

# What qualities in a potential HIV pre-exposure prophylaxis service are valued by black men who have sex with men in London? A qualitative acceptability study

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## Abstract

Black men who have sex with men (BMSM) have higher HIV incidence and prevalence when compared to other MSM, despite similar levels of condom use and testing. Pre-exposure prophylaxis (PrEP) could be a useful intervention to reduce these inequalities. This research therefore aims to understand the dimensions of acceptability of a potential PrEP service for BMSM aged 18–45 years in London. In-depth semi-structured interviews were conducted with 25 PrEP-eligible BMSM between April and August 2016. Interviews were recorded and transcribed verbatim, then subject to a thematic framework analysis, informed by intersectionality theory. BMSM had distinct preferences for sexual health services, which have implications for PrEP service development. Three primary domains emerged in our analysis: proximity and anonymity; quality, efficiency and reassurance; and understanding, empathy and identity. These relate, respectively, to preferences regarding clinic location and divisions from community, features of service delivery and staff characteristics. Due to concerns about confidentiality, community-based services may not be useful for this group. Careful consideration in regards to components used in service development will facilitate ongoing engagement. Interpersonal skills of staff are central to service acceptability, particularly when staff are perceived to be from similar cultural backgrounds as their patients.

## Keywords

Europe, HIV, prevention, pre-exposure prophylaxis

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Globally, HIV prevention increasingly focuses on biomedical interventions to reduce transmission among groups most at risk of infection. Clinical trials and modelling evidence have demonstrated that the provision of antiretroviral HIV medications to HIV-negative individuals can be highly effective in reducing HIV acquisition and can reduce costs to the health service.<sup>1–6</sup> In England, the PROUD study reported a reduction of 86% in new infections among men who have sex with men (MSM) allocated to the group who were given immediate access to PrEP.<sup>2</sup>

Access to PrEP in England has thus far has been disjointed. Some individuals access the intervention through clinical trials, while a growing number self-import generic drugs.<sup>7,8</sup> These inconsistencies in access

will continue for the immediate future. Following a high-profile legal challenge, rather than commissioning a national PrEP service, the English National Health Service (NHS) has instead implemented a further trial giving access to at least 10,000 people.<sup>7</sup>

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Although MSM have the highest HIV incidence of all groups in England, further health inequalities exist.<sup>9–11</sup> Recent cross-sectional and systematic review evidence indicates that black MSM (BMSM) have higher HIV incidence than other MSM despite similar rates of condom use and of HIV testing.<sup>10–12</sup> Further, HIV incidence peaks in MSM between the ages of 18 and 45, indicating that this group could most benefit from PrEP.<sup>9,13</sup>

It seems likely that, for the foreseeable future, PrEP in England will be delivered through genito-urinary medicine clinics (GUM). Given the disparity in HIV prevalence, it is important that the delivery of PrEP attends to the diverse needs of sub-groups of MSM, including black MSM. Care in GUM settings in the UK has focused on an acute model of delivery and clinics have had little incentive to retain individuals over time. The provision of PrEP challenges this model and makes longer term engagement crucial for effective follow-up.

To enable this, it is important to first understand which barriers and facilitators should be considered in the design of a potential service and whether or not any of these are particularly salient for BMSM.<sup>14</sup> Given that PrEP requires on-going clinical engagement, this study focuses on elements of service development that might help retain individuals in care. No evidence currently exists from the UK describing PrEP service acceptability for BMSM.

This research aims to understand the dimensions of acceptability of a potential PrEP service for BMSM aged 18–45 in London. We examine BMSM's accounts of service preferences across the domains of proximity and anonymity; quality, efficiency and reassurance; and empathy and professionalism, paying close attention to their implications for PrEP service development.

## Methods

This was a qualitative study including 25 in-depth semi-structured interviews conducted between April and August 2016. We engaged with intersectionality theory throughout conceptualisation, data generation and analysis.<sup>15,16</sup> Intersectionality seeks to understand the ways in which different social identities have interactive effects which shape behaviours and their outcomes. It acknowledges the heterogeneity of minority populations, who are frequently misconceptualised as homogenous.<sup>17</sup> Intersectionality theory was used on the basis that the qualities intersectionality emphasises as having interactive effects (e.g. ethnicity, gender and sexual orientation) were perhaps those which mediated access to services for BMSM. Using intersectionality to theoretically inform the analysis enabled a more

attentive focus investigating the unique experiences of BMSM when accessing services.

