critical realism in social sciences and healthcare research.
19. Is there evidence of weak or unconvincing analysis, such as: <ul style="list-style-type: none"> • Too many or two few themes? • Too many theme levels • Confusion between codes and themes. 	No	See the results section (2-11 to 2-20).
20. Do authors make problematic statements about the lack of generalisability of their results, and or implicitly conceptualise generalisability as statistical probabilistic generalisability (see Smith 2017)?	No	See discussion of generalisability in limitation (2-26 and 3-11)

Appendix 2-C - Sample Excerpt of Coded Labels on Transcript (recreated)

Researcher 5:53
And in terms of things like getting an appointment, how was that?

Participant 1 5:59
It was super easy. Let's just speak to either of them over the phone or at a desk, and there was literally no blockage there at all. They seemed to have a lot of appointments free at like times which I could visit them.

Researcher 6:13
Brilliant. And has this continued to be easy during the course of taking PrEP?

Participant 1 6:18
Yes, um, I don't think I've ever had a time where I felt like I needed to see a nurse and not been able to get an appointment. They've always been available to me.

Researcher 6:28
And since taking it, do you think there's been any sort of changes for you maybe in your mental health psychologically?

Participant 1 6:36
I think it definitely reduces some of the frightening aspects of sex especially because of the gay community having such a trauma around the AIDS epidemic -in the 80s and how it killed off so many people, it makes us as modern day queers, I feel very safe and able to just enjoy what people say is quite an enjoyable part of life.

Researcher 7:08
Can you just tell me a bit more about that. That's so interesting.

Participant 1 7:11
So yeah, um, I think that people would say that like connecting people sexually is a big part of the modern day gay culture. Not all of it, but it's a big part of it, and something that has sprouted from is the openness of the 50s and 60s, where sexuality was being first explored in the 80s. That all came to a head with the fact there was this virus going about and so many people died. I mean, the story is the L which is first in the LGBTQ+ is lesbian. Because they were giving blood, looking after these men [with AIDS] in hospital. And just knowing that history and knowing that I now have this drug that keeps me safe from that makes that part like exploring my sexuality, being open a bit so much more freeing. I don't have to be weighed down by that worry and it comes with also some of the positives of being gay. Like there's no pregnancy risk, so it just makes that part of the community feel more free and open to live as they want.

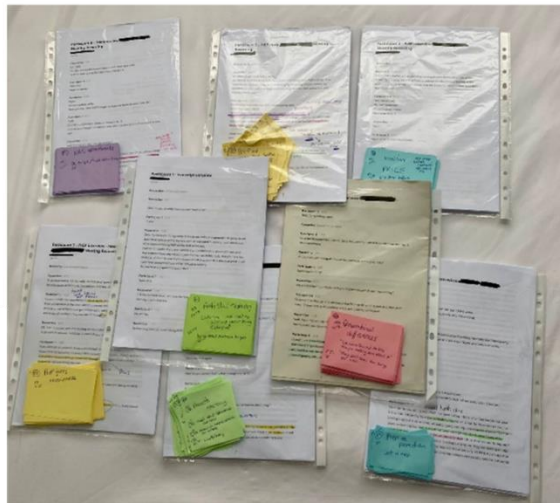
Researcher 8:13
And do you think it changed your approach personally?

- Author ⋮ ✎ 🗑
 Positive experience associated with availability of services
- Author ⋮ ✎ 🗑
 Reduces the frightening aspects of sex
- Author ⋮ ✎ 🗑
 Trauma from the AIDS epidemic
- Author ⋮ ✎ 🗑
 Generational differences
- Researcher ⋮ ✎ 🗑
 safety
- Researcher ⋮ ✎ 🗑
 Safe and able to enjoy
- Researcher ⋮ ✎ 🗑
 Sex is a big part of life (and wellbeing)
- Researcher ⋮ ✎ 🗑
 Sexuality in the queer community has a historical context
- Researcher ⋮ ✎ 🗑
 PrEP safety within historical HIV/AIDS context

Participant 1 8:18
I think if I'd say it made me slightly less risk-averse in the sense that I now knew that I was safe from contracting like this horrible disease. And it didn't totally change. I haven't changed my risk, though I don't now go for because- I don't go for it willy nilly still. I'm very much ~~still~~ ~~risk aware~~ still looking at the risks. But it really takes one big factor away from like-especially if you're on a high out and you go home with someone quite drunk, it's one less thing to think about in the morning.

Researcher 8:58
And quite big thing really.

Participant 1 9:00
[laughs] it's a massive thing. It's like it's one of the big things that as a community we had created quite a culture around testing and making sure that you knew your [HIV] status and making sure you're protecting anyone you're getting with. And now there's this drug that makes us just safe from that risk. It's completely changed community outlook and I think it makes the Community more able to just live as they want. It makes people less scared to get with people. [e]



- 1 Researcher ... Less fearful of sexual behaviour that might be deemed as "risky" Reply
- 1 Researcher ... Safety Reply
- 1 Researcher ... HIV still considered "horrible disease" Reply
- 1 Researcher ... Perception that there is a wrong way to behave on PrEP Reply
- 1 Researcher ... Sense of responsibility Reply
- 1 Researcher ... Considering personal behaviour is risk analysis Reply
- 1 Researcher ... Impact of alcohol on prep use Reply
- 1 Researcher ... Culture around HIV testing Reply
- 1 Researcher ... Sense of responsibility Reply

Appendix 2-D - Sample of Code Clustering



Appendix 2-E - Sample of Theme Development

Theme name	Description	Codes	Quotes
Risk analysis at every turn	The experience of accessing PrEP involves a process of evaluation at every major decision point. This begins before accessing PrEP; individuals evaluate whether they consider themselves “at risk” for HIV and whether this “justifies” the potential for side effects. Some ‘risk’ seems to be mediated by the regular renal checks offered as part of accessing PrEP through the NHS. Individuals feel they were being checked more often (for renal decline and STIs), which balanced the potential for increased STIs or medical impacts of PrEP. Individuals are also considering the potential for others' perceptions of them if they are discovered using PrEP. They also weigh up the use of PrEP in combination with other preventative methods (i.e. condoms, serosorting etc) with the intention of reducing risk. When considering condomless sex, side effects of PrEP are often weighed up against the psychological relief associated with PrEP.	<p>Risk analysis (internal)</p> <p>Personal risk analysis</p> <p>Analysis of own circumstances</p> <p>“my risk”</p> <p>Doubled edged sword (increased risk mediated by increased checks)</p> <p>Risk of side effects</p> <p>Risk of HIV</p> <p>Side effects vs HIV</p> <p>Risks of daily PrEP</p> <p>Risk of Event-based</p> <p>Risk of forgetting</p> <p>“belt’s and braces approach” – stacked approach to risk reduction</p> <p>Risk of increased STI’s</p> <p>Risk of STI versus risk of HIV</p> <p>Risk of stigma</p>	<p>P1 8:18 <i>“I think if I'd say it made me slightly less risk-adverse in the sense that I now knew that I was safe from contracting like this horrible disease. And it didn't totally change. I haven't changed my risk, though I don't now go for because- I don't go for it willy nilly still. I'm very much...[trails off]</i></p> <p><i>-still risk aware- still looking at the risks.”</i></p> <p>P8 5:15 <i>“it was a a risk analysis basically and the potential for contracting HIV far outweighed, in my mind, any potential side effects.”</i></p> <p>6:00 <i>“So you do wonder what's important, what's available if you do react badly to it or something like that, you know and but no, it was just a risk analysis against the dangers of HIV to me, which far outstripped any</i></p>

	<p>STIs appear to come out lesser in this analysis, with individuals feeling they are less harmful than HIV.</p> <p>These formulations are deeply personal and require an understanding of one's own circumstances and tolerances. They are repeated and do not stop once PrEP has been initiated. As people's circumstance and life situations change, so do these formulations.</p>		<p><i>other argument in the end.”</i></p> <p>P3 3:54 <i>“Alright, I was single and I was living in [redacted] which I knew had to high prevalence of HIV and not just people living with HIV, but sort of undiagnosed and and uncontrolled or untreated and I felt it was a sensible thing”</i></p> <p>P2 13:21 <i>“Yeah, it's just finding out what you like. What you don't like? And this takes away some of those... infection risk factors. Because you can get vaccinated for somethings and other things you can't”</i></p>
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Appendix 2-F - Sample of Reflexive Journal

29th November 2023

Participant interview 6

Themes:

- “prep was like my armour” Prep provides a real sense of safety but wonder if armour means you are going into battle – is the battle sex? Or is the battle HIV?
- “False sense of invincibility” – he felt like PrEP let him do what ever he wanted, whenever he wanted (he was referring to engaging in chemsex) but this was a “bad” thing.
 - o Maybe an indication that there is still internalised stigma attached to queer sex/free sex?
- The right and wrong way to use PrEP - morality
- Generational differences “the younger ones not treating prep with the respect of aim it was created for”

Personal reflections

- Felt a strong sense of wanting to share my own position within the queer community. He commented on two occasions that it was “our community” when talking about the queer community and I wanted to agree!
- This was maybe related to the uncomfortableness of being associated with the NHS. Felt very aware that I was being associated with the NHS (who in theory hold the keys to PrEP). Maybe he was self-censoring to say the things he thinks I wanted to hear, or the things that will keep PrEP available to him.

30th November 2023

Further reflections on Participant 6

- I have since found out that Participant 7 was referring to Tina which is crystal meth (Methamphetamine) which is commonly used in chemsex. I felt a bit silly for not knowing this. During the interview, I felt pulled to share a sameness with Participant 6, but not knowing Tina meant drugs highlighted how much I don’t know of his experience.
- Felt one foot in, one foot out. I know but I don’t know.

Section Three: Critical Appraisal

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Critical Appraisal

The use of the first person within this appraisal is deliberate and intended to assist the researcher's personal reflections and critical examination of the project as a whole.

In this critical review, I will first provide a brief overview of the systematic scoping review and empirical paper, then expand upon and review key elements of carrying out this research. Secondly, in keeping with reflexive qualitative methods, I will also discuss my experiences and motivations when developing the project, as well as my own subjectivity and positionality within the research. Thirdly, I will pay further attention to the project's strengths and limitations. Finally, I will discuss the clinical implications resulting from both papers and what this indicates for research in the future.

