

Not PrEPared

Barriers to
accessing HIV
prevention drugs
in England



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Background

HIV pre-exposure prophylaxis (PrEP) is a game-changing drug, but it is not reaching its potential.

PrEP is relatively inexpensive in generic form and a vital tool in efforts to end new HIV transmissions. PrEP use, alongside other HIV combination prevention tools, has been a key factor in the incredible reductions in HIV cases seen in England – particularly in gay and bisexual men (GBM) and other men who have sex with men (MSM).

PrEP is a valuable HIV prevention tool for other communities at risk of HIV – but this opportunity is not yet being realised. Knowledge of PrEP in these groups remains low. We need to collectively act to raise awareness of PrEP and its possibilities.

We believe that everyone who could benefit from PrEP has a right to access PrEP for free, at services they already use, or that are convenient for them. The NHS provision of PrEP must change and improve to reflect this.

PrEP has been routinely available via sexual health services, initially in Scotland (April 2017), Wales (July 2017), and England (October 2020). However, in Northern Ireland, PrEP is not routinely available but is provided by an extended pilot.

The limited, but routine, provision of PrEP is under performing. Throughout 2021-2022 PrEPster and Terrence Higgins Trust received ongoing requests from PrEP users, and those seeking to use PrEP, to assist with accessing PrEP from sexual health services. These requests included help to access PrEP initiation, refills and routine monitoring. A number of these concerns can be attributed to COVID-19's impact on service provision, but many of these problems persist.

In order to get a more comprehensive picture on what is happening with PrEP services across the UK, Terrence Higgins Trust, National AIDS Trust, PrEPster, Sophia Forum and One Voice Network collected data from local authority sexual health commissioners, clinical staff, PrEP users, and those who sought to access PrEP.

This survey was devised and launched before the monkeypox outbreak, and several responses were received before NHS services were impacted. This report provides the results of three surveys, firstly of PrEP service users and those seeking to use PrEP, secondly a survey of clinicians involved in providing PrEP, and thirdly sexual health service commissioners and providers across the UK.



Key evidence headlines

Services

- In total, local authorities reported that **24,859** people were enrolled in PrEP services in England. The median number of people enrolled per service was **203**, with an overall range of 15 to 1,500 PrEP users per service.
- The median reported wait time by local authorities from requesting a PrEP appointment to PrEP initiation was **7 days**.
- Of the local authorities who provided demographic data of service users, **75%** reported current PrEP usage being highest amongst white GBM/MSM.
- No local authorities reported that they had more than a handful of women that were PrEP users (typically **under 5** per service).
- **16%** of local authorities reported that they did not hold any data on patient age, gender, ethnicity, or sexual orientation.

Staff workforce issues

- Nearly half of clinicians¹ (**47%**) felt that their clinic did not have sufficient workforce levels to meet current demand for PrEP. **28%** of respondents specifically mentioned challenges in maintaining appropriate staffing levels, **13%** mentioned the challenges of a lack of appointments for patients and **9%** mentioned challenges regarding keeping up with patient demand for PrEP services.
- One third of clinicians (**34%**) felt well-supported to meet current PrEP demand levels. Of those who did not feel well-supported to meet current demand levels, the most common reasons cited were staffing issues (**20%**) and issues related to appointments (**8%**).
- Nearly 1 in 5 clinicians (**18%**) did not feel they had enough support or training for themselves or their colleagues in assessing PrEP eligibility. Similarly, **15%** of clinicians did not feel there was enough support or training to prescribe PrEP.
- For services which did not have outreach plans, barriers to outreach work for groups at risk of HIV included staffing issues (**12%**), capacity issues (**11%**) and the implementation of new services (**6%**).

