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Barriers and facilitators to pre-exposure prophylaxis (PrEP) uptake in England: Experiences of people newly diagnosed with recently acquired HIV

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INTRODUCTION

In 2023, there were **6,008 people newly diagnosed with HIV in England**. This is a 51% rise from 3,975 in 2022, and a 56% rise from 3,859 in 2019 (1).

However, there are **clear differences in trends among different demographic groups**. Although in 2023, the number of new HIV diagnosis increased by 7% from 761 in 2022 to 811 in 2023 among **men who acquired HIV through sex with men, this group still shows greatest improvement** as this represents a 35% decrease in new infections since 2019 (from 1,242 to 811). This is **likely due to scaling up the combination prevention approach.**

Among heterosexual men, the number of new HIV diagnoses rose by 36% from 445 in 2022 to 605 in 2023 and by 30%, and among heterosexual women from 602 in 2022 to 780 in 2023. Among men who acquired HIV through sex with men in 2023 who were of white ethnicity (57%), there was an increase in diagnoses of 3%, compared to 2022 (446 to 461). In contrast, diagnoses among men of all other ethnicities combined rose by 7% (from 248 to 266). The largest increase (+42%) was among black men, with diagnoses rising from 55 to 78. Among heterosexual individuals of white ethnicity, there was a 3% increase in diagnoses (301 to 310) in 2023, compared to a 45% increase (649 to 942) among all other ethnic groups combined. The largest increase was among black African individuals (+64%) from 420 to 688. The only decrease was among those of mixed or other ethnicity (-11%), from 101 to 90.

Working towards the English government's target of ending HIV transmission by 2030 and reducing inequalities in HIV prevention uptake, in 2018, UKHSA introduced enhanced surveillance of people with new diagnoses (**SHARE: Surveillance of HIV Acquired Recently: Enhanced**). This aimed to complement HIV surveillance with behavioural data on HIV prevention and testing. **Specifically, one of the research questions aimed to address what the barriers and facilitators to the uptake of HIV presentation including PrEP (pre-exposure prophylaxis) were.**

METHODS

SHARE recruited people aged 18 and above who received care at a HIV clinic in England and showed evidence of recent HIV acquisition or of seroconversion illness. Prospective participants were identified by clinics or the UKHSA surveillance team.

Interviews took place between April 2021 and July 2022. UKHSA interviewers with working experience in HIV/ sexual health conducted 1 to 1 interviews (30 minutes to 2 hours). The interviews were audio recorded and transcribed.

A total of **26 individuals were interviewed**: 21 were male, 5 female, 20 GBMSM, 1 heterosexual man, 5 heterosexual women, 18 were of British or other white ethnicity, 5 black African or Caribbean, 1 Asian, 2 mixed ethnicity. The majority (81%) was between 25 and 49 years.

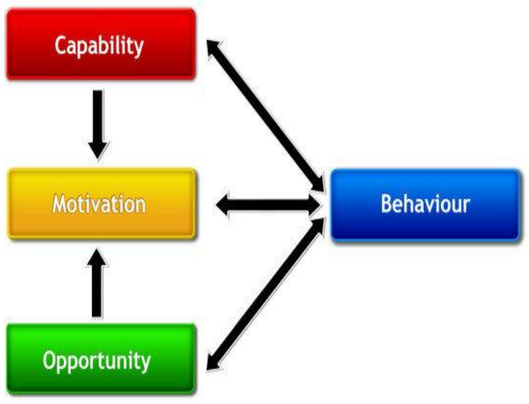

Figure 1 – The COM-B model

The data was analysed using the **COM-B model** (2) (**Figure 1**) which postulates that **capability, motivation and opportunity explain the uptake of a behaviour** (here; uptake or consideration of PrEP): Capability refers to having the knowledge, skills, cognition and motor skills to engage in a behaviour; opportunity to the social influence and physical infrastructure that enable or impede a behaviour; and motivation to beliefs, attitudes, and habits. The data was analysed **thematically**; first deductively according to the COM-B domains then inductively within each domain.

RESULTS

	Capability themes (number of participants)	**Summary**
Barriers	• No or insufficient knowledge about PrEP or how to access it (14) • Insufficient language skills to understand what PrEP or PEP is and what it does. (1)	When participants didn't know about PrEP or didn't know how to access it, as well as what the difference between PrEP and PEP was, this undermined using PrEP (this persisted after the PrEP Impact Trial)
Facilitators	(no facilitators identified)	
	Opportunity themes (number of participants)	**Summary**
Barriers	• Missed opportunities in health care settings to learn about and discuss PrEP needs (12) • PrEP need not identified by sexual health services (2) • No free or difficult access to PrEP (7) • Reassurance by their sexual partners of low or no HIV risk (2)	Interpersonal and structural influences, such as reassurances by sexual partners, restricted or no access to PrEP, as well as missed conversations with health care professionals about PrEP or PrEP needs undermined participants opportunities to use PrEP (this might be most relevant for the time during the PrEP Impact Trial).
Facilitators	• Having learnt about PrEP from others and different outlets (10) • Associating PrEP with a new chapter in life. (1)	Participants were also positively influenced by others and other structural channels by learning from them about PrEP.
	Motivation themes (number of participants)	**Summary**
Barriers	• Low self-relevance for PrEP (7) • PrEP not a priority (3) • Perceptions of PrEP/PEP as medication (7) • Trusting sexual partners (PEP) (2) • Anticipating stigma and logistical problems accessing PrEP and PEP (4)	PrEP use was undermined when people did not think they fit the idea of who PrEP was intended for, or they did feel it was relevant, but they wanted to avoid anticipated stigma, when they didn't want to take a medication (often because of side effects, knowing their partners), or anticipated long wait times/logistical issues.
Facilitators	• Previous negative experiences with sexual partners and concerns about lifestyle (4) • Being precautious or afraid (2) • Perceptions of PrEP/PEP as medication (1)	Increased risk perception promoted self-relevance and fostered PrEP use.