Overview of findings

The systematic scoping review, titled “Knowledge, Perceptions, and Attitudes towards Pre-Exposure Prophylaxis (PrEP) in the United Kingdom”, involved systematically searching electronic databases for original research articles pertaining to the research topic. 47 papers were identified and summarised using descriptive numerical summary analysis and further synthesised using narrative synthesis. Overall, the research included suggested a large bias towards gay, bisexual and other men who have sex with men (GBMSM) participants in the literature body, with most research focussing on barriers and facilitators to various factors of PrEP implementation. Varying levels of knowledge regarding PrEP were demonstrated, with GBMSM typically showing the highest levels of awareness compared to other groups, such as Black African Communities and PWID. Further analysis revealed that multiple opposing attitudes towards PrEP exist in the UK, with political, social and cultural norms adding further complexity. Stigma towards PrEP was variable but was often associated with moralising views of sex and promiscuity. The analysis also highlighted the emerging

literature on experiences of PrEP outside of the biomedical prevention of HIV, with a minority of papers warranting further exploration into the psychosocial impact of PrEP.

The empirical paper, titled “Navigating the Health Seas: Experiences of accessing freely available PrEP on the National Health Service”, utilised semi-structured interviews to speak with eight individuals about their experiences of accessing PrEP through the NHS, in order to have a better understanding of how PrEP might impact health and wellbeing. Results were analysed using reflexive thematic analysis (RTA), and three main themes were identified. The first theme, ‘Choosing PrEP - risk analysis at every turn’, explored participants’ repeated experiences of personal risk analysis throughout their journey with PrEP initiation and uptake. The second theme, ‘To be is to be perceived’, explored the importance of feeling seen, heard and cared for by healthcare services. Positive experiences were underpinned by a sense of being recognised by services as having a PrEP need and feeling that services are accessible when they are needed. Conversely, negative experiences, often experienced as rigid and formulaic, left participants feeling unseen or ignored by services. The third theme, ‘Added Benefits: lifting the weight of risk and freedom to explore pleasure’, detailed the additional positive psychological impacts that PrEP had on participants’ lives, such as “peace of mind”, increased confidence and increased self-efficacy in relation to their sexual health.

Developing the Thesis Topic

My first job at 16 was as a sexual health educator, travelling with my local GP and other sexual health professionals to local schools (including my own) to discuss sex and relationship education (SRE). It was hoped that involving a young person as a peer educator when discussing SRE would increase acceptability and encourage relationships between young people and local sexual health providers. This was an incredibly positive experience personally and seemed to be received well by the schools and young people we visited. I

believe this exposure to sex-positive (Woodford, 2013) health promotion and positive experience of peer education laid the foundation for my interest in PrEP and HIV research. It fostered my enthusiasm and belief in an individual's right to influence the policies and education that affect them (“nothing about us without us”) (Tucker et al., 2021). Later, I was offered a role in the extended STI testing programme at my university, which involved offering STI tests in community locations such as nightclubs and student unions (Chandra et al., 2017; LaMontagne et al., 2004;). Most days, I was met with worried and anxious students who wanted to ask about STIs, their potential impact on their health and how to access care. Fears of stigma, anxiety about others' perceptions, and poor information were common themes which have also been found in qualitative research (Duncan et al., 2001; Holgate & Longman, 1998; Redfern & Hutchinson, 1994). It was during this role that I began to conceptualise the relationship between psychological well-being and sexual health (Anderson, 2013). Including, sexual health as an integral aspect of total well-being (Hansen et al., 2004).

Therefore, when I was offered the opportunity to explore PrEP implementation in the UK, I was genuinely passionate about developing a project that could elevate the voices of those using PrEP and inform ongoing service provision. My thesis supervisor and field supervisor provided a crucial link with clinical psychology, both working in HIV services as clinical psychologists.

During the process of actualising the research topic, the main concern was exploring PrEP within the context of the UK health system and the unique elements that this entails. It seemed particularly apparent that the NHS context was a missing element in the existing PrEP implementation literature, often based in the US or internationally, which would be helpful to explore. There was also a dearth of research situated outside of the major clinical trials in the UK (IMPACT, Sullivan et al., 2023; PROUD, McCormack et al., 2016).

However, I was particularly aware of the historical difficulties in recruiting socially stigmatised and difficult-to-locate diverse samples of “hidden populations” in the area of HIV and sexual health, which was further complicated by the limited time frame of the clinical psychology doctorate course.

A qualitative method was felt to be the most appropriate approach for the empirical project. This method provides a platform for those using PrEP to speak freely, providing rich descriptions of their experiences within identifiable local contexts (Austin & Sutton, 2014; Miles & Huberman, 1994). In this regard, semi-structured interviews can be considered “a conversation with a purpose” (Burgess, 2002, p.102).

However, this needed to be considered with the understanding that, as a person who does not take PrEP, I was not part of the group I was inviting to take part in the research; and held inherent subjectivity and bias. This would inevitably bleed into my analysis and inform my understanding of participants' experiences. Therefore, Reflexive Thematic Analysis (RTA, Braun & Clarke, 2019) seemed the most logical method to honour this distinction.

Conducting RTA from a critical realist position suggested that participants' voices would be further served by additional exploration of the specific social context surrounding them. PrEP has been subject to wide-reaching media, social and cultural narratives since its introduction, which would be undoubtedly important in the analysis of participant data, and therefore, a literature review exploring these within a UK context was thought to be essential. Together, it was hoped that the systematic scoping review might support a better understanding of the landscape in which PrEP is situated within the UK and would, therefore, give context to individual participants' experiences from the empirical research.

The choice to use Reflexive Thematic Analysis (RTA)

It has become common practice to discuss why other methods were not appropriate in the development of a research project. However, this is typically discouraged within RTA as it potentially suggests that there is always only one ideal method for a project. Braun and Clarke (2022, p125) advise avoiding the “methodological survey” approach to method rationales and instead suggest focusing on why the selected method was suited to the particular needs of the project. Similarly, seeking design coherence (Braun & Clarke, 2013) or methodological integrity (Levitt et al., 2017) is far more likely to result in a project which aligns with the research project's theoretical assumptions and overarching research questions. Therefore, I aim to use this section to provide a justification for RTA, what it offered for this project and how it was applied.

Most importantly, RTA offered a focus on subjectivity and researcher reflexivity, which was important in this project due to the multiple positions I occupied as a researcher working with commonly marginalised groups.

In addition, RTA's theoretical flexibility was important in this project because it facilitated the highlighting of lived experiences, often from minoritised groups such as GBMSM or those with increased risk of HIV, whilst also locating these within wider sociocultural discourses, for example HIV-stigma, homophobia and racism. In this sense, RTA enabled simultaneous exploration of the relationship between the personally reported psychological impact of accessing PrEP and the societal discourses surrounding preventative HIV medicine.

Similarly, the flexibility RTA offered was particularly helpful in regard to data set composition and size, as RTA has few mandatory restraints (Braun & Clarke, 2022, p. 27). Before starting this project, potential interest in participation was unknown and recognising the historical difficulties in recruiting for HIV-related research and other sensitive topic areas,

I was aware this was something that needed to be considered. Data saturation is typically seen as not consistent with the values of RTA (Braun & Clarke, 2022, p28) as it implies meaning is waiting to be found in the data rather than generated as the outcome of analysis (Braun & Clarke, 2006; Braun & Clarke, 2019). Alternatively, this research sought “information power”, which argues that the ‘power’ of an interview sample is determined by various dimensions such as “study aim, sample specificity, use of established theory, quality of dialogue, and analysis strategy” (Malterud et al., 2016). In practice, this involves dynamic trade-offs between various dimensions to determine a sufficient sample size. For example, in this study, a broad study aim (more participants needed) is balanced with rich interview dialogue (fewer participants needed) and dense sample specificity (fewer participants needed). Information power does not produce a numerical calculator for how many participants are needed but offers systematic considerations to explore throughout the recruitment and analysis process that is more epistemologically aligned with RTA (Braun & Clarke, 2022, p28; Malterud et al., 2016;).

Reflexivity, subjectivity and self-reflection

Braun and Clarke (2022, p8) are clear that “researcher subjectivity is the primary tool” in RTA, and rather than being managed or controlled, should be understood as a resource in knowledge generation and analysis (Gough & Madill, 2012). However, this process requires interrogation of one’s own position, values and research practices. This section intends to explore a section of these personal considerations I explored during this research project.

When speaking with participants throughout this project, I have thought deeply about my identity and the power ascribed to different elements of it. I engaged in the exploration of my own “conceptual baggage” (Kirby & McKenna 1989). In particular, I thought about this in regard to how access to power might influence my relationship with participants and, in

turn, how this dynamic may impact participants' responses to questions. As a white cis-gendered woman on a funded clinical doctorate course, I was entering into these conversations with an unspoken but visible amount of privilege and power. Furthermore, I was asking about their experiences of the NHS, from a place of being personally employed by the NHS and completing research on behalf of the NHS. Similarly, I also have never taken PrEP.

There are conflicting perspectives on 'outsider' researchers conducting exploratory work into groups to which they do not belong. It is often assumed that being a member of the population you wish to examine is preferable (and arguably more ethically sound) as it invites trust from participants by bringing an insider advantage (Clarke et al., 2010). However, I believe that through the process of this research, I have learned that it is more important to recognise and acknowledge the positions we occupy and how these might relate to being part of the in-group or out-group. In this instance, the integration of my own positionality was an essential part of reflexivity within this project (Braun & Clarke, 2022, p. 216).

Furthermore, I felt that as a researcher, I was neither an insider nor an outsider but had "one foot in, one foot out" (Levins, 2008). I identify as being part of the larger LGBTQI+ umbrella, and my beliefs have been profoundly affected by my exposure to topics in this area, such as sex positivity (Harle, 2022) and sex as a meaningful and essential part of overall well-being. However, I am not someone who accesses or has tried to access PrEP. This experience of "one foot in, one foot out" was also highlighted to me during the empirical data collection when participant 6 showed confusion in how to relate to me.