PrEP access challenges

- PrEP users facing the biggest challenges across all regions were: those trying to access first-time PrEP (**68%**), followed by those trying to get repeat prescriptions for PrEP (**24%**) and those trying to re-start PrEP after taking a break from it (**8%**).
- Trying to book an appointment for PrEP online (**40%**) was the most reported challenge for patients, followed by difficulties getting through to clinics by phone (**30%**) or through email booking systems (**16%**).
- **23%** of the respondents to the community survey who were finally able to get through to clinics on the telephone reported being turned away as there were no available appointments. The regions that people were most commonly turned away from PrEP services were the North West (**21%**), London (**18%**) and the South East (**11%**), which is particularly worrying given these are the three areas of England with highest levels of identified PrEP need.
- The top three waiting times for a callback reported by the community were 12 weeks (**35%**), 2-4 weeks (**30%**) and 1-2 weeks (**17%**).
- Out of those who indicated being placed on a PrEP waiting list, more than half (**57%**) had waited more than 12 weeks. Of those waiting more than 12 weeks, **41%** were from the East of England.
- At the time of responding to our survey, only **35%** of community respondents reported that they were finally able to access PrEP from sexual health services.
- **58%** of clinicians had concerns about missed opportunities for PrEP initiation.
- Nearly half (**48%**) of local authorities reported that COVID-19 had affected the number of PrEP appointments that were available.
- **71%** of local authorities had plans for targeted outreach to communities under-represented in PrEP prescribing in their service, and **81%** of authorities with plans had them currently funded. The interventions planned included targeted communications and campaigning activities, and hiring staff with specific responsibility for outreach and partnership working.

1. The clinicians who responded to the survey were at multiple levels – doctors, nurses and health care assistants

Other HIV prevention methods used while trying to access PrEP

- The top three reported methods of HIV prevention whilst waiting to access PrEP were, using condoms for most or all of the time (**28%**), followed by using a temporary supply of PrEP, for example borrowing from friends or buying online (**18%**), and changing the type of sex they had (**16%**).
- Of those who provided further information on the methods of HIV prevention whilst waiting to access PrEP, 59 community respondents reported abstaining from sex and 27 engaged in non-penetrative sex instead.



Impact of PrEP access delays

- A significant number of respondents to the community survey reported mental health related issues whilst trying to access PrEP (**48%**), with **21%** reporting impacts to their dating/sex lives – this included anxiety, fear and depression.



Key recommendations

For the Government and national health bodies

- **As the HIV Action Plan promised, there needs to be a national PrEP Action Plan to drive change and improve access.**
- **As part of this Action Plan, the Government needs to commit to implement PrEP access beyond sexual health services,** to increase access to PrEP more widely amongst underrepresented, at-risk demographics. This should include GPs and community pharmacies, plus termination of pregnancy and gender services. This should include voluntary and community sector provision. This will also free up service capacity within sexual health clinics to focus on groups at higher risk of HIV who have lower levels of PrEP take-up.
- **Urgently increase resources to sexual health services** to relieve capacity issues and circumvent existing staffing pressures.
- **More funding should be given to sexual health commissioners to fund more targeted outreach programmes.** This is essential based on current findings and ongoing reports of lack of knowledge and uptake of PrEP services amongst many other groups aside from white MSM. Not undertaking further outreach action risks leaving these groups at risk of HIV transmission.
- **PrEP services should be subject to a standardised monitoring and evaluation process with snapshot reports at regular intervals.** PrEP services should be audited annually in order to identify areas in need of improvement with improvement goals set for the following year. Such standards should focus on commissioning and delivering services which are fit for purpose, functional and accessible. Accountability for these processes should sit with each local commissioner.
- **UKHSA should continue and improve national monitoring and data collection on eligibility and uptake of PrEP,** particularly drawing out demographic differences in uptake, to give service commissioners a greater understanding of the demographic groups they need to target in their outreach programmes. It is vital that services submit full data sets and improve data reporting consistency to enable this.
- **Targeted additional funding and support should be given to help local authorities in regions that are reporting specific issues.** For example, to target funding to reduce PrEP appointment wait times in the East of England, to improve service user data collection in the North East and South West, or to provide more targeted outreach programmes in the West Midlands. Specific measures should be considered for clinics in the Greater Manchester area, which many community members reported specific issues with.
- **Funding should be available to increase clinical staff's PrEP awareness and training on PrEP prescribing.** This is essential in building the capacity of clinical staff to confidently provide PrEP services and reduce delays in PrEP access.
- **PrEP eligibility criteria should be radically altered, and PrEP made available to everyone that needs it.** The current eligibility criteria are resulting in missed opportunities for initiating PrEP, either through a lack of understanding by the clinical staff or by excluding those that have self-identified their HIV risk.
- **Government should commit to provide funding to explore missed opportunities for PrEP initiation in recently diagnosed individuals.** Similar work had begun in collaboration between (the former) Public Health England, Chelsea & Westminster NHS Trust, Homerton NHS Trust and community representatives, but was disrupted by COVID-19.

