UNDERSTANDING THE PrEP AND SEXUAL HEALTH NEEDS AND EXPERIENCES OF YOUNG (18-25) GBMSM IN LONDON

QUALITATIVE RESEARCH REPORT

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"DIFFICULTIES ACCESSING SEXUAL HEALTH CLINICS IS THE NUMBER ONE BARRIER TO ACCESSING PrEP AMONG YOUNG GBMSM."

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1. RATIONALE

Indicators suggest that young (aged 18-25) gay, bisexual and other men who have sex with men (GBMSM) are a sub-population with particular needs and experiences of sexual health. For instance, 2022 data from the UK Health Security Agency shows that young GBMSM have the highest diagnoses of the most common STIs – chlamydia, gonorrhoea and syphilis.[1,2]

Data also suggests that young GBMSM may have a different relationship to HIV PrEP compared to older men. Reports from England's 2017-2020 PrEP IMPACT Trial show that young GBMSM were less likely than other men to take up HIV PrEP – an observation that has been flagged by researchers and clinicians as "of particular concern."[3]

Undergirding the slower uptake of HIV PrEP among young GBMSM is the possibility that this cohort have a different relationship to HIV compared to other generations. Many young GBMSM have made their sexual debut since the advent of HIV PrEP – its free provision by the NHS and it becoming established (in part, through campaigning) as an important tool for HIV prevention – as well as significant advances in the treatment of HIV (including the collective awareness that HIV cannot be sexually transmitted if a person has an 'undetectable' viral load). These advances have made measurable differences to the landscape of sexual health and HIV within which newly or recently sexually active GBMSM are coming of age[4] and these shifting relationships to the HIV epidemic may or may not account for some of young GBMSM's sexual health decision making.

Taken together, these observations suggest there is a need for a greater understanding of young GBMSM's relationships to sexual health and sexual health services – in particular, HIV PrEP provision. Not only is such an understanding integral for better defining the needs of young GBMSM – needs that are only roughly sketched by quantitative (numerical) data – it is a vital way of ensuring that resources and programmes of work developed to meet these needs are tailored to the experiences of the people they intend to serve.

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1 See: https://www.gov.uk/government/statistics/sexually-transmitted-infections-stis-annual-data-tables/sexually-transmitted-infections-and-screening-for-chlamydia-in-england-2022-report

2 The 2022 UKHSA data highlights GBMSM, young people (aged 18-24) and Black communities as "populations with greater sexual health needs" based on elevated rates of diagnosis (UK Health Security Agency, 2023). The data provided by UKHSA indicates that these trends sharpen for sub-populations at the intersections of these three groups. For example, as stated, young GBMSM are at the highest risk among all GBMSM of testing positive for an STI. More granular data showing the rates of diagnosis among young, Black GBMSM is not available to comment on.

3 See Sullivan et al. (2023): https://doi.org/10.1016/S2352-3018(23)00256-4

4 It is worth noting that young GBMSM are not the only cohort of GBMSM that may have recently made their sexual debut. A number of GBMSM may only begin to identify as gay or bisexual or explore sex with men at a later age. As such, a number of the findings presented in this document may apply not only to GBMSM who are young in chronological age but also to GBMSM of any age who have recently made their sexual debut.

2. METHODS

In order to better understand their relationships to sexual health, sexual health services and, in particular, HIV PrEP, The Love Tank CIC conducted focus groups with young GBMSM (18-25) in October and November 2023. These focus groups were also conducted in support of a related piece of research, evaluating the acceptability of a potential model for providing HIV PrEP outside of sexual health clinics. The feedback on the HIV PrEP model provided by focus group participants is not presented in this report but is available upon request (by email to research@prepster.info).

To be eligible for the study, participants had to be GBMSM – including transgender men and non-binary people who have sex with GBMSM – aged between 18 and 25 and living in London. To ensure a broad range of perspectives, the focus groups were conducted with a mix of both HIV PrEP users and non-users (i.e. people who were not currently using HIV PrEP but are eligible for it)[5]. Non-users included both people who have never used HIV PrEP before and people who have used HIV PrEP before but have, for any reason, discontinued.