Participant 6 - "Yeah...I can't say that my community...sorry I don't even know... I'm not assuming but... the gay community, the queer community, is using it rightfully"

In this instance, there was potential for social identification, which might have offered empathy, trust, access, and availability, but he seemed confused about the dual positionality. After the fact, it has allowed me to reflect on my beliefs about how much to share of oneself in an interview situation when working with groups who so often face marginality and discrimination.

Strengths and Limitations

The main strength of this project, is its ability to offer both a broad overview and then a specific exploration of PrEP within the UK. The review offered a broad, overarching map of how PrEP is understood in the UK, in different groups, and across wider societal norms. The empirical paper emphasised the direct experiences of those using PrEP in a real-world sample, offering insights into service provision, the psychological impact of PrEP, and ongoing barriers to PrEP access.

The systematic scoping review was the first, to my knowledge, to systematically explore knowledge, attitudes, and perceptions towards PrEP in the UK. Although it would be inappropriate to draw causal conclusions from this paper, the results do offer rich descriptions of the various narratives surrounding PrEP in different populations. Particularly, it validated previous research suggesting barriers to PrEP access must be understood within the specific context of the cultural narratives of the affected group. The quantitative papers included in the review suggested a lack of longitudinal research and research heavily focussed on individual-level barriers and facilitators to PrEP uptake and adherence. A minority of these papers focussed on the evaluation of PrEP service provision. Overall, the review offered some novel insights into gaps and strengths in the current body of literature.

The systematic review, however, also presented some methodological challenges due to the spread and variety of guidance on scoping reviews in healthcare research. An initial framework was proposed by Arksey and O'Malley (2005), later updated by Levac et al.

(2010), although neither included step-by-step methodological guidance. Since then, the Joanna Briggs Institute (JBI) has produced a detailed and comprehensive framework to address this gap and support the practical implementation of the method (Pearson et al., 2005; Peters et al., 2015). However, some specific methodological considerations remain. For example, the choice to complete a critical appraisal of data in scoping reviews is often contested, with some suggesting this is optional and not typically recommended as it is not aligned with the aims of a scoping review (Munn et al., 2018). Conversely, others suggest the omission of quality appraisal makes scoping review results difficult to interpret (Brien et al., 2010) and limits the applicability to policy and practice (Grant & Booth, 2009). The lack of consensus in this instance was challenging within the context of the present scoping review. However, it was decided that the scoping purpose of the study, ‘What is the current state of knowledge, perceptions, and attitudes towards PrEP in the United Kingdom?’, did not provide suitable justification to conduct a quality assessment, and therefore, this was not conducted. Furthermore, the wide range of the review also made quality assessment unfeasible. Despite this, it is recognised that the exclusion of this process may place value on the existence of studies over their quality, leaving the potential for bias in the results. Any specific questions that emerge from the results of this project would provide a foundation for further systematic review, which could address this limitation, by taking into account the strength of the research included.

One strength of the empirical paper was its exploratory nature, which offers insight into the psychological impact of a primarily biomedical intervention. Importantly, this research provides a rationale for further research to explore this phenomenon in under-represented groups such as cis-women or transgender individuals.

Furthermore, the empirical research offers a foundational understanding of how societal, cultural and structural barriers may prevent access to PrEP, even once the factor of

cost is removed. In this regard, the results offer lived experiences of health services, which can be used to inform future service design and prescribing guidelines.

In comparison, the empirical research conducted as part of this project faced great challenges during the recruitment phase and final characteristics of the participant group. Participants were self-selecting, and although a number of methods for recruitment were explored (approaching local community venues, student unions, leaflets, Facebook, X, engaging with social media groups regarding PrEP), the participants that made up the final sample ended up being largely GBMSM. Results from the systematic scoping review suggest this may potentially continue to reinforce the over-representation of GBMSM in PrEP research.

Within qualitative research, there has been a move away from discussing the ‘generalisability’ of results based on a sample (Smith, 2017), often due to its epistemological assumptions (Braun & Clarke, 2022, p. 142). Many have suggested alternative routes for situating qualitative results, such as transferability (Tracy, 2010), inferential-transferability (Ritchie et al., 2003) or intersectional generalisability (Fine et al., 2008). In the case of RTA, lack of statistical generalisability is not seen as a limitation (Braun & Clarke, 2022, p.146); however, critical engagement with the characteristics of the participant group is recommended, particularly because these characteristics may shape or influence researchers' interpretation of the results (Braun & Clarke, 2020). Importantly, in this empirical research, the participant group did not tap into specific populations that might have benefited from their voices and experiences being highlighted, such as cis-gendered women or heterosexual individuals. For cis-women, emerging research has suggested that research must consider the biological factors involved in PrEP use for women (Karim et al., 2022; Sheth et al., 2016) and the potentially different factors that might impact adherence (Bradley et al., 2019). Regarding the results from this empirical study, the theme “risk analysis at every turn” done by

individuals during the initiation and uptake of PrEP might have overlooked considerations for cis-women, such as PrEP and hormonal contraception. While the reasons for failing to access this group are likely due to the small numbers of these populations actively accessing PrEP in the UK (Cabecinha, 2023), further excluding these individuals perpetuates continuing inequalities in access. Additionally, cis-women account for over a quarter of new HIV diagnoses in the UK (Cairns, 2023). Further PrEP research would benefit from a specific focus on these groups, with recruitment strategies developed with these groups in mind (Dubé et al., 2023; Falcon et al., 2011).

Clinical Implications and Future research

Together the results from both papers highlight an underlying idea that service providers need 'cultural competence' and awareness of the specific factors which impact those with an increased risk of HIV. Campaigns hoping to address the wide disparity and inequitable access to PrEP will need to identify these specific factors and address them within their interventions. For example, media campaigns hoping to increase PrEP awareness amongst specific groups such as women, will need to make it clear how PrEP can be helpful for them, in their frame of reference. This requires a comprehensive understanding of the different factors affecting different groups; for example, medication interactions between PrEP and hormonal contraception are rarely an issue for gay cis-gender men but would be something to consider for cis-gender women or transmen. There is no one-size-fits-all, and it appears that individuals who recognise themselves in health promotion work are more likely to engage.

Similarly, self-perception of HIV risk is a key factor in individuals' decision to use PrEP, but this may look very different in different populations. Evidence from this project suggests that the psychological impact of reduced HIV anxiety, evident in GBMSM, may

present differently in populations not as stigmatised by the HIV epidemic. However future research would be required to explore this.

Combined results also potentially support previous suggestions that the psychological impact of PrEP could be included in prescribing criteria. It is evident that these additional benefits are a key motivator for uptake and continued adherence. There is some emerging international guidance already implementing clinical discretion in prescribing PrEP (Department of Health, 2020), particularly for those who experience severe HIV-anxiety (ASHM, 2018). While this might raise some discomfort in service providers by treating the ‘worried well’ (Calabrese et al., 2017; Smith et al., 2021), results from this project demonstrate that assessing risk of HIV is a deeply personal process which may be difficult for some individuals to share for a variety of reasons. Furthermore, while there was some evidence of PrEP being associated with promiscuity or irresponsible sexual behaviour, these were largely understood as barriers to initiating PrEP rather than risks of use. Service providers must be aware of the possibility that the ‘worried well’ may still have a PrEP need that they are not disclosing. In this way, merely requesting PrEP, should be a legitimate reason for eligibility in the UK. While this may lead to potential issues, such as incorrect adherence to specific protocols (for example, event-based protocols can require a start-up dose of two pills taken a minimum of two hours before sexual contact as well as a follow-up dose) or increased cost to the NHS. Ultimately, widening PrEP prescription criteria offers a potential solution to overcoming some of the structural and societal barriers to PrEP uptake in the UK.

This project also suggests a role for clinical psychologists in supporting clinical staff to run psychologically informed services which promote psychological safety. Clinical psychologists could also support services in facilitating meaningful co-production for underrepresented groups.

Finally, the empirical results from this project are ultimately informed by those who have successfully managed to navigate the NHS system to be prescribed PrEP. Therefore, it does not speak to individuals' experiences who have attempted and been unsuccessful. Potentially, these individuals could offer further insight into specific service barriers that have not been captured in this project. Future research would benefit from speaking with this group of people. However, it is likely that special attention would be required in the recruitment phase as the barriers that prevented them from accessing service may also make engaging with research challenging.

Conclusion

To conclude, this thesis has added novel findings to the evidence base exploring the psychological impact of PrEP. In the critical appraisal I have discussed key decision points of the research process, including strengths and limitations of the research, personal reflexivity, clinical implications, and potential areas for further research. It is hoped that these insights may inform sexual health service design and provide a foundation to further explore the psychological impacts of PrEP in underrepresented groups.

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Section Four: Ethics

Ethics Application

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Research Ethics Application Form v1.9.5

Research Ethics Application Form v1.9.5

RECR



Experiences of PrEP being freely available on the National Health Service: findings from a qualitative study in England - Approved

Information Regarding this Research Project

Are you conducting a research project?

(for more information on research projects please see our [ethics pages](#))

Yes No

Does your research only involve animals?

Yes No

Are you undertaking this research as/are you filling this form out as:

- Academic/Research Staff
- Non Academic Staff
- Staff Undertaking a Programme of Study
- PhD or DClinPsy student or MPhil
- Undergraduate, Masters, Master by Research or other taught postgraduate programme

Which Faculty are you in?

Faculty of Science and Technology

Which department are you in?

Psychology

Please note:

Please be aware that if you are doing a DClinPsy course you need to select Department for Health Research not Psychology.

Will your project require NHS REC approval? (If you are not sure please read the guidance in the information button)

Yes No

Do you need Health Research Authority (HRA) approval? (Please read the guidance in the information button)

Yes No

Have you already obtained, or will you be applying for ethical approval, from another institution outside of Lancaster University? (For example, an external institution such as: another University's Research Ethics Committee, the NHS or an institution abroad (eg an IRB in the USA)? Please select one of the following:

- No, I do not need ethical approval from an external institution.
- Yes, I have already received ethical approval from an external institution.
- Yes, I will be applying for ethical approval from an external institution after I have received confirmation of ethical approval from my Faculty Research Ethics Committee (FREC) at Lancaster University, if the FREC grants approval.