For sexual health services and clinics

- **Training on dispensing & prescribing PrEP needs to be expanded to more staff working in sexual health services.** This includes specific training on patient group directions and better training provision for consultants, doctors, nurses and health advisors.
- **There needs to be specific training about eligibility for PrEP, to address bias (including gender bias) and inequity in access.** This training could be delivered by senior clinicians with experience of prescribing and/or dispensing PrEP, and would include training on how to risk assess patients.
- **Recruitment and retention of staff within sexual health services who have the experience to dispense and prescribe PrEP is key,** as staffing issues were consistently raised as a barrier by respondents to delivering higher capacities of service.
- **Encourage patients to provide anonymised data, to identify gaps in service provision of PrEP to different demographic groups** and to provide a guide on which groups need to be targeted by outreach programmes.
- **Undertake an audit comparing pre- and post-COVID-19 appointment capacity for PrEP and evaluate whether capacity needs to be expanded.** Training more staff to be able to dispense and prescribe PrEP is essential to clear waiting lists and reinstate services to pre-COVID-19 levels.
- **Conduct an audit to determine if the clinic is improving access to PrEP for communities who are not currently accessing services.** This audit could include a review of how clinics are engaging with communities and demographics who access PrEP less commonly. It should outline how clinics and clinicians are addressing systemic and structural barriers to PrEP access for these groups.
- **Clinics should offer a greater variety of appointment options (such as virtual or online consultations) that might help to reduce wait times quickly and more effectively.**
- **All services should provide longer prescriptions of PrEP (6 months or perhaps even 12 months) to bring down demand for appointments in areas with wait lists/low appointment or staff availability.** In the local authority survey, **90%** of commissioners reported offering 3-month prescriptions for PrEP, suggesting that this prescription length is more commonplace. These longer prescriptions should be for 'non-complex' patients and can be combined with regular home HIV and STI sampling services.
- **Implement a system to monitor PrEP appointment requests** – to improve the number of PrEP requests that eventually get seen by the clinical team at clinics and also help provide a more accurate picture of national PrEP need.
- **Provide acknowledgements for appointment requests, along with clear updates or pre-recorded messaging for people accessing PrEP** – including a realistic timescale for a call back. This will also reduce the mental health stress experienced by PrEP service users.

For service commissioners

- **Produce guidance on how clinics can expand appointment capacity within clinics in which there are barriers to PrEP take up** – both to clear waiting lists and to relieve service pressures on clinics with limited capacity. More guidance on how to dispense and prescribe PrEP would also help local authorities identify those who need PrEP or might benefit from it.
- **Look to expand capacity within services that report long waiting lists for PrEP.** Wait times need to be reduced to prevent HIV transmission within key populations and to prevent geographic inequality in access to services.
- **Sign-posting methods to access PrEP in your local authority area.** This will reduce the anxiety and stress experienced by PrEP users trying to access services for the first time and will also act to raise awareness of PrEP to other communities.
- **Commissioners should take an active role in monitoring access to PrEP services and be directly accountable for improving access.** It was clear from our responses that many commissioners are not aware of what PrEP services are, or are not taking place in their commissioned services. They should engage in active dialogues with their providers about PrEP services.
- **PrEP services should be commissioned using evidence-based principles of best practice.** There are current examples of effective service delivery models that could be replicated across geographical areas that could contribute to better performance in areas that are under-delivering.

Methods

This project used several research methods including:

Local Authority/providers survey

The Local Authority survey ran from 5th April 2022, with responses received until 16th June 2022. The questionnaire was sent as a Freedom of Information (FOI) request to all local authorities across England. The vast majority of local authorities in England responded to the FOI requests (134 out of 151), either directly, or via their service providers.

Clinical staff and community surveys

The community and clinical staff surveys were both hosted on SNAP and were available online from 8th June to 17th July 2022 and collected data from PrEP service users and PrEP service providers respectively.

Eligibility criteria for the community survey included individuals having tried either successfully or unsuccessfully to access PrEP and also having experienced difficulties in doing so. These experiences had to be recent, having occurred from October 2021 up until the close of the survey in July 2022. The cut-off time frame accounts for the time after national COVID-19 lockdowns.