Table 1 – Themes explaining PrEP uptake or consideration by COM-B domain and barriers and facilitators

The main barrier of **capabilities** to engage with PrEP was not or **not having sufficient knowledge about PrEP, including event-based PrEP or how to access it**. We further identified that PrEP and post-exposure prophylaxis (PEP) were sometimes referred to interchangeably, indicating a lack of awareness.

> ***"I didn't even know that there are medicines that make you undetected and things like that. I didn't know, I didn't know, you know, before."***
> (P16, 35 to 44 years, female, heterosexual, black African)

Missed opportunities in health care settings to learn about PrEP or being identified as having a PrEP need (especially for people other than GBMSM) were the main **opportunity** barriers to the uptake of PrEP. In some cases, participants expressed difficulty accessing PrEP.

> ***"I would have liked somebody to say, hey, you know, PrEP works and if you ever have, even if it's just one on an occasional basis, have unprotected sex, please really think about taking it. This is information and this is how it works and so on."***
> (P12, 35 to 44 years, MSM, white other)

The main **motivational** barrier to PrEP uptake or consideration was a **low self-relevance**, for example, holding stigmatizing views about for whom it presumably was. Some participants also explicitly mentioned that PrEP wasn't a priority. Some participants expressed concerns about **side effects of PrEP, anticipating there to be stigma or logistical problems** accessing PrEP, as well as **trusting their sexual partners.**

> ***"And I just didn't think […] I didn't think I had enough sexual partners to be able to go in, and to be able to go in. and have been having a drug that you take every day. I don't know. And yeah , I just didn't think it would be relevant to me"***
> (P2, 25 to 34 years, MSM, white British)

The analysis of **facilitators** was mostly hypothetical since most participants had not taken PrEP, leading us to examine the uptake and *consideration* of taking PrEP. PrEP facilitators were in most instances the inverse of the barriers identified, e.g., **learning about PrEP from others or not trusting sexual partners.**

The data was not always specific regarding whether it referred to PrEP or HIV prevention more generally. We identified that some **'overarching' factors** may have influenced the uptake or consideration of HIV prevention, too. Among these were a lack or outdated knowledge of HIV, HIV risk or prevention (7 participants), poor mental health (5 participants); a lack of social support to find out more about HIV prevention (9 participants), of conversations with sexual partners about sexual health (9 participants), and of HIV campaigns (5 participants); a change of HIV risk perception due to external factors (3 participants), low overall HIV self-relevance (14 participants), a lowered HIV risk perception which was not attributable to low HIV self-relevance (3 participants), and too selectively targeting HIV campaigns (2 participants).

DISCUSSION

Our results are in line with existing research on barriers to PrEP (e.g., 3, 4). Awareness, interactions, access, and beliefs about applicability seemed to explain levels of engagement with PrEP and HIV prevention more broadly. These insights can inform behavioural interventions and inform health care professionals and community-based organisations about opportunities to improve or adjust the promotion and provision of HIV prevention. This can contribute to decreasing new HIV diagnoses and achieve the English government's target of ending HIV transmission by 2030.

Limitations were low variability in demographics of the sample and accounts being made post-diagnosis. This hinders the results to fully capture the voices of under-researched populations (women, heterosexual men). Many background factors (e.g., the PrEP Impact Trial, Covid-19 pandemic) may have caused potential differences in perceptions and behaviours across the sample. Finally, participants' accounts ranged from merely confirming factors as barriers/ facilitators to giving elaborate explanations, and some themes include accounts of only few participants. More studies are needed to further identify and elaborate on these narratives.

PARTICIPANT RECOMMENDATIONS

We also derived participants' perceptions and feelings regarding recommendations that can inform health care professionals and community-based organisations about opportunities to improve or adjust the promotion and provision of PrEP and HIV prevention more generally:

- Expand the spaces were PrEP is promoted and consider community-specific outreach as well as local sexual health spaces.
- Improve PrEP communication and promotion for everyone, including visibility and campaigns.
- Provide free and easy access to PrEP and PEP for everyone.
- Educate people in universities on PrEP and foster conversations about sexual health.
- Improve sexual health screening procedures, including considering sexual partners in screening questions.
- Provide better training to GPs in matters of sexual health.

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