Is this an amendment to a project previously approved by Lancaster University?

Yes No

Will your research involve any of the following? (Multiple selections are possible, please see i icon for details)

- Human Participants
- Data relating to humans (Secondary/Pre-existing data only)
- Data collection from online sources such as social media platforms, discussion forums, online chat-rooms
- Human Tissue
- None of the above

Project Information

Please confirm/amend the title of this project.

Experiences of PrEP being freely available on the National Health Service: findings from a qualitative study in England

Estimated Project Start Date

15/03/2023

Estimated End Date

30/03/2024

Is this a funded Project?

Yes No

Research Site(s) Information

Will you be recruiting participants from research sites outside of Lancaster University? (E.g. Schools, workplaces, etc; please read the guidance in the information button for more information)

Yes No

Please provide the number, type and location of external research sites that you are using (please see help text for details).

Lancaster University is the primary research site. However, Manchester NHB Foundation Trust have agreed for recruitment materials to be available in their clinics. No specific groups will be identified by MFT or targeted for recruitment.

The R&D department at MFT have confirmed that this project does not require HRA or NHBREC approval as no participants will be identified by the trust. They confirmed that advertising by poster is not recruitment activity.

Applicant Details

Are you the named Principal Investigator at Lancaster University?

Yes No

Please check your contact details are correct. You can update these fields via the personal details section located in the top right of the screen. Click on your name and email address in the top right to access "Personal details". For more details on how to do this, please read the guidance in the information button.

First Name

Holly

10 June 2024

Reference #: FHM-2023-1403-REC-2

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Search for your supervisor's name. If you cannot find your supervisor in the system please contact rso-systems@lancaster.ac.uk to have them added.

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Bourne

Department

Division of Health Research

Faculty

Faculty of Health and Medicine

Email

k.bourne@lancaster.ac.uk

Do you need to add a second supervisor to sign off on this project?

Yes No

Additional Team Members

Other than those already added, please select which type of team members will be working on this project:

- I am not working with any other team members.
- Staff
- Student
- External

Please list all external contacts here:

[Redacted]

First Name

Sarah

[Redacted]

Surname

Rutter

[Redacted]

Organisation

North Manchester General Hospital

Details about the participants

[Redacted]

As you are conducting research with Human Participants/Tissue you will need to answer the following questions before your application can be reviewed.

If you have any queries about this please contact your [Ethics Officer](#) before proceeding.

[Redacted]

What's the minimum number of participants needed for this project?

6

[Redacted]

What's the maximum number of expected participants?

12

[Redacted]

Do you intend to recruit participants from online sources such as social media platforms, discussion forums, or online chat rooms?

Yes No

[Redacted]

Will you get written consent and give a participant information sheet with a written description of your research to all potential participants?

Yes No I don't know

Will any participants be asked to take part in the study without their consent or knowledge at the time or will deception of any sort be involved?

Yes No I don't know

Is your research with any vulnerable groups?

(Vulnerable group as defined by Lancaster University Guidelines)

Yes No I don't know

Is your research with any adults (aged 18 or older)?

Yes No

Is your research data collected with completely anonymous adult (aged 18 or older) participants, with no contact details or other uniquely identifying information (e.g. date of birth) being recorded?

Yes No

Is your research with adult participants (aged 18 years, or older) in private interactions (for example, one to one interviews, online questionnaires)?

Yes No

Is your research with any young people (under 18 years old)?

Yes No I don't know

Does your research involve discussion of personally sensitive subjects which the participant might not be willing to otherwise talk about in public (e.g. medical conditions)?

Yes No I don't know

Could the study induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in a participant's usual, everyday life?

Yes No I don't know

Is there a risk that the nature of the research topic might lead to disclosures from the participant concerning either:

- Their own or others involvement in illegal activities
- Other activities that represent a threat to themselves or others (e.g. sexual activity, drug use, or professional misconduct)?

Yes No I don't know

Does the study involve any of the following:

- Physically intrusive procedures including touching or attaching equipment to participants
- Administration of substances
- Ultrasound or sources of non-ionising radiation (e.g. lasers)
- Sources of ionising radiation, (e.g. X-rays)
- Collection or use of samples of Human Tissue (e.g. Saliva, skin cells, blood etc.)

Yes No I don't know

Details about Participant relationships

Do you have a current or prior relationship with potential participants? For example, teaching or assessing students or managing or influencing staff (this list is not exhaustive).

Yes No I don't know

If you need written permission from a senior manager in an organisation where research will take place (e.g. school, business) will you gain this in advance of undertaking your research?

Yes No I don't know N/A

Will you be using a gatekeeper to access participants?

Yes No I don't know if I will be using a gatekeeper

Will participants be subjected to any undue incentives to participate?

Yes No I don't know

Will you ensure that there is no perceived pressure to participate?

Yes No I don't know

Participant data

Will you be using video recording or photography as part of your research or publication of results?

- Yes No

Will you be using audio recording as part of your research?

- Yes No

Will you be using audio recordings in outputs (e.g. giving a presentation in a conference, using it for teaching)?

- Yes No

Will you be using portable devices to record participants (e.g. audio, video recorders, mobile phone, etc)?

- No
- Yes, and all portable devices will be encrypted as per the Lancaster University ISS standards, in particular where they are used for recording identifiable data
- Yes, but these cannot be encrypted because they do not have encryption functionality. Therefore I confirm that any identifiable data (including audio and video recordings of participants) will be deleted from the recording device(s) as quickly as possible (e.g. when it has been transferred to a secure medium, such as a password protected and encrypted laptop or stored in OneDrive) and that the device will be stored securely in the meantime

Will you be using other portable storage devices in particular for identifiable data (e.g. laptop, USB drive, etc)? (Please read the help text)

- No
- Yes, and they will be encrypted as per the Lancaster University ISS standards in particular where they are used for recording identifiable data

Will anybody external to the research team be transcribing the research data?

- Yes No

Online Sources

Does your research comply with the site(s) terms and conditions? Before completing the section below please read the ['Social Media Guidance for Researchers'](#)

- Yes No It's unclear in the terms and conditions

Is there a reasonable expectation of privacy?

- Yes No

Because there is a reasonable expectation of privacy, you must obtain consent from site users. Therefore you will need to upload a copy of the Participant Information Sheet & Consent form that you intend to use to obtain their informed consent.

General Queries

Does any member of the research team, or their families and friends, have any links to the funder or organisations involved in the research?

- Yes No I don't know

Can the research results be freely disseminated?

- Yes No I don't know

Will you use data from potentially illicit, illegal, or unethical sources (e.g. pornography, related to terrorism, dark web, leaked information)?

- Yes No I don't know

Will you be gathering/working with any special category personal data?

- Yes No I don't know

Are there any other ethical considerations which haven't been covered?

- Yes No I don't know

REC Review Details

Based on the answers you have given so far you will need to answer some additional questions to allow reviewers to assess your application.

It is recommended that you do not proceed until you have completed **all of the previous questions**.

Please confirm that you have finished answering the previous questions and are happy to proceed.

I confirm that I have answered all of the previous questions, and am happy to proceed with the application.

Questions for REC Review

Summarise your research protocol in lay terms (indicative maximum length 150 words).

Note: The summary of the protocol should concisely but clearly tell the Ethics Committee (in simple terms and in a way which would be understandable to a general audience) what you are broadly planning to do in your study. Your study will be reviewed by colleagues from different disciplines who will not be familiar with your specific field of research and it may also be reviewed by the lay members of the Research Ethics Committee; therefore avoid jargon and use simple terms. A helpful format may include a sentence or two about the background/"problem" the research is addressing, why it is important, followed by a description of the basic design and target population. Think of it as a snapshot of your study.

PrEP (pre-exposure prophylaxis) is a medicine taken by people at risk for HIV to lower their chances of getting the virus. PrEP was made freely available on the National Health Service (NHS) in England in March 2020 in an effort to end HIV transmission by 2030. In other countries, taking PrEP has been shown to also offer other benefits such as decreasing sexual anxiety, increasing sexual pleasure, and fostering feelings of "reassurance".

Despite this, not much is known about the difference it has made to people in England who access PrEP on the NHS. Existing research mostly comes from other countries and focuses on factors which may not be relevant in the UK, such as insurance-based healthcare.

This project aims to use interviews to explore the experiences of those who have been accessing PrEP through the NHS in England in order to better understand their experiences in the NHS and the impact that accessing PrEP has on their life. The interviews will be used to look for common themes in their experiences to better understand the impact of accessing and taking PrEP.

State the Aims and Objectives of the project in Lay persons' language.

What is the experience of individuals who access pre-exposure prophylaxis through the national health service in England?

Secondary Research Question

How does accessing pre-exposure prophylaxis through the national health service impact individuals' life and mental well-being?

Participant Information

Please explain the number of participants you intend to include in your study and explain your rationale in detail (eg who will be recruited, how, where from; and expected availability of participants). If your study contains multiple parts eg interviews, focus groups, online questionnaires) please clearly explain the numbers and recruitment details for each of these cohorts (see help text).

This study aims to include between 6 and 12 participants in total.

Recruitment

Participants will be recruited simultaneously through self-selection and social media.

Physical posters will be used to encourage participants to participate in the study. Manchester NHS foundation trust have agreed for these posters to be put up within their building but do not consider this recruitment activity and therefore this does not require further ethical approval. If individuals would like to be involved in the study, they are encouraged to make contact with the research team.

Through social media, the study will be advertised through Twitter, Facebook and selected online support groups. The advert will include contact details for the research team. Once contact has been made, eligibility will be confirmed, and participants will be provided with PIS and offered an opportunity to discuss any questions prior to consent to participate being sent.

If the participant wishes to proceed with study participation, then a convenient time will be arranged to conduct the interview. This will be via phone or MS teams.

Unfortunately, as there is no funding for this study, we are unable to finance interpreters. Therefore, individuals who are unable to speak conversational English to the level needed for the interview are not eligible to take part.