The clinical staff survey was open to all staff working in services that provide PrEP. The survey focused on providing a snapshot of PrEP services asking about practice, PrEP prescribing and supply issues.

Terrence Higgins Trust, National AIDS Trust, PrEPster, Sophia Forum and One Voice Network promoted the clinical staff and community surveys through Twitter, Instagram, newsletters, online news outlets and reaching out to their contacts. Following a review of the survey responses two weeks post launch, the project team decided that providing further promotion through paid advertisement would be beneficial in attempting to increase awareness of the survey among women, Black communities and people living outside London and North West England. We ran targeted online advertisements from 27th June to 12th July 2022.

79 clinicians responded to the Healthcare Provider survey and 1,120 service users responded to the community survey.

Case studies

Survey responses from PrEP users were supplemented by case studies. These were individuals who had responded to our community survey and opted-in for further contact. The research team contacted 12 individuals, from a wide geographical area, wide demographics, and who reported different narratives of difficulty accessing PrEP. Everyone who responded was given a telephone interview to share more about their experiences.

Interpreting findings and limitations

Following the data collection and initial analysis, the study team came together to reflect and discuss the findings. The study team identified key themes within each data source and any that emerged across the different sources. We identified that most of the data was not fully representative of the UK and therefore, we decided to limit the recommendations in this report to England. However, there are likely to be learnings that could be used in other nations as appropriate to devolved health systems.

Additionally, the snapshot provided in this report was just before the outset of the monkeypox outbreak, so may not fully reflect the current picture. However, it has been reported that access to PrEP services has been negatively impacted due to displacement of services caused by testing, treatment, and vaccination for monkeypox, as outlined by the British Association of Sexual Health and HIV (BASHH)².

The PrEP community and clinical staff surveys were only available online and in English, so any PrEP user or NHS staff that did not have access to an online platform would have been unable to complete them.

Note that not all questions were answered by all survey and FOI respondents and percentages relate only to those who responded to each question.

2. <https://www.nat.org.uk/press-release/consensus-statement-response-monkeypox-outbreak>

Participant demographics



134 local authorities and providers responded to the FOI request



79 clinicians responded to the survey



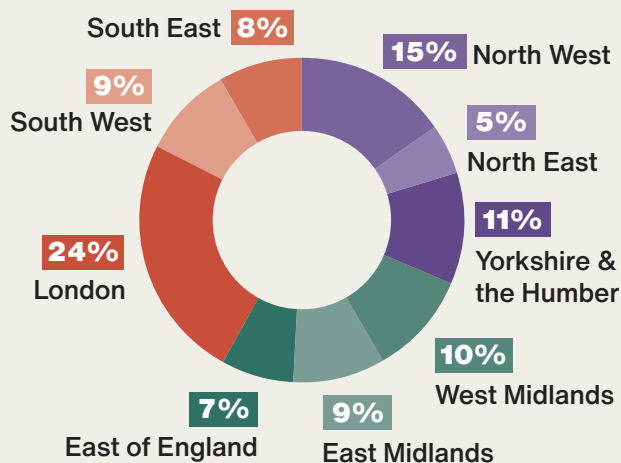
1,120 Community survey responses



4 case studies

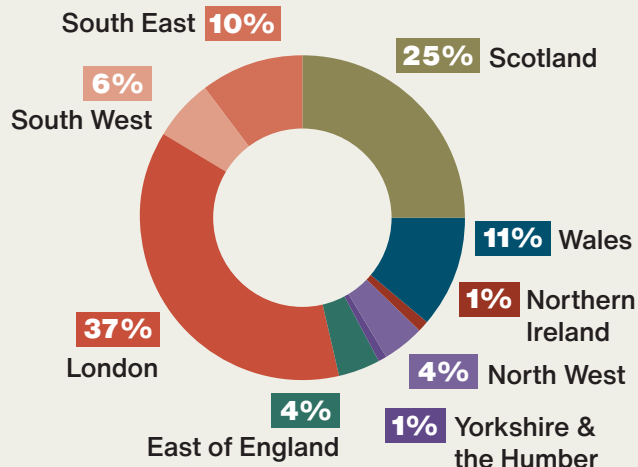
Local Authority/providers survey*

All local authorities in England were sent a Freedom of Information (FOI) request, asking for data about the PrEP services commissioned in their area. In total, **134** local authorities in England (or their service commissioner partners) responded to the FOI request.