Participants were recruited to the study through mailing lists known to The Love Tank (including university mailing lists), broadcasts on Grindr (the hookup app), and social media posts on X (formerly known as Twitter) and Instagram. Potential participants were invited to complete a survey to express their interest and confirm their eligibility for the study. Individuals selected to take part were contacted by email and asked to complete a consent form and provide some basic demographic information.

In all, 18 young GBMSM – including 13 PrEP users and 5 non-PrEP users (3 of whom had never used PrEP) – participated in four, 90-minute focus groups at The Love Tank's offices in East London. Participants were ethnically diverse: the majority (10) coming from non-white or mixed backgrounds.[6] It is important to note that, because of the eligibility criteria, no participants in the study were living with a positive HIV diagnosis.

In the first half of the focus groups, participants were asked questions about their experiences of and relationships to sexual health services and information, their relationships to HIV and sexual health in general, and their experiences of HIV PrEP. The second half of the focus groups concerned the PrEP provision model described above. By way of thanks, all participants were given £30 at the end of the session.

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5 We define PrEP eligibility as someone who has tested HIV-negative at the time of their last HIV test and has had condomless anal sex with a new male partner since that test *or* an intention or desire to have condomless anal sex with men.

6 The self-reported ethnicities of participants were as follows: White British (7), White European (1), Latin American (1), White and Latin American (1), White and Black African (2), Black British (3), Black (1), Caribbean (1), Chinese (1).

3. FINDINGS

Major findings from the focus groups are outlined below. Where it is beneficial, key findings are illustrated with anonymised quotes from participants (who are identified as a PrEP user or non-user where this is considered relevant).

3.1 Relationships to HIV and PrEP

i. Acceptability of PrEP

Across all participants, PrEP was considered a highly acceptable and valued tool for HIV prevention. Even non-users – including people who had never used PrEP before – regarded PrEP as something favourable and expressed only mild concerns about using it (see Section 3.2.iii).

PrEP users were flexible about how they took PrEP with some participants taking PrEP daily and others taking PrEP in an event-based capacity. Some participants described regularly switching between event-based and daily dosing depending on how much sex they were having with new sexual partners – for instance, when opening up a monogamous relationship. A number of participants described taking up daily dosing of PrEP (moving either from event-based dosing or reinitiating PrEP entirely) when coming out of a 'dry spell' into an extended period of having lots of sex with new partners.

> **"When I know I'm going to be more sexually active, I take PrEP for like two, three weeks, four weeks – whatever I feel like – and when that desire kind of fades down, I stop taking because I don't see myself having sex."** ***(PrEP user)***

One participant noted that he had moved from daily dosing to event-based dosing because he had been struggling to get regular clinic appointments (see Section 3.3.ii). Participants clearly valued the flexibility of PrEP dosing regimens – and had a good understanding of how they worked – but only when they were in control of making a change and not when they felt compelled to do so.

ii. PrEP and HIV anxieties

Participants who used PrEP universally expressed that taking PrEP helped to eliminate anxieties they felt about acquiring HIV. Participants felt that this enabled them to have sex without worry and to feel more satisfaction regarding sex in general (for instance, feeling that they could be more carefree, have sex more spontaneously, or with many different partners).

The majority of participants also noted that other advances in the landscape of HIV treatment and prevention had helped to change their feelings about

acquiring HIV. For instance, many participants suggested that the knowledge that 'undetectable = untransmittable' (or 'U=U') had altered their perceptions of HIV. Equipped with PrEP and an understanding that HIV is both treatable and manageable, some participants said they felt little-to-no concern about their risks of acquiring HIV.

"I've now got like the safety net of PrEP. I used to have a fear of [acquiring] it whereas now I know much more about being undetectable and the fact that transmission risk is effectively zero. [...] And then with me taking PrEP, I feel like there's enough science now that I feel like I've become educated on those things" ***(PrEP user)***

"And then also like U=U. [...] So, like, [HIV] used to be a big deal [but now] it's not really a problem." ***(PrEP user)***

Participants felt that their diminished HIV anxiety was, in part, a product of their age. Some of the youngest participants in the groups noted that while they felt it was important to understand the history of HIV and AIDS – and often spoke of HIV and AIDS crisis as an episode of the past – they thought that the most acute worry about it was experienced by older generations. Indeed, a large number of participants suggested that they now scarcely worried at all about acquiring HIV and were more concerned about acquiring common STIs.