Participants will be asked to talk about their experiences of accessing PrEP via the NHS. Questions will be asked based on their responses. Participants will not be required to talk about anything they don't wish. An individual can choose to stop the interview at any time or move on from a question at any point.

Sample

Participants must have accessed PrEP via the National Health Service (NHS) in England since March 2020. Participants will not be excluded if they have also accessed PrEP via the NHS funded IPREx or IMPACT trial in the past, but this information will be collected alongside demographic data to inform the data set.

Inclusion Criteria

- Participant is willing and able to give informed consent for participation in the study.
- Has received PrEP via the NHS
- Participants should be 18 or older

Exclusion Criteria

The participant may not enter the study if ANY of the following apply:

- PrEP was accessed via the Scottish or Welsh NHS
- Aged under 18
- Cannot speak conversational English

Prize Draw

A £30 prize draw has been authorised by Lancaster University (Dr Ian Smith Research Director Senior Lecturer) as an incentive to participate. This is because the targeted population (individuals who have accessed PrEP HIV medication through the NHS) is typically hard to reach through research.

You have selected that the research may involve personal sensitive topics that participants may not be willing to otherwise talk about. Please indicate what discomfort, inconvenience or harm could be caused to the participant and what steps you will take to mitigate or manage these situations.

For the participant there is minimal potential risk during research participation. This study will not directly enquire about experiences of distress but that this may be brought up by participants based on their personal experiences related to accessing PrEP.

The researcher conducting the study (i.e. performing the interviews) is a trainee clinical psychologist who is able to assess for signs of distress and act accordingly. If an individual appears distressed at any point in the interview, the researcher will stop the interview and follow the distress protocol. The interview will only be resumed if the participant is willing and feels able to do so.

In relation to potential burdens for research participants only relevant questions will be asked to keep interviews to an hour. Interviews will also endeavour to be scheduled at a time that best suits participants.

You have indicated that you will collect identifying information from the participants. Please describe all the personal information that you gather for your study which might be used to identify your participants.

Basic demographic data: Name, age, ethnicity, gender.

The Interviews will also be recorded via Microsoft Teams and transcribed.

Please describe how the data will be collected and stored.

Personal data on paper will be made electronic and destroyed immediately afterwards.

Electronic personal data will be kept securely on the university secure network or on a secure cloud (e.g. OneDrive) accessible through the university and which has similar security credentials to the university network.

All personal data will be kept confidential. Qualitative data (transcribed interviews) will be anonymised as far as possible for publication. Names and identifiable information will not be used in any published quotes. Basic demographic information may be included alongside their quote but every effort will be made to anonymise participant identifiable data

Please describe how long the data will be stored and who is responsible for the deletion of the data.

Consent forms and transcripts will be stored for 10 years or 10 years from publication, whichever is longer. These will be anonymised and kept separately. Audio recordings will be kept until the thesis examination at the viva and then destroyed. All other personal data (e.g. to send participants a consent form/copy of the results) will be destroyed within 6 months of the study completion. Katy Bourne (supervisor), or other nominated staff member, will be responsible for the deletion of the data.

Participant Data

Explain what you will video or photograph as part of your project, why it is appropriate and how it will be used.

Interviews will be recorded using the Microsoft Teams recording function. This is to allow for transcription to be carried out and analysed at a later date.

How will you gain consent for the use of video/photography?

Consent for this will be gained through the participant information sheet and consent form.

State your video/photography storage, retention and deletion plans and the reasons why.

Recordings will be kept until the thesis examination at the viva and then destroyed. They will be recorded using the Microsoft Teams recording function and moved to the university secure network or on a secure cloud (e.g. OneDrive) accessible through the university and which has similar security credentials to the university network.

If a participant requests to invoke their 'right to be forgotten' or 'right to erasure' I will contact the Information Governance Manager, for advice. For more information about this please read the guidance [here](#).

I confirm that I will contact the Information Governance Manager.

Will you take all reasonable steps to protect the anonymity of the participants involved in this project?

Yes No

Explain what steps you will take to protect anonymity.

The study staff will ensure that the participants' anonymity is maintained. The participants will be identified only by a participant ID number on all documents. All documents will be stored securely and only accessible by study staff and authorised personnel. The study will comply with the Data Protection Act, which requires data to be anonymised as soon as it is practical to do so.

Information about the Research

What are your dissemination plans? E.g publishing in PhD thesis, publishing in academic journal, presenting in a conference (talk or poster).

This research will be used in part for a doctorate in clinical psychology thesis. It is possible the results may be submitted for publication in an academic journal after the completion of the doctorate.

Online Sources

You have indicated site users have a reasonable expectation of privacy and therefore you will need to obtain consent to use their data for this project. Please explain how you propose to obtain consent.

Informed consent will be sought from participants prior to participation through the use of the participant information sheet and consent form.

General Queries

You have indicated that you will be gathering/working with special category data. Please confirm here how you will comply with data protection law (GDPR) for use of special category personal data.

During the project, the main researcher will store data securely in encrypted files within password-protected folders, within Lancaster University's OneDrive. The user account is also password protected. The passwords for the folders will only be known by the main researchers. Email address data will be stored in the same way, with different passwords applied. An audit trail will be made available for the data file to monitor changes and deletions, meaning older files will be available should any information be modified unintentionally. Long term storage following the end of the project will be facilitated on site at Lancaster University and managed by the Doctorate of Clinical Psychology administration team. Access to this data will be requested if needed by the thesis supervisor Katy Bourne.

Data Storage

How long will you retain the research data?

The research data will be stored for a minimum of 10 years in line with Lancaster University data storage policy.

Personal data on paper will be made electronic and destroyed immediately afterwards.

Electronic personal data will be kept securely on the university secure network or on a secure cloud (e.g. OneDrive) accessible through the university and which has similar security credentials to the university network.

All personal data will be kept confidential and separate from interview responses. Qualitative data will be anonymised as far as possible for publication.

Consent forms and transcripts will be stored for 10 years or 10 years from publication, whichever is longer. These will be anonymised and kept separately. Audio recordings will be kept until the thesis examination at the viva and then destroyed.

How long and where will you store any personal and/or sensitive data?

Email address data will be stored in a password protected file and password protected folder, within a password protected system on Lancaster University's OneDrive. It will be immediately deleted following use for the prize draw and any requested disseminations of the research results summary. The passwords will only be known by the main researchers. The other sensitive anonymised data relates to demographic information. This will also be stored securely in encrypted files within password-protected folders, within Lancaster University's OneDrive. The user account is also password protected.

Please explain when and how you will anonymise data and delete any identifiable record?

Participants will be allocated a unique identifier once the interview has been completed. This can be used to delete any data that has been withdrawn by the participant up to 2 weeks the interview.

All personal data will be kept confidential. Qualitative data will be anonymised as far as possible for publication. Names and identifiable information will not be used in any published quotes. Basic demographic information may be included alongside their quote but every effort will be made to anonymise participant identifiable data

Project Documentation*

Important Notice about uploaded documents:

When your application has been reviewed if you are asked to make any changes to your uploaded documents please highlight the changes on the updated document(s) using the highlighter so that they are easy to see.

Please confirm that you have read and applied, where appropriate, the guidance on completing the Participant Information Sheet, Consent Form, and other related documents and that you followed the guidance in the help button for a quality check of these documents. For information and guidance, please use the relevant link below:

[FST Ethics Webpage](#)

[FHM Ethics Webpage](#)

[FASS-LUMS Ethics Webpage](#)

[REAMS Webpage](#)

I confirm that I have followed the guidance.

In addition to completing this form you must submit all supporting materials.

Please indicate which of the following documents are appropriate for your project:

- I have no updated documents and confirm that all relevant documents were included in previous submissions.
- Advertising materials (posters, emails)
- Research Proposal (DClinPsy)
- Letters/emails of invitation to participate
- Consent forms
- Participant information sheet(s)
- Interview question guides
- Focus group scripts
- Questionnaires, surveys, demographic sheets
- Workshop guide(s)
- Debrief sheet(s)
- Transcription (confidentiality) agreement
- Other
- None of the above.

Please upload the documents in the correct sections below:

Please ensure these are the latest version of the documents to prevent the application being returned for corrections you have already made.

As you are in a DClinPsy course please upload your Research Proposal for this project.

Documents					
Type	Document Name	File Name	Version Date	Version	Size
Research Proposal	Full protocol	Full protocol.docx	03/03/2023	1	1.3 MB

Please upload all consent forms to be used in this project.

Documents					
Type	Document Name	File Name	Version Date	Version	Size
Consent Form	ConsentForm	ConsentForm.docx	03/03/2023	1	226.0 KB

Please upload all Participant Information Sheets:

Documents					
Type	Document Name	File Name	Version Date	Version	Size
Participant Information Sheet	Participant Information Sheet	Participant Information Sheet.docx	03/03/2023	1	50.2 KB

Please upload all advertising materials (posters, emails)

Documents					
Type	Document Name	File Name	Version Date	Version	Size
Advertising materials	Advert	Advert.pdf	03/03/2023	1	854.7 KB

Please upload all different Interview Question Guides.

Documents					
Type	Document Name	File Name	Version Date	Version	Size
Interview question guide	Question schedule	Question schedule.docx			47.2 KB

Please upload a copy of your Debrief sheet.

Documents					
Type	Document Name	File Name	Version Date	Version	Size
Debrief sheet	Debrief form	Debrief form.docx	03/03/2023	1	50.6 KB

Declaration

Please Note

Research Services monitors projects entered into the online system, and may select projects for quality control.

All research at Lancaster university must comply with the LU data storage and governance guidance as well as the General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018. ([Data Protection Guidance webpage](#))

- I confirm that I have read and will comply with the LU Data Storage and Governance guidance and that my data use and storage plans comply with the General data Protection Regulation (GDPR) and the UK Data Protection Act 2018.

Have you that you have undertaken a health and safety risk assessment for your project through your departmental process? ([Health and Safety Guidance](#))

- I have undertaken a health and safety assesment for your project through my departmental process, and where required will follow the appropriate guidance for the control and management of any foreseeable risks.