Clinical staff survey

79 clinicians working within PrEP services in the UK responded to our survey.



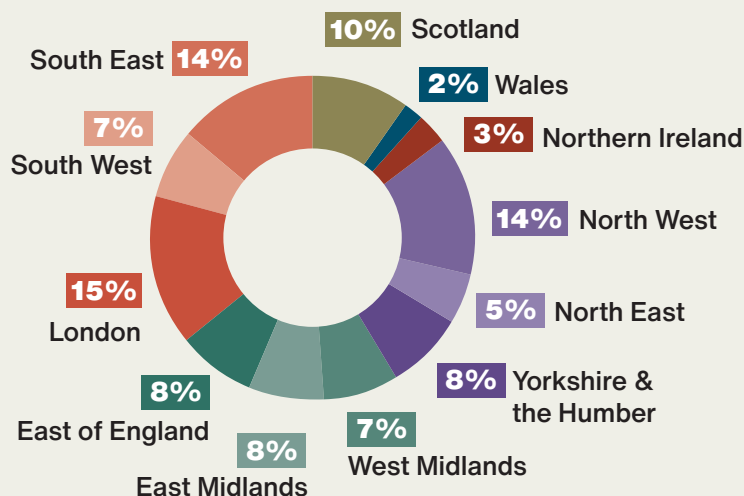
Community survey

1,120 eligible responses from people that experienced difficulties accessing PrEP services since October 2021 were taken forward for analysis.

Just over 93% of the respondents self-identified as gay or bisexual men (GBM), 4% as queer and <1% identified as heterosexual.

Most survey respondents identified as white 87%, around 6% Asian, 3% mixed ethnicity and 2% Black African and Black Caribbean.

The highest number of responses were from people aged 25-34 (34%), followed by those aged 35-44 (27%), then those aged 24 and under (13%).



*All percentages in these graphs are rounded

Discussion

Unmet need for PrEP

The current level of commissioned PrEP services is inadequate, with around half the clinics surveyed reporting being under-resourced to provide PrEP services. This pressure is reflected in our community survey, with only **35%** of respondents getting access to PrEP at the time of responding, the majority of whom were first time PrEP requests. This is deeply worrying and unacceptable.



Only 35% of respondents reported getting access to PrEP at the time of responding, the majority of whom were first time PrEP requests

Those who try but are unable to access PrEP continue to be at risk of acquiring HIV. Such HIV transmissions are entirely preventable with swift access to PrEP and wrap-around support services. Around **62%** of people who provided information on how they eventually managed to access PrEP outside of sexual health services, indicated that difficulties in accessing PrEP have resulted in large out-of-pocket expenditure, or them having to borrow PrEP from friends. This strategy is not sustainable for many and particularly disadvantages those from poorer backgrounds unable to self-fund access to PrEP.

Clinics reported the median wait time from requesting a PrEP appointment to PrEP initiation was 7 days, but **over 80%** of the PrEP users in our community survey report waiting over a week to receive a call back from clinics. Many respondents report being placed on waiting lists, with the longest waiting times of **12 weeks and above** in the East of England. Long wait times for PrEP is not acceptable. Waiting weeks or months to access a HIV prevention medication is a major problem that needs to be remedied.

In the recently released PrEP monitoring and evaluation framework³, the first indicator, 'Determining PrEP need' measures people who manage to access sexual health service (SHS) clinics. However, the enormous barriers to access highlighted in this report indicates the national data could grossly underestimate PrEP need, and this is without accounting for the unmet needs within heterosexual, trans, Black African, Black Caribbean, and other ethnic minority communities.

Issues accessing PrEP

The most challenging experiences for potential PrEP users across all regions were faced by those trying to access first-time PrEP (**68%**). This was followed by those trying to get repeat prescriptions for NHS PrEP (**24%**) and those trying to re-start PrEP after taking a break from it (**8%**).

23% of community respondents reported being turned away from their clinic as they didn't have any available appointments

Expanding capacity in services is essential to prevent people who need to access PrEP from having long wait times – including by expanding appointment capacity. This need is clear, because of the difficulties reported by the community in booking appointments to access PrEP. **40%** of community respondents reported difficulties in trying to book a PrEP appointment online, **30%** reported difficulties in getting through to their clinics by phone and **16%** reported difficulties with email booking systems. **23%** of community respondents similarly reported being turned away from their clinic as they didn't have any available appointments.