"[When I have sex] I do sometimes think like, God, am I gonna walk away with gonorrhoea again, or something? But in terms of transmission, HIV's the lowest of my considerations now." ***(PrEP user)***

Not all participants felt the same way about acquiring HIV, however. A small number of participants noted that, although they used PrEP and considered 'U=U', they still felt anxious about the possibility of seroconversion. Explaining their anxieties, these participants cited the knowledge that HIV was a lifelong (albeit treatable) condition and also shared experiences of growing up in households or cultures where there was significant taboo or stigma about HIV and homosexuality.

3.2 Barriers to PrEP Uptake

Speaking about their experiences of and relationships to PrEP, users and non-users alike described a number of potential barriers to PrEP uptake; barriers that may explain why they or their peers were not using PrEP (despite the broad acceptability described in Section 3.1.i).

i. Stigma about PrEP

A number of participants highlighted stigma about PrEP that might affect people's decision to use it. For one, participants noted that, among GBMSM, there could be whispered moralising about PrEP, with PrEP being regarded by some men as a promiscuity pill or a pill only for people who have a lot of (or 'too much') sex.

Other participants noted that PrEP was sometimes regarded as a pill 'for' gay men. They suggested that this framing could dissuade people from accessing PrEP, especially those who might want to avoid open association with gay men (e.g. men who identify as straight but have sex with men).

"A lot of the guys I've dealt with, let's say like, a good 40% of them were DL. They were pretending they weren't gay [...] I'd never see them getting on PrEP because they would see it as a pill that gay men would use." ***(PrEP user)***

ii. Access difficulties

Across the focus groups, individuals who had never used PrEP regarded PrEP favourably (as described in Section 3.1.i) and expressed a desire to initiate it. These participants identified a single factor as the foremost barrier to their accessing PrEP: sexual health services and their infrastructures were excessively complicated to navigate. These participants, all of whom were migrants, suggested that these systems were especially difficult to navigate for recent arrivals to the UK – particularly without support or guidance from someone more fluent in how services are organised.

"I haven't been to a clinic before. I moved here two years ago. [...] It's unnecessarily complicated. And especially for immigrants." ***(Non-user)***

Participants suggested that these difficulties with access were compounded by other factors, including struggles with ADHD and general perceptions of appointments at sexual health clinics being inconvenient, hard to access and time expensive. A more detailed discussion of the impact of poor appointment access is presented in Section 3.3.ii.

iii. Perceptions of impact on the body

As described in Section 3.1.i, PrEP was considered universally acceptable and highly valued by all participants. However, a few participants gestured to concerns they (or their peers) held, or had held, about the impact of PrEP on the body. People who had never taken PrEP, for instance, all suggested they had some concerns about the potential for side effects when taking PrEP – although none suggested these concerns were sufficient to stop them using it. Others

noted that they had friends who were increasingly suspicious of inorganic interventions (including medications and vaccines) and feared that PrEP might have an adverse impact on their organs. Two PrEP users did suggest that they had worried about whether taking PrEP on a daily basis would affect their health.

"I started taking it event based maybe like three years ago. And then once I started sleeping with more and more people for work, I then was like, "No, this makes sense for me to take it every single day." But I was scared about what it could do to my liver." *(PrEP user)*

3.3 Experiences and Perceptions of Sexual Health Services

This final section presents key findings from the focus groups pertaining to participants' experiences and perceptions of sexual health services – including clinics and at-home testing kits.

i. Confidence in sexual health services

Focus group participants broadly expressed their confidence in the utility of services provided by sexual health clinics, noting especially that they tended to trust clinic staff to instruct them on vaccine protocols.