When you are satisfied that this application has been completed please click "Request" below to send this application to your supervisor for approval.

Signed: This form was signed by Dr Katy Bourne (k.bourne@lancaster.ac.uk) on 05/04/2023 16:51

As you have stated that you are not the PI you will need to have the PI sign off on this application.

As the applicant please click "**Request**". Please note that you cannot request a signature from yourself.

Signed: This form was signed by Dr Katy Bourne (k.bourne@lancaster.ac.uk) on 05/04/2023 16:51

Please read the terms and conditions below:

- You have read and will abide by [Lancaster University's Code of Practice](#) and will ensure that all staff and students involved in the project will also abide by it.
- If appropriate a confidentiality agreement will be used.
- You will complete a data management plan with the Library if appropriate. [Guidance from Library](#).
- You will provide your contact details, as well as those of either your supervisor (for students) or an appropriate person for complaints (such as HoD) to any participants with whom you interact, so they know whom to contact in case of questions or complaints?
- That University policy will be followed for secure storage of identifiable data on all portable devices and if necessary you will seek [guidance from ISS](#).
- That you have completed the ISS Information Security training and passed the assessment.
- That you will abide by Lancaster University's lone working policy for field work if appropriate.
- On behalf of the institution you accept responsibility for the project in relation to promoting good research practice and the prevention of misconduct (including plagiarism and fabrication or misrepresentation of results).
- To the best of your knowledge the information you have provided is correct at the time of submission.
- If anything changes in your research project you will submit an amendment.

Applicant Only: To complete and submit this application please click "Sign" below:

Signed: This form was signed by Holly Sidaway (h.sidaway@lancaster.ac.uk) on 05/04/2023 17:12

Appendices

Appendix 4-A - Approval evidence

Firefox

<https://outlook.office.com/mail/id/AAMkADRmYzU2MTk1LTY0N...>

[External] FHM-2023-3433-RECR-2 Ethics Approval from FREC

donotreply@infonetica.net <donotreply@infonetica.net>

Tue 18/04/2023 13:17

To: Sidaway, Holly (Postgraduate Researcher) <h.sidaway@lancaster.ac.uk>

Cc: Bourne, Katy <k.bourne@lancaster.ac.uk>

📎 1 attachments (118 KB)

Letter.pdf

This email originated outside the University. Check before clicking links or attachments.

Name: Holly Sidaway

Supervisor: Katy Bourne

Department: Clinical Psychology

FHM REC Reference: FHM-2023-3433-RECR-2

Title: Experiences of PrEP being freely available on the National Health Service: findings from a qualitative study in England

Dear Holly Sidaway,

Thank you for submitting your ethics application in REAMS, Lancaster University's online ethics review system for research. The application was recommended for approval by the FHM Research Ethics Committee, and on behalf of the Committee, I can confirm that approval has been granted for this application.

As Principal Investigator/Co-Investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licences and approvals have been obtained.
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress).
- submitting any changes to your application, including in your participant facing materials (see attached amendment guidance).

Please keep a copy of this email for your records. Please contact me if you have any queries or require further information.

Yours sincerely,

Dr Laura Machin

Chair of the Faculty of Health and Medicine Research Ethics Committee

fhmresearchsupport@lancaster.ac.uk

Appendix 4-B - Full protocol**SYNOPSIS**

Study Title	Experiences of PrEP being freely available on the National Health Service: findings from a qualitative study in England
Internal ref. no. / short title	TBC
Study Design	Qualitative study, Thematic analysis.
Study Participants	Individuals who have accessed PrEP via the NHS.
Planned Sample Size	6-12
Planned Study Period	January 2023 – 2025
	Objectives
Primary	This study aims to examine and gain an in-depth understanding of the experiences of those who access PrEP through National Health Service in England.

BACKGROUND AND RATIONALE

It's estimated that 37.7 million people across the globe are living with human immunodeficiency virus (HIV) (HIV.gov, 2021), 97,740 of which are living with HIV in England. Pre-exposure prophylaxis (PrEP) is a medication that has been shown to be highly effective in reducing the likelihood of HIV transmission when taken correctly. Some research has suggested that with consistent daily use, PrEP can be up to 99% effective in reducing sexually transmitted HIV (Grant et al., 2010).

As well as being a highly effective biomedical intervention, PrEP has also been found to offer profound psychological benefits such as a decrease in sexual anxiety, increased sexual and a sense of "security" and "reassurance" for users (Brooks et al., 2012; Hojilla et al., 2015; Whitfield et al., 2019). As our understanding of the psychological impact of HIV and HIV medication increases, there is a growing emphasis on the role of Clinical Psychology within HIV care. In the 'Standards for psychological support for adults living with HIV' document set out by the British HIV Association in 2011, it states that all people living with HIV should have access to a range of psychological care (BHIVA, 2011). This is because not only do those living with HIV have a higher prevalence of mental health difficulties (Hartzell, Janke, & Weintrob, 2008; Lorenc et al., 2014), but they are also more likely to belong to groups who experience high levels of stigma and discrimination vulnerable and stigmatised groups (BHIVA, 2011).

PrEP became freely available in England via the National Health Service in the autumn of 2020 as part of the UK government's commitment to the UNAIDS target to end HIV transmission by 2030 (Terrence Higgins Trust, 2019; UK Health Security Agency, 2020).

Since there has been an observed decrease in new HIV diagnoses in the UK, especially for gay and bisexual men who say a 41% reduction in 2019 to 2021, but it is unclear how much of this is related to the impact of the COVID-19. The pandemic resulted in lower documentation, lower testing, and lower availability of HIV services. Illustrative of this is the fact that for the first time the annual UK HIV report (UK Health and Security Agency, 2021) which documents the previous year's HIV epidemic trends was published largely based on only English statistics as figures from Scotland were not available and those from Wales and Northern Ireland were incomplete. Additionally, as PrEP was only made routinely available in late 2020 for the UK, it is unknown whether PrEP use has increased or decreased since then. It is therefore vital that we continue to explore the experience of PrEP users in England.

Aside from numerous reviews on how to improve PrEP adherence (Young et al., 2020; Sin and DiMatteo, 2014; Safren, Gershuny, & Hendriksen, 2003) and service delivery, there is a significant lack of qualitative research into individuals experience of how accessing PrEP impacts their lives. Of the research that does exist; it is location specific, typically based in the United States, and overshadowed by the nuances of non-public health care (e.g. insurance, cost, poverty).

There are also clear geographical gaps within the literature, with little novel research coming out of the United Kingdom since the IMPACT trial. Key policies are in place to drive forward a reduction in new HIV infections in the United Kingdom but there is little research into service users' experience of the impact of PrEP on their mental health, wellbeing and daily lives. Furthermore, research that has explored barriers in PrEP uptake have also demonstrated that there is lack of universality and these barriers are often population-specific, with co-occurring systemic inequalities such as homophobia, poverty, lack of education, socio-economic disparity, and racism.

The United Kingdom presents an innovative perspective on the accessibility of PrEP within a national health service that is free at the point of access. UK-specific research may provide new insights into how

RESEARCH QUESTION/AIMS

Principle Research Question

What is the experience of individuals who access pre-exposure prophylaxis through the national health service in England?

Secondary Research Question

How does accessing pre-exposure prophylaxis through the national health service impact individuals' life and mental well-being?

STUDY DESIGN AND METHODS OF DATA COLLECTION AND DATA ANALYSIS

Design

This project has a qualitative design using reflective thematic analysis (RTA). A qualitative approach was chosen specifically to focus on developing a contextualized understanding of

this topic. By providing a contextualized perspective of accessing PrEP via the NHS, qualitative research has valuable utility in informing the design, implementation, and dissemination of the medication by seeking information on the experiences of those who have already done so.

Data collection

The primary aim of the study is to gain an understanding of participants' experiences by collecting data on the experiences of individuals who have accessed pre-exposure prophylaxis through the National Health Service in England.

Semi-structured interviews will therefore be conducted to gain participants' experiences and their thoughts and opinions on these experiences. This data will be analysed using RTA which is a method for developing, analysing and interpreting patterns across a qualitative dataset. Reflective TA capitalises on the researcher's unique and unavoidable position in the process of analysis.

Recruitment

Participants will be recruited simultaneously through self-selection and social media.

Physical posters will be used to encourage participants to participate in the study. Manchester NHS foundation trust have agreed for these posters to be put up within their building but do not consider this recruitment activity and therefore this does not require further ethical approval. If individuals would like to be involved in the study, they are encouraged to make contact with the research team.

Through social media, the study will be advertised through Twitter, Facebook and selected online support groups. The advert will include contact details for the research team. Once contact has been made, eligibility will be confirmed, and participants will be provided with PIS and offered an opportunity to discuss any questions prior to consent to participate being sort. If the participant wishes to proceed with study participation, then a convenient time will be arranged to conduct the interview. This will be via phone or MS teams.

Unfortunately, as there is no funding for this study, we are unable to finance interpreters. Therefore, individuals who are unable to speak conversational English to the level needed for the interview are not eligible to take part.

Participants will be asked to talk about their experiences of accessing PrEP via the NHS. Questions will be asked based on their responses. Participants will not be required to talk about anything they don't wish. An individual can choose to stop the interview at any time or move on from a question at any point.

Service user involvement

Experts in the subject area have been involved in the study design; HIV Support - Renaissance UK provided consultation on research materials.

SAMPLE AND RECRUITMENT

Sample

Participants must have accessed PrEP via the National Health Service (NHS) in England since March 2020. Participants will not be excluded if they have also accessed PrEP via the NHS funded iPrEx or IMPACT trial in the past, but this information will be collected alongside demographic data to inform the data set.

Inclusion Criteria

- Participant is willing and able to give informed consent for participation in the study.
- Has received Prep via the NHS
- Participants should be 18 or older

Exclusion Criteria

The participant may not enter the study if ANY of the following apply:

- PrEP was accessed via the Scottish or Welsh NHS
- Aged under 18
- Cannot speak conversational English

Consent

The participant must personally sign and date the latest approved version of the Informed Consent form before any study specific activities are undertaken.