There was however a clear disconnect between potential PrEP users' reports of appointment booking systems and those reported by clinicians. Only **19%** of clinicians specifically mentioned appointment capacity as a specific concern, and only **15%** stated a desire to improve appointment capacity within their clinics. This disconnect needs to be addressed.

3. PrEP monitoring and evaluation framework, 2022 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1059310/UKHSA-PrEP-monitoring-and-evaluation-framework-for-England-2022.pdf

Access to appointments is a key barrier to people who need to be able to access PrEP. Without an increase in appointment capacity, it will not be possible to reach all groups who need PrEP and to ensure they have access to medication. The majority of respondents to the community survey were white (**87%**), male (**96%**) and identified as gay or bisexual (**93%**) – suggesting that many groups at-risk for HIV are not accessing PrEP, including women and ethnic minorities, and even those who are aware of PrEP and make the effort to try to access, are facing major barriers navigating these system issues.



The top waiting time for a call back reported by the community was **12 weeks (35%)**

There were also clear differences in the wait times for appointments experienced by those who answered the community survey, and those reported by clinicians and local authorities. The top three waiting times for a call back reported by the community were 12 weeks (**35%**), 2-4 weeks (**30%**) and 1-2 weeks (**17%**). This contrasted with data from local authorities, **95%** of whom said that there was no waiting list for PrEP in their service, and who reported a median wait time from requesting a PrEP appointment to PrEP initiation of just **7 days**.

Local authorities in certain regions reported specific pressures. For example, in the East of England, **50%** of local authorities reported a higher-than-average wait time for PrEP appointments. From those respondents to the community survey that indicated being placed on a PrEP waiting list, more than half (**57%**) had waited more than **12 weeks**, and **41%** of those people were from the East of England. It is imperative that an audit of PrEP services is conducted in the East of England to address these issues, with a follow-up audit conducted 12 months later.

Overall, only **35%** of community respondents reported that they were finally able to access PrEP from PrEP services. This is an alarming statistic and demonstrates a need for the HIV sector to act about access to PrEP services in England. This is also reflected in the fact that **58%** of clinicians had concerns about missed opportunities for PrEP initiation from their patients, despite only **41%** of clinicians reporting awareness of such missed opportunities occurring. This data suggests there may be a large amount of unmet PrEP need in the system, with people taking alternative strategies to access PrEP, or giving up.



The need for equity in PrEP access

Our research identified that communities beyond gay and bisexual men are still not aware of PrEP – no local authority reported more than 5 women using their PrEP services. Similarly, only **12 respondents (1%)** of our community survey were women. This suggests that women’s engagement with PrEP services remains poor, and there is more work for service commissioners and providers to do to engage with women specifically.

No local authority reported more than 5 women using their PrEP services

Additionally, **less than 1%** of the respondents captured by our survey were heterosexuals and only 2% Black African/Caribbean. This is despite the use of targeted paid advertisement to raise awareness of the survey.

This demonstrates that not much progress has been made in advancing PrEP awareness to other communities since the PrEP IMPACT Trial, despite most local authorities indicating having plans and funding for targeted outreach to communities under-represented in PrEP prescribing within their services. Signposting for PrEP services or how to navigate requesting PrEP and options in doing so are also limited.

PEDRO'S STORY

“I would like to walk in or make an online appointment ... I am not confident in using the phone

Pedro has wanted to use PrEP since he moved to the UK but he has no experience of how to navigate NHS services. In the area he lives, on the outskirts of London, the clinic does not offer walk-ins and he is unable to find a way of booking an appointment online or by using email. Instead, he can only book an appointment by phoning. “I would like to walk in or make an online appointment” he says. “But I am not confident in using the phone: like many people of my generation, we’re not good with phones, and even though my English is pretty good, there are things I don’t always understand when speaking on the phone”.

Pedro finds it hard to understand why the process is so hard to navigate, especially given how so many other parts of our lives are navigated online. As such, Pedro has not been able to access PrEP.