"I just take whatever they put in my arm [...] It's a testament to how much I trust them." *(PrEP user)*

In a similar vein, participants who frequently used sexual health clinics suggested that they valued them as key sources of sexual health information. Many participants noted that sexual health clinics were key to their early education about STI and HIV prevention methods – including PrEP. However, many participants explained that they only received this information upon their first visit to a clinic as a young person, typically following an unmediated (i.e. condomless and without PrEP) sexual encounter that left them anxious about exposure to HIV. Participants noted that, in this way, clinics were an ad hoc replacement for early and inclusive sex and relationship education (in schools or elsewhere).

Participants also praised clinics that they deemed GBMSM-friendly. Participants tended to value non-judgemental encounters with practitioners and, where possible, forming welcoming and friendly relationships with the staff of clinics that they frequented (which tended to make the experience of visiting clinics much more pleasant).

"[At my clinic], I like the environment there, I feel like there's no judgement there." *(PrEP user)*

ii. Service access issues and impact

However, across all focus groups, participants described significant difficulties accessing appointments at clinics. Participants complained about the scarcity of bookable appointments - whether for PrEP, STI treatment, or symptomatic or non-symptomatic testing - at their chosen clinic. Appointments that were available were often at times that were impossible to attend (e.g. during the working day). For walk-in clinics with no option of advanced booking, participants complained about excessively long waiting times (which sometimes made it impossible for them to attend) and a number of participants shared a similar experience of queuing for appointments in the early morning only to be turned away. A number of individuals felt that these failures of service access had worsened since COVID, noting that there had not been a reversion from cumbersome systems adopted in response to the pandemic.

> **"In London, especially, it's like gold dust trying to get these appointments."** ***(PrEP user)***

Participants also noted that difficulty accessing appointments made it more difficult to acquire PrEP - even for people who are already using it. One participant noted that he had been 'caught short' in the past - unable to get a PrEP appointment before his own supply ran out and was only able to continue using PrEP because his housemates also had a supply. Another participant shared that he had changed from daily to event-based dosing because of how difficult he found it to secure appointments in time.

iii. 'Gaming' the system and its barriers

Some participants shared methods of 'gaming' the system to get an appointment - for instance, by reporting a symptomatic STI when they didn't have one or by searching for appointments across a number of different London clinics (one participant estimated that he sometimes had to look across four or five different clinics before he could make a booking).

It should be noted that while clinic hopping may be a way that some people secure clinical appointments, participants' experiences suggested that it is a precarious route of access that has drawbacks and a negative impact on the level of care received. For instance, participants noted that moving clinics routinely made keeping track of and on top of vaccination protocols difficult because necessary records were not shared between clinics.

These ways of accessing appointments are, of course, also a barrier for a number of (overlapping) groups - like young people and migrants - who may not be aware of these methods and for whom navigating sexual health infrastructure may already be difficult or overwhelming. Participants reported that young people

(especially those moving into London or just making their sexual debut) may find navigating sexual health services for the first time particularly confusing.

"I know a lot of my friends around my age find it so difficult to be able to go to sexual health clinics when they need to because, you know, they've barely signed up for a GP let alone discovered where's good and then the next thing you know, when you've got [symptoms] you don't know where to treat it and no one can treat you because they don't have space." ***(PrEP user)***

Migrants in the focus groups also shared experiences of difficulties getting to grips with health infrastructures in London, describing uncertainty about what services they were entitled to access; fears about accessing services in case it threatened their migration status; and being overwhelmed by what they felt was the confusing bureaucratic architecture of sexual health services. One migrant participant reported that they found the process of accessing an appointment so laborious that they often put off getting tested for long periods of time. Another said that, for the same reason, they had never visited a sexual health clinic and had only tested once (using a self-testing kit) since moving to the UK three years ago.

iv. Views on online testing

For many participants, online Sexual Health London (SHL) self-testing kits were a much-valued alternative to clinical appointments. Some participants described a pattern of alternation between receiving testing in the clinic and self-testing at home (e.g. using SHL every other time they tested or going to the clinic after six months of testing at home). For most participants, this pattern of alternation was a product of either how difficult they found it to get appointments or how much time appointments could take up. Online testing was considered a convenient and highly valued alternative. For one participant, following a negative experience at a sexual health clinic, they preferred only to screen for STIs using self-test kits, visiting clinics only when they needed a supply of PrEP.