The Participant Information sheet and Informed Consent sheet will be presented to the participants detailing no less than: the exact nature of the study; what it will involve for the participant; the implications and constraints of the protocol; any risks involved in taking part. It will be clearly stated when the participant can withdraw their data.

Participants will have at least 24 hours to read the PIS before consenting to take part. Participants will be given as much time as they like to think about taking part or asking questions whilst the project is actively recruiting.

Informed Consent will then be obtained by means of participant dated signature and dated signature of the person who presented and obtained the Informed Consent.

Assessment and management of risk

Potential Risk and Management for Participants

For the participant there is minimal potential risk during research participation. This study will not directly enquire about experiences of distress but that this may be brought up by participants based on their personal experiences related to accessing PrP.

The researcher conducting the study (i.e. performing the interviews) is a trainee clinical psychologist who is able to assess for signs of distress and act accordingly. If an individual

appears distressed at any point in the interview, the researcher will stop the interview and follow the distress protocol. The interview will only be resumed if the participant is willing and feels able to do so.

In relation to potential burdens for research participants only relevant questions will be asked to keep interviews to an hour. Interviews will also endeavour to be scheduled at a time that best suits participants

Potential Risk and Management for Researcher

Interviews will be conducted remotely so there is no in-person risk to the researcher.

If the researcher experiences distress during the study they will be able to speak to their supervisors and they will receive regular supervision throughout the study.

STUDY ACTIVITIES

Recruitment

For this project, participants will be recruited through self-selection through advertising and social media.

Through social media, the study will be advertised through Twitter, Facebook and selected online support groups. The researcher will be contacted by any interested participants.

If participants would like to become involved in the project, consent forms and more detailed information on the project will be shared. Once this is complete the interview will be scheduled.

Discontinuation/Withdrawal of Participants from Study

Each participant has the right to cease participation in the study at any time

In addition, the researcher may discontinue a participant from the study at any time if the researcher considers it necessary for any reason including:

- Ineligibility (either arising during the study or retrospectively having been overlooked at screening)
- Significant protocol deviation
- Significant non-compliance with study requirements
- Withdrawal of Consent

If participants wish to withdraw from the study at any point before or during taking the interview, their data will be removed and destroyed. In this case data means the information, views, ideas, etc, that participants have shared. If participants complete the interview, they have two weeks after this to withdraw if they no longer want their data included.

Unfortunately, after this point, all data will be anonymised and pooled with data from other participants, so it will no longer be possible to identify and withdraw their data.

Definition of End of Study

The end of study is the date of the dclinpsy viva defence.

ANALYSIS

The statistical method chosen to analyse the data in this study will be thematic analysis as described by Braun and Clarke (2021), which suggests six phases. The six phases include reading the data, generating codes, generating themes, reviewing themes, defining and naming themes, and producing the report. Thematic analysis lends itself to use in exploratory interviews, where there will not be a preconceived idea of the possible results. It is also advantageous as it can be used collaboratively with participants, which is particularly relevant within this study, as collaboration is necessary to build a trusting relationship, and therefore necessary to produce the data desired for this project.

A critical realist epistemological stance to analysis will be taken, recognising that there are multiple individual realities, but taking a pragmatic approach to analysing data at face value, drawing on the perspectives of individuals as they choose to represent themselves through discussion.

The Number of Participants

This study aims to include between 8 and 12 participants in total

DATA MANAGEMENT

Data Recording and Record Keeping

Personal data on paper will be made electronic and destroyed immediately afterwards.

Electronic personal data will be kept securely on the university secure network or on a secure cloud (e.g. OneDrive) accessible through the university and which has similar security credentials to the university network.

All personal data will be kept confidential. Qualitative data will be anonymised as far as possible for publication. Names and identifiable information will not be used in any published quotes. Basic demographic information may be included alongside their quote but every effort will be made to anonymise participant identifiable data

ETHICAL AND REGULATORY CONSIDERATIONS

Written informed consent to participate and be Recorded will be obtained from all participants. Data management and storage will be subject to the UK Data Protection Act 1998. Ethical approval for the current study was obtained from the Faculty of Health and Medicine Research Ethics Committee (FHM-2023-3433-RECR-2).

Approvals

The protocol, informed consent form, participant information sheet and any proposed advertising material will be submitted to an appropriate Research Ethics Committee.

The researcher will submit and, where necessary, obtain approval for all substantial amendments to the original approved documents.

Participant Confidentiality

The study staff will ensure that the participants' anonymity is maintained. The participants will be identified only by a participant ID number on all documents. All documents will be stored securely and only accessible by study staff and authorised personnel. The study will comply with the Data Protection Act, which requires data to be anonymised as soon as it is practical to do so.

Other Ethical Considerations

This project requires careful thought regarding ethical considerations. HIV is already known to affect some of the most vulnerable individuals in society and this research is hoping to engage a population who may have experience of historical inequalities and discrimination. It is therefore important to acknowledge that asking questions about accessing HIV-related health care may bring up some strong emotions for participants. This project will also utilise informed consent to mitigate some of the potential risks of asking emotionally charged questions during the interview. It may also be helpful to develop a simple risk protocol for managing distress within the context of the interview. For example, a modified version of Draucker et al's (2009) 'Distress Protocols for research on Sensitive Topics'.

Co-production

This project includes an consultation from expert by experience group (Renaissance), one research supervisor (KB) and one field supervisor (SR). The expert by experience group will be involved in various aspects of the research, including design, recruitment, write-up and dissemination.

In developing the project, the research team has also consulted the service user involvement leads at specific National Health Service organisation. It is hoped that co-production with service users, clinicians and researchers will continue throughout the project.

PUBLICATION POLICY

The researcher and research supervisors will be involved in reviewing drafts of the manuscripts, abstracts, press releases and any other publications arising from the study. Authors will acknowledge that the study was funded by the University of Lancaster. Authorship will be determined in accordance with the ICMJE guidelines and other contributors will be acknowledged.

Authorship – Holly Sidaway, Dr Katy Bourne, Dr Sarah Rutter

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Appendix 4-C - Participant Information Sheet (PIS) and Consent form**PARTICIPANT INFORMATION SHEET*****Experiences of PrEP being freely available on the National Health Service in England***

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is Holly Sidaway, and I am conducting this research as a student on the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore the experiences of those who have been accessing PrEP through the National Health Service (NHS) in England in order to better understand their experiences in the NHS and the impact that accessing PrEP has on their life.

Why have I been approached?

You have been approached because the study requires information from people who have accessed PrEP through the NHS at some point between March 2020 and now.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. Your participation is voluntary, and you are free to withdraw at any time without giving any reason.

What will I be asked to do if I take part?

If you decide you would like to take part, you will be asked to speak with me about your experiences accessing PrEP through the NHS. I will organise a date with you on which we can speak over MS teams. This will take around an hour. I will ask you some questions on your experiences related to PrEP and the effect it has had on your life. Following this interview, I will transcribe the data and analyse it, along with information from other people who take part, to look for key themes.

Will my data be Identifiable?

- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this project.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, are at significant risk of harm, I may have to break confidentiality and speak to a colleague about this to ensure the safety of you and others. If possible, I will tell you if I have to do this.

Will my data be stored securely?

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data.

- Recordings will be destroyed and/or deleted once the project has been submitted for publication/examined

What will happen to the results?

The results will be summarised and reported in a dissertation and may be submitted for publication in an academic or professional journal.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation, you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

We are offering participants the chance to enter a prize draw for a £30 voucher as a thank you for your time.

What if I change my mind?

It's okay to change your mind. If you wish to withdraw from the study at any point before or during taking the interview, I will remove your data and destroy it. Data means the information, views, ideas, etc, that you and other participants will have shared with me. If you complete the interview, you have two weeks after this to withdraw if you no longer want your data included. Unfortunately, after this point, all data will be anonymised and pooled with data from other participants, so it will no longer be possible to identify and withdraw your data.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact:

Holly Sidaway (Trainee Clinical Psychologist)

Email: h.sidaway@lancaster.ac.uk

Division of Health Research

Health Innovation One

Sir John Fisher Drive

Lancaster University

Lancaster

LA1 4AT

Katy Bourne (Lecturer in Clinical Psychologist)

Email: k.bourne@lancaster.ac.uk

Health Research

Division of Health Research

Health Innovation One

Sir John Fisher Drive

Lancaster University

Lancaster

LA1 4AT

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Name of Research Director for your Division: Dr Ian Smith

Tel: (01524) 592282

Email: i.smith@lancaster.ac.uk

Division: Research Director Senior Lecturer of Clinical Psychology

Lancaster University
Lancaster
LA1 4YG

If you wish to speak to someone outside of the Doctorate of Clinical Psychology Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

Resources in the event of distress

Should you feel distressed either as a result of taking part or in the future, the following resources may be of assistance:

1. [NHS Sexual Health Clinic](#) - Find a sexual health clinic near you (NHS)
2. [Terrence Higgins Trust](#) - Online counselling for people living with HIV -
3. [Prepster](#) - Educating and agitating for PrEP in England and beyond
4. [The HIV Justice Network](#) - The HIV Justice Network (HJN) is the leading community-based non-governmental organisation building a co-ordinated, effective global response to HIV criminalisation

There are also some organisations in the local Lancashire area that have provided consultation on this study:

1. [Renaissance UK](#) - Renaissance UK, (formerly Drugline Lancashire), is a Sexual Health and Substance Misuse charity based in the North West of England.
2. [BePrEPed.co.uk](#) - BePrEP.co.uk is a Renaissance UK-powered campaign to raise awareness about Pre-Exposure Prophylaxis.
3. [Out In The Bay](#) - Out in the Bay support the LGBTQI community in Morecambe and Lancaster through offering Equality and Diversity training to the local community and holding various support groups.

If you feel you need to talk to someone right away, the [NHS mental health helpline](#) page has a list of organisations you can call for immediate support.