Outreach programmes are not specifically translating into PrEP access for these communities and groups. In the development of future outreach programmes, service commissioners should consider specific interventions to identify and overcome any systemic barriers or biases that people might experience in accessing PrEP services.

Our research also highlights the inequalities in PrEP access outside major regions such as London, North West and South East of England.

ASAD'S STORY

Asad first accessed PrEP in London in 2020, and found it easy to access, leaving with his first bottle on that same day. After moving out of London, he tried to access PrEP via a local satellite sexual health service, but they were unable to prescribe PrEP. They told him to try his GP: advice that he knew was incorrect. He tried at a sexual health clinic, and discovered the nurse knew very little about PrEP.

“The nurse told me information about the impact of PrEP on my liver that wasn't true – I know enough about medicine to know this wasn't right. But they wouldn't give me PrEP

Because of this incident, Asad has gone without PrEP for 6 months, until he gets the opportunity to return to his original London clinic. He says he “uses his own risk assessments” to manage his HIV risk, and will be borrowing PrEP from a friend before attending a large up-coming pride event.

Outreach to target communities is a key priority for both clinicians and local authorities, with **71%** of local authorities having plans for targeted outreach to key communities who would need PrEP. Barriers to implementing such work included: staffing issues (**12%**), capacity issues (**11%**) and conflicting priorities with implementing other new services (**6%**).



Tight PrEP eligibility assessment should be changed in favour of wider risk-based criteria

There are clear issues with current PrEP eligibility criteria, which are currently too restrictive and may prevent those at risk of HIV transmission from accessing PrEP. Current criteria reinforce stereotypical views about who is, and who is not, at risk of HIV. Removing current eligibility criteria and creating a more uniform standard criteria based entirely on a full range of activities and situations that increase HIV transmission risk would lead to more appropriate assessment of PrEP need. Equally, any request for PrEP should also be taken seriously based on the fact that not all individuals may be comfortable discussing what activities they do or do not undertake, particularly in certain communities. This might also allow easier access to PrEP for vulnerable groups who are currently less engaged with PrEP services in England (including women, heterosexuals and those from Black African communities).

TIMMY'S STORY

“ [The nurse] *shamed me for having sex outside of my relationship* ”

Timmy was using PrEP before it was available on the NHS and, when the IMPACT Trial started, was told that he did not meet the risk criteria for the trial. He sourced PrEP privately and, once PrEP became more widely available, attempted to source it via his local NHS clinic. During his clinic visit, he overheard the nurse making derogatory comments to a colleague about him and reported that the nurse “shamed me for having sex outside of my relationship”. He was told that he could not have PrEP because “you can afford to buy it” and that “giving out PrEP was a drain on the NHS”. He made a complaint but said he was not taken seriously. He bought a supply online and then had a positive experience of accessing PrEP from a clinic in the North West.



One in five (**18%**) clinicians surveyed reported concerns over competence in assessing PrEP eligibility, with only **15%** feeling there was enough support or training to prescribe PrEP. Staff in the sector need to be supported with additional/further training on identifying PrEP need, and prescribing and dispensing PrEP. In particular, **8%** of clinicians spontaneously cited concerns about staff using patient group directions to prescribe PrEP, with **4%** spontaneously sharing concerns relating to issues with eligibility criteria. The training offer for these clinicians could be improved to build their confidence in using an updated eligibility criteria.

Impacts of delayed PrEP access on HIV prevention

From 555 survey respondents who provided further free text responses, **21%** (115) reported impacts on their dating or sex lives whilst waiting to access PrEP services. Whilst being unable to access PrEP services, many respondents highlighted needing to use other methods of HIV prevention. The top three reported methods of HIV prevention whilst waiting to access PrEP were using condoms for most or all of the time (**28%**), followed by using a temporary supply of PrEP e.g., borrowed from a friend or bought online (**18%**) and reports of changing the type of sex they had (**16%**).

Although some of the respondents to our community survey indicated that they abstained from sex, forced abstinence is not a solution to these issues. 59 community respondents reported abstaining from sex and 27 engaged in non-penetrative sex. Instead of requiring people to change their sexual behaviour as a result of having been unable to access PrEP, provision needs to be upscaled across the UK to ensure that people are able to have the sex they want safely, with access to the most effective HIV prevention tools available. Otherwise, we will see continued and increased HIV transmissions and an undermining of the progress which has been