"But now I just prefer to test at home. It's just easier, it's quicker, I don't have to go to the clinic, commuting there like half an hour and commuting back, waiting there. Appointments are pretty much impossible to get. One time I got to the walk-in clinic, was queuing up, they turned me away because there were too many people." ***(PrEP user)***

Not everyone valued online testing equally. In addition to the loss of what they valued about clinics, some participants commented that they found self-testing difficult and even unpleasant to do, particularly when it came to drawing blood. A few participants said they found it so difficult to draw blood from their finger using the apparatus supplied by SHL that they sometimes

forewent providing a sample for a blood test (for HIV, syphilis, and hepatitis B or C) entirely or simply provided a scant blood sample that they knew was insufficient for testing. One participant - the migrant man who said that he never visited clinics because of how hard they are to access - said that he found self-testing so unpleasant that he tried it just once and never tried it again (he said that he relies now on his three, trusted, regular sexual partners to share their recent STI and HIV test results to know his status).

v. Negative experiences of clinical care and organisation

A handful of participants described having significant negative experiences in sexual health clinics that impacted them in various ways. One participant had an encounter with a doctor who he felt was judgmental about his sexual behaviour. This participant described how, because of this experience, he considered not returning to the clinic. However, he was convinced to try again by the quality of care he received from another member of staff. Another participant described the poor quality of care he received when he visited the clinic because he was worried that he had acquired HIV. This episode, which he considered to be scaremongering, caused him significant anxiety and amplified the distress he already felt about possibly seroconverting. As a result, this participant has not visited a clinic for testing since. The participants mentioned here (both from Black backgrounds) described experiences of growing up in communities where there was a taboo about homosexuality, HIV and AIDS - experiences that made these clinical encounters all the more jarring.

"That's how scared I was of getting HIV [...] I grew up in a very traditional African household, very Christian, very, "if you have sex with a man, you're gonna catch HIV and you're gonna die." ***(PrEP user)***

One participant pointed to the gendering of care at sexual health clinics as a source of discomfort. This participant, who explained that they were currently exploring their gender identity beyond the male/female binary, expressed frustration with how gendered they found sexual health clinics in the UK to be (in comparison to clinics they had attended in the USA, where they used to live). This individual suggested that this tended to make them avoidant of clinics and unable to attend them as often as they felt they should.

4. DISCUSSION

The findings from the focus groups presented here aid in developing an understanding of young GBMSM's relationship to sexual health. They may also be instructive for continued efforts to improve the delivery of sexual health services and access to them.

4.1 PrEP Promotion and Access

i. PrEP promotion and HIV education

PrEP is a highly favoured approach to HIV prevention amongst young GBMSM (in London) – even amongst those who have not ever used or are not currently using PrEP. The findings presented in this report suggest that young GBMSM value PrEP for the sexual freedom it can provide them and regard the tool as alleviating HIV anxiety that has historically been shouldered by older generations. In this way, PrEP – as well as related advances in HIV care and prevention like 'U=U' – has fundamentally altered young GBMSM's relationship to HIV. However, an appreciation and understanding of the history of the epidemic has ensured that young people are not blasé to the importance of PrEP or the historical moment within which they reside.

These findings suggest that there is a continued value in promoting PrEP to young people (since there is clear support for it). Moreover, they suggest (i) that there may also be a value in PrEP promotion that stresses the historical importance of the intervention and (ii) there is a clear benefit to education in the history of HIV and AIDS for GBMSM's sexual health today.

ii. Improving access to PrEP

Clinicians have expressed concerns about lower-than-anticipated PrEP uptake among young GBMSM. The focus groups highlighted a number of barriers to uptake that, if addressed, might address inequities in uptake among this cohort.

First, participants highlighted problems with existing clinical infrastructure and organisation that render PrEP less accessible (or inaccessible) even for those GBMSM that want it. Two issues were particularly glaring: excessive difficulty accessing appointments and a hard-to-navigate, confusing architecture of PrEP provision. To address these issues, sexual health clinics sorely need to reform appointment booking systems and consider streamlining requirements for PrEP access – with an emphasis on simplicity and with additional support (including multi-lingual and translation services) for those who are less familiar with how services operate e.g. young GBMSM and migrant GBMSM. Moreover, if clinics are struggling with capacity, providers should continue to explore methods of PrEP provision outside of

clinical settings – not least because sexual health clinics are not universally acceptable settings for many individuals (see Sections 3.3.v and 4.3).