CONSENT FORM

Project Title: Experiences of PrEP being freely available on the National Health Service in England

Name of Researchers: Holly Sidaway - Email: h.sidaway@lancaster.ac.uk

Please read the following carefully:

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. If I withdraw within 2 weeks of commencement of the study my data will be removed.
3. I understand that any information given by me may be used in future reports, academic articles, publications or presentations by the researcher/s.
4. I understand that my name will not appear in any reports, articles or presentation without my consent.
5. I understand that any interviews recorded and transcribed and that data will be protected on encrypted devices and kept secure.
6. I understand that data will be kept according to University guidelines for a minimum of 10 years after the end of the study.
7. I agree to take part in the above study.

Name of participant:	Date:	Signature:

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of Researcher/person taking the consent _____

Date _____ **DD/MM/YYYY**

One copy of this form will be given to the participant and the original kept in the files of the researcher at Lancaster University

Appendix 4-D - Debrief Form**DEBRIEF FORM**

Project title: Experiences of PrEP being freely available on the National Health Service in England
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Thank you for your participation in this research study!

What you should know about this study: This study aims to explore individuals experience with PrEP through the National Health Service in England. Previous studies have indicated there may be psychological benefits associated with accessing PrEP medication. Some of these are; a decrease in sexual anxiety, increased sexual esteem and a sense of "security" and "reassurance" for users (Brooks et al., 2012; Hojilla et al., 2015; Whitfield et al., 2019).

PrEP became freely available in England via the National Health Service in the autumn of 2020 as part of the UK government's commitment to the UNAIDS target to end HIV transmission by 2030 (Terrence Higgins Trust, 2019; UK Health Security Agency, 2020). Despite this, there have been no studies specifically exploring individual's experience of how accessing PrEP might impacts their lives. Of the research that does exist; it is location specific, typically based in the United States, and overshadowed by the nuances of non-public health care (e.g. insurance, cost, poverty).

Therefore, this study wants to further explore the psychological impact of PrEP within the specific context on the National Health Service in England.

Aims of the study:

This project aims to explore the experiences of those who have been accessing PrEP through the NHS in England in order to better understand their experiences in the NHS and the impact that accessing PrEP has on their life.

Confidentiality:

The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. All reasonable steps will be taken to protect the anonymity of the participants involved in this

project. All your personal data you have provided will be confidential (such as name, email address etc) and will be kept separately from your interview responses.

The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data.

- Recordings will be destroyed and/or deleted once the project has been submitted for publication/examined

There are some limits to confidentiality: if what is said in the interview makes me think that you, or someone else, are at significant risk of harm, I may have to break confidentiality and speak to a colleague about this to ensure the safety of you and others. If possible, I will tell you if I have to do this.

What if I change my mind?

It's okay to change your mind, however, now the interview has been completed you have two weeks after today to withdraw if you no longer want your data included. Unfortunately, after this point, all data will be anonymised and pooled with data from other participants, so it will no longer be possible to identify and withdraw your data.

Feedback of results:

If you would like to receive a copy of the completed study, please contact Holly Sidaway at h.sidaway@lancaster.ac.uk and provide consent for your email to be stored separately. You will be informed once the project is completed and receive a digital copy of the report.

Complaints:

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Name of Research Director for your Division: Dr Ian Smith

Tel: (01524) 592282

Email: i.smith@lancaster.ac.uk

Division: Research Director Senior Lecturer of Clinical Psychology

Lancaster University
Lancaster
LA1 4YG

If you wish to speak to someone outside of the Doctorate of Clinical Psychology Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973

Chair of FHM REC Email: l.machin@lancaster.ac.uk

Faculty of Health and Medicine
(Lancaster Medical School)

Lancaster University
Lancaster
LA1 4YG

Resources

Should you feel distressed either as a result of taking part or in the future, the following resources may be of assistance:

5. [NHS Sexual Health Clinic](#) - Find a sexual health clinic near you (NHS)
6. [Terrence Higgins Trust](#) - Online counselling for people living with HIV -
7. [Prepster](#) - Educating and agitating for PrEP in England and beyond
8. [The HIV Justice Network](#) - The HIV Justice Network (HJN) is the leading community-based non-governmental organisation building a co-ordinated, effective global response to HIV criminalisation

There are also some organisations in the local Lancashire area that have provided consultation on this study:

4. [Renaissance UK](#) - Renaissance UK, (formerly Drugline Lancashire), is a Sexual Health and Substance Misuse charity based in the North West of England.
5. [BePrEPed.co.uk](#) - BePrEP.co.uk is a Renaissance UK-powered campaign to raise awareness about Pre-Exposure Prophylaxis.

6. [Out In The Bay](#) - Out in the Bay support the LGBTQI community in Morecambe and Lancaster through offering Equality and Diversity training to the local community and holding various support groups.

If you feel you need to talk to someone right away, the [NHS mental health helpline](#) page has a list of organisations you can call for immediate support.

Appendix 4-E - Advert

CALL FOR PARTICIPANTS!

Have you taken  on the NHS?

We are currently seeking participants to take part in a study exploring what it has been like to access pre-exposure prophylaxis (PrEP) via the National Health Service (NHS) in the UK.

If you are living in England and you have accessed PrEP using the NHS, we would love to hear from you.

You must be:

- Someone who has accessed PrEP via the NHS
- Aged 18 or over
- Speak English

You can contact me directly at:
H.sidaway@lancaster.ac.uk or



Lancaster
University



NHS

Appendix 4-F - Question Schedule**PrEP PROJECT QUESTION SCHEDULE****Semi-structured interview guide**

Thank you for agreeing to talk with me today. The questions I am going to ask don't have right or wrong answers. I am interested in learning more about your experiences accessing PrEP via the NHS in England. Reminder about the recording/ consent/ use of work/anonymity

Warm-up questions

How long have you been taking PrEP?

Do you know any other people who take PrEP?

Verify PrEP Use Status

OK, just to verify: have you ever taken PrEP (pre-exposure prophylaxis, sometimes known as Truvada), the pill that helps prevent HIV infection?

- YES/ NO (thank and discontinue interview)/ DON'T KNOW (thank and discontinue interview)

Questions**Decision to take PrEP**

1. How did you first hear about PrEP? (IF NEEDED: What kinds of things had you heard about? Did you know other people taking it?)
2. What made you interested in taking PrEP? Vs Why did you decide PrEP was for you?
 - *Probe:* Risk perceptions, other HIV prevention options, other people who may have influenced decision (partner, outreach worker, etc.)

Experience Using PrEP

3. How was the experience of getting PrEP (prescriptions)?
 - *Probe:* How did you access it? Was it easy to find out? Was it easy to get an appointment? Positive/negative reflections. Has this changed over time? Has any of this changed over time? E.g. did it take time to have any positive psychological benefits or was it quite instant?
4. Can you tell me a little bit about how PrEP fit into your life?
 - *Probe:* effect on life, sexual behaviour, mental health, physical health. Has any of this changed over time? E.g. did it take time to have any positive psychological benefits or was it quite instant?

5. Tell me about how you used PrEP? (direct delivery/weekly clinic pick-up/schedule).
 - *Probe:* What do you see as the benefits of the delivery method you chose? What do you see as the negative aspects of the delivery method you chose? What are the positive/negative aspects of the other method?
 - *Probe:* What sorts of things matter when thinking about how to get PrEP (e.g., convenience, stigma, privacy, etc.)? What other delivery methods would you like to see offered?
6. Did you have any concerns about taking PrEP?
 - *Probe:* Cost, effectiveness, clinic visits, side effects, access to the medication, storing medication, stigma, etc. Did they raise this with medical staff or anyone else? If so, how did they respond? Was it helpful?
7. How did taking PrEP change your sexual experience?
 - *Probe:* (e.g., related to condom use, choice of partners, or other issues around sex? Decreased anxiety, sense of control, ways of hooking up, types of sex)

Continued/discontinued use of PrEP

8. Do you still take PrEP?
 - *Probe:* why/why not?
9. Looking back, what kind of things might have helped you have a better experience with PrEP or helped you to stay on PrEP?
10. DO you think PrEP has had any impact on how you feel about yourself
 - *Probe:* Experiences of the views of others - staff / family / friends / society as a whole and how these impacts on them?
11. Anything else?
 - *Probe:* If there was one thing you could change, what would it be? Wider societal issues, or could be small and specific about process of accessing PrEP?

Appendix 4-G - Distress Protocol for Participants**DISTRESS PROTOCOL (FOR PARTICIPANTS)****Distress**

A participant indicates they are experiencing a high level of stress or emotional distress.

OR

Exhibit behaviours suggestive that the discussion/interview is too stressful such as uncontrolled crying, shaking etc

Stage 1 response

1. Stop the discussion/interview.
2. Offer support and allow the participant time to regroup
3. Assess mental status (with the intention of determining if the participant is experiencing acute emotional distress beyond what would normally be expected in an interview about a sensitive topic):
 - Tell me what thoughts you are having?
 - Tell me what you are feeling right now?
 - Do you feel you are able to go on about your day?
 - Do you feel safe?

Review

If participant feels able to carry on resume interview/discussion

If participant is unable to carry on go to stage 2

Stage 2

End discussion and support participants to contact their mental health provider (e.g. GP, emergency room or local crisis service) or provide alternative mental health support (such as support lines). The researcher can also offer, with participant consent, for a member of the research team to contact services on their behalf OR contact a member of the health care team treating them at for further advice/support

If the participant's distress reflect imminent danger, seek to contact local authorities to support the participant and immediately inform the research supervisor.

Follow up

Follow participant up with a courtesy call (if participant consents)

Appendix 4-H - Distress Protocol for Interviewer**DISTRESS PROTOCOL (Researcher)****Pre-collection data**

- The researcher should consider the potential physical and psychological impact on the researcher of the participant's description of life experiences
- The researcher will be limited to 4 interviews per week.
- The researcher should be aware of the potential for emotional exhaustion

Data collection stage

- There should be regularly scheduled debriefing sessions with the researcher's research tutor during research collection
- The researcher should journal their thoughts and feelings, which may then become part of fieldwork notes in some research approaches

Analysis

- The researcher should alert the other individuals involved in the analysis of the data to any potentially "challenging" or "difficult" interviews.
- Those involved in the analysis should attend regularly scheduled debriefing sessions with the research supervisor.

Follow up

- The researcher should be encouraged to access a research supervisor if they experience increased distress in the hours/days following transcription.