We recruited participants through gay-specific geo-location social networking applications (apps), social media and the PROUD study mailing list through the Medical Research Council Clinical Trials Unit. Prospective participants were directed to a survey (see online supplementary material) which asked for demographic and behavioural details, their contact details and consent for contact. Men who were aged between 18 and 45, self-reported HIV-negative or untested status, described their ethnicity as black or mixed race and reported one or more instances of condomless anal intercourse (CAI) in the preceding three months were eligible to participate.

In the survey, men were asked about previous PrEP experience. Participants who had not attempted to access PrEP were classified as *PrEP naïve*, those who had attempted unsuccessfully as *unable to access* and those who had ever accessed and used were classed as *PrEP experienced*.

Interviews were conducted face-to-face, and participants were compensated £40. We used a topic guide exploring PrEP knowledge, sexual behaviour and risk, health service use and social contacts and peers. Interviews were audio recorded and transcribed verbatim. In an approach informed by framework and thematic analyses,<sup>18,19</sup> all authors familiarised themselves with the transcripts by searching for emerging themes and collectively developed a thematic framework. CW and AB piloted and refined this framework, then applied it to all transcripts. This manuscript relates to an analysis of the health service section of the interviews.

This study received approval from the observational research ethics committee at the London School of Hygiene & Tropical Medicine (ref: 10569).

## Results

We recruited 25 BMSM who varied in ethnicity, age, educational attainment and previous use of health services and experiences of PrEP. For sample characteristics, refer to Table 1.

Three primary domains of intervention acceptability emerged in our analysis: 'proximity and anonymity', 'quality, efficiency and reassurance' and 'understanding, empathy and identity'. These three themes capture the inter-related issues of place, clinical features and staffing that were central to what participants valued in a potential PrEP service.

**Table 1.** Participant demographics.

Attribute	Options	Count
Age (years; mean: 31.1)	18–25	8
	26–35	10
	36–45	7
Ethnicity	Black/Black Caribbean	7
	Black/Black African	14
	Black/Black British other	4
Sexual orientation	Gay/homosexual	19
	Bisexual	5
	Other	1
Education	Low <sup>a</sup>	1
	Medium <sup>b</sup>	9
	High <sup>c</sup>	15
Last HIV test	>3 months	18
	>12 months	4
	<12 months	3
PrEP experience	PrEP naïve	17
	Unable to access PrEP	3
	PrEP experienced	5

PrEP: pre-exposure prophylaxis; HIV: human immunodeficiency virus.

<sup>a</sup>GCSEs and below.

<sup>b</sup>A-levels or equivalent, higher education below degree level.

<sup>c</sup>Degree or higher.

## Proximity and anonymity

For many, acceptability of a potential PrEP service was shaped by concerns about the degree to which accessing said service could make oneself vulnerable to HIV stigma and homophobia. Because of this, participants felt that location was an important element of service accessibility.

Although some were comfortable accessing services in any location, many felt that for a service to be widely acceptable to BMSM it had to not only be in a convenient location, it also had to be removed from places with links to family and community; ideally located outside of what participants frequently described as traditionally ‘black’ areas. This applied especially to areas with immediate links to family and friends and was usually grounded in a concern for homophobia from black communities. This concern was most pronounced in younger men and in those who were PrEP naïve.

*If you build another [PrEP] service I'd say build it in a place that's close to a black community. Not necessarily in the community because of that fear thing. [...] A lot of people would be scared and I get that, especially how homophobic the black community can be. So I would make it somewhere that's close and accessible so I'd have one in West London and one in South London because those are [near to] heavy black communities. (28 year-old gay man, Black British Caribbean, PrEP experienced).*

This issue was considered especially pronounced for a PrEP service where men would need to attend frequently over time and where barriers to initial access may be higher. Although convenience was important, the primary concern for many was a clear separation from black communities and those associated with family in order to ensure anonymity.

Concerns about proximity existed on a spectrum and shifted over time. For men who described increasing acceptance of their sexuality in their wider social circles, these concerns were often no longer relevant. For individuals whose social and sexual identities were not felt to be in conflict, accessing services was embedded in narratives of responsibility. The possibility of being observed was not problematic because accessing services was a demonstration of self-care. When describing a historical decision to switch STI testing clinics to one further from his community, one participant said:

*I think it was too close and at that point in time at that age. Right now I probably wouldn't have that much of an issue, I would probably feel like well it's not something to look down on I suppose and to laugh at because it's just part of being a responsible person to get checked. I wouldn't really have a problem going there now but I go through Central London so much and it just makes sense, the location's good for me and it's easier, it's like a better place. (28-year-old gay man, Black British African, unable to access PrEP)*

Concerns about stigma related to proximity to sexual health, HIV and homosexuality were major barriers to service access, therefore impacting on service acceptability. For some these concerns diminished with increasing confidence and self-acceptance, but this was by no means universal.

## Quality, efficiency and reassurance

Retention in services (including regular HIV and liver function testing) is key to effective delivery of PrEP. Therefore, understanding preferred intervention characteristics that facilitate engagement is a central concern in developing interventions which meet the needs of BMSM. Components of GUM service delivery which were very highly valued by BMSM were service attributes that were understood to be markers of high quality; those which increased efficiency; and that facilitated reassurance.

Perceived service quality was important for BMSM. Well-maintained facilities demonstrated that a service was well run. The availability of same day results from tests was a marker of a modern service which also denoted quality.

Efficiency of services was crucial for long-term engagement. Specific intervention components which provided this were the ability to book appointments online or via text message, and systems which reduced waiting times.

*A friend recommended [redacted] but actually the main reason I tried it [the clinic] was because I can get results a lot quicker. Also, because I could book an appointment by text. [...] So I was at work and I just texted that: 'I need this appointment time at this time. (25 year-old gay man, Black British Caribbean. PrEP-naïve)*

Clinics which had long waiting times, or reliant on walk in appointments were poorly regarded and most stated they would not return to such a clinic.

Those who tested regularly did so partly to seek reassurance of a continuing HIV-negative status. In line with that aim, clinics reliant on pathways which were felt to increase anxiety were considered sub-optimal.

### Empathy, understanding and identity

Staff were consistently highlighted as the greatest determinates of service acceptability, particularly in the context of extended engagement. Nearly all positive experiences described hinged on staff attitudes and the handling of emotionally charged situations. Men valued staff who treated them with empathy and professionalism, and valued interactions when staff made efforts to develop rapport across cultures. There were concerns from a significant minority about accessing care from an individual from a similar ethnic background.

Staff who developed rapport and who treated patients with empathy and professionalism made men feel well cared for, thereby providing an important supportive element to a service. This was more pronounced among BMSM who were younger, bisexual, PrEP-naïve, and described difficulty reconciling ethnic and sexual identities. Many had anxiety about accessing services because of past experiences of homophobia from family and peers alongside experiences of discrimination from service providers related to racially ascribed stereotypes of hypersexualisation, which deemed black men to be highly promiscuous. This left some feeling vulnerable to discrimination from multiple angles. When discussing a valued clinic, one participant said:

*Oh my god, they were so lovely and great there. The woman that, the nurse person, oh she was divine. Most times they've been alright. There are some times when I go look man, the people who work in sexual health clinics*

*just have some sort of empathy about you. Yes, we've got ourselves in that predicament to have to get checked, but you don't need to treat us like an inmate. There have been a few occasions when I've felt like an inmate or like a dirty slag because the way they've treated me. [...] Have some warmth about you. You know? (32 year-old bisexual man. Black British African. PrEP-naïve)*

For this individual, it was the demonstration of acceptance and empathy that provided validation and normalised accessing GUM services.

A common theme in our analysis was that men found accessing services from staff perceived to be from a similar ethnic background to themselves to be challenging, even problematic. Links to community were typically not valued in a service, as men had concerns that their confidentiality could be compromised or that the person providing the service would be judgemental. This was most pronounced in men of black African ethnicities, although it was also described by black Caribbean men.

*If you have someone from your own culture you probably think you are going to get judged more so you will be less open especially when they ask you about your sexual history and you are like 'oh my God I have to go through my black book' and it is like 'um-hum' [Laughter] 'are you sure it's ten people' so yeah it is important to have the right type of people, type of person. (34-year-old Black British Caribbean man, PrEP experienced)*

Participants found that these concerns could be easily countered when staff made additional efforts to develop rapport. Further, these concerns tended not to exist when the staff member was perceived to be gay or bisexual as these staff were felt to provide an additional sense of understanding and acceptance.

### Discussion

The most important domains of service acceptability arising from our study were: proximity and anonymity; quality, efficiency and reassurance; and empathy, understanding and identity. BMSM tended to prefer services that were conveniently located but, because of confidentiality concerns, also removed from primarily 'black areas'. BMSM also had clear preferences surrounding service delivery components that increased efficiency, gave the sense of a high-quality service and reduced anxiety. Staff were important determinants of service acceptability, both in terms of their interpersonal skills and their personal characteristics. Although we specifically focused on PrEP for this enquiry, many of these features will also be highly relevant in the

development of other sexual health services. What is critically different in the case of PrEP is, firstly, that the adoption of a novel technology will likely be profoundly shaped by these concerns. Secondly, this introduction provides the opportunity to develop best practice early in public provision, perhaps working to reduce established health inequalities.

Established wisdom within public health and health promotion indicates that interventions should be embedded within the communities which they serve.<sup>20–22</sup> However, our findings suggest that while convenience is an important element of service acceptability, issues relating to confidentiality and stigma may be so considerable a barrier that it is preferable to establish PrEP services outside of areas with large black African or black Caribbean populations. This impact on accessibility appears especially pronounced when BMSM engage with sexual health services for the first time, when their support needs could perhaps be highest. This suggests that community-based PrEP services may not have advantages over clinically-delivered services.

BMSM with established health-seeking routines relating to their sexual healthcare have clear preferences for the service components which attract them to services. For PrEP interventions to retain patients and establish continuity of care, these will need to be incorporated into intervention design. These findings are not novel to BMSM and will apply to almost all prospective patients, yet emphasising them remains important. This group is a key population for engagement, and continued financial pressure on the health service will tempt commissioners to rationalise costs, perhaps worsening care.

The ability of staff to develop rapport and facilitate positive interactions with those receiving interventions were absolutely central to service acceptability. What was unanticipated was the degree to which men preferred not to access services from staff who were perceived to be of similar cultural backgrounds to themselves. This runs contrary to the ethos of community-delivered services for this group.<sup>23,24</sup> The divergence of these results and those from the US could be attributable to profound differences in both the diasporic histories of these communities and national health systems.<sup>25</sup> Indeed, UK BMSM are perhaps more likely to be first or second generation migrants from African and Caribbean countries, whereas BMSM in the US are predominantly descendent from communities forcibly brought to America in servitude. For that reason, in regards to sexual health service access, the experience of BMSM in the UK may be more comparable to other recent migrant groups in the US rather than American BMSM.

Staff of all backgrounds working with BMSM should be mindful to use affirmative language in the recognition that many in this group (especially those who are young, not gay identified and not open about their sexuality) experience additional barriers compared with other MSM when accessing services, often because of experiences of homophobia intersecting with ethnic and cultural identities. Demonstrations of engagement in patient's care and affirmation of their individual realities can also facilitate productive interactions. This is particularly true for those from black and minority ethnic backgrounds who are providing services to BMSM.

Efforts to engage MSM from minority ethnic backgrounds will need to be attentive to a diversity of preferences in regards to personnel delivering services given the tensions between visibility and proximity. While representation of peers perceived to be gay among clinical staff may well be valued by many in this group, links to community can also represent a serious barrier to meaningful engagement. A one size fits all approach is unlikely to meet the needs of a wide range of potential PrEP users, including BMSM.

This is the first research in the UK that specifically seeks to understand the dimensions of acceptability for PrEP services among BMSM. However, a number of limitations are noted. Firstly, challenges in recruiting men with lower levels of educational attainment meant we were unable to examine the values and preferences of this particular population, known to have pronounced HIV prevention need.<sup>11,12,26,27</sup> Secondly, all of our sample had some degree of engagement with GUM services, indicating that they had been able to overcome any personal or structural barriers that may have been perceived previously. As such, these findings may not reflect the perspectives of those who have found service engagement more challenging, such as those never tested for HIV. In addition, participants were not balanced on PrEP experience, perhaps amplifying the views of the PrEP naïve. For that reason, special attention was paid to the accounts of those who were unable to access PrEP and the PrEP experienced. Finally, this study was conducted with a relatively small sample of BMSM in a geographically defined area. Local context will likely shape acceptability, particularly in settings which are more compact, offer far less service choice or both. This could potentially exacerbate concerns related to proximity and stigma.

#### **Declaration of conflicting interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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