Second, participants highlighted that narrow framings of PrEP as 'for' gay men may delimit access. Accordingly, providers must work with health promoters to challenge existing narratives and broaden awareness about PrEP, especially among groups who might be dissuaded by a perception of PrEP as a 'gay drug' (e.g. men who do not identify as gay or bisexual but have sex with men).

Finally, participants noted some concerns – ranging from mild to significant – about the impact of PrEP on wider systemic health. To address these, PrEP education must take seriously concerns about side effects and, where possible, provide potential users with clear evidence and considerate advice about the impact of PrEP on health.

4.2 Tailoring Work for Young People

As has been noted in Sections 3.1.ii and 4.1.i, young GBMSM in the focus groups spoke openly about how, in the current moment of HIV prevention and treatment, they had a relationship to HIV and STIs that might be considered distinct from older generations. Participants suggested that sexually transmitted infections other than HIV were often at the forefront of their minds when having sex – in part because they had access to PrEP, in part because they understood 'U=U' and in part because they regarded HIV with less anxiety than in previous decades (as something manageable and treatable).

These findings are instructive for sexual health workers and health promoters in a number of ways. First, they underscore the success (and value of) education about HIV and HIV prevention amongst young GBMSM. Second, they circle a need for equivalent work (and success) for young GBMSM pertaining to STIs other than HIV – since these have been highlighted as a priority (and, therefore, object of concern) among this cohort.

Finally, as well as underscoring new and emergent priorities for sexual health promotion, these findings can also inform their style, content, and form. Specifically, work in sexual health that seeks to address young GBMSM as an audience must be attuned to the way many young GBMSM relate to and experience HIV and STI transmission. For instance, HIV prevention programmes should consider how to sustainably address a generation of young GBMSM who may never have experienced HIV as a 'crisis' and, therefore, who may not respond to language that connotes feelings of, say, urgency. That said, health promotion work must also remain alive to differences in the experiences of young GBMSM from different backgrounds – for instance, young GBMSM of colour who may have experienced high levels of HIV stigma or taboos about homosexuality and, therefore, who may experience greater HIV anxiety than their peers.

Taken together, these findings underscore the continued need for tailored work in sexual health that meets target populations where they are: speaking to their needs, priorities, values, feelings, and experiences.

4.3 Sexual Health Beyond Clinics

While participants shared what they felt was the value of sexual health clinics, their testimony also pointed to a number of problems with clinical provision that require addressing. These include: difficulty accessing appointments; uncertainties and confusion about access (especially for migrant men); experiences of judgement or discrimination within clinical settings and the excessive gendering of clinics. These findings suggest the need for continued investment in the provision of sexual health services and resources in non-clinical settings and via outreach work.

Outreach work and provision in non-clinical settings supplements the work of sexual health clinics, opening up the possibility of providing support to communities who need it in settings that are safe and familiar. As The Love Tank CIC has evidenced through its outreach work, provision of services in non-clinical settings is particularly effective at over-serving those who are typically underserved by sexual health clinics – including GBMSM migrants and GBMSM of colour – because they experience multiple barriers to access. In addition to providing frontline services, this kind of outreach work also holds the possibility of improving trust and understanding of clinics (and how they function) in communities through triaging and additional support to access.

These non-clinical encounters are also frequently valued by community members because they are considered more convenient than trying to source appointments. For the same reasons, sexual health workers should continue to promote online, self-testing kits as amenable alternatives to testing in-clinic (although, it should be noted, that not everyone finds these kits easy or pleasant to use and the sector should continue to explore means of assuaging and addressing community concerns about self-testing).

The focus group participants also highlighted a dearth of sexual health education prior to their first visit to a clinic, which may render young GBMSM vulnerable to a number of sexual risks. This redoubles the importance of targeted outreach work with young GBMSM – especially those who are making their sexual debut – as a means of supplementing current absences in sex and relationship education at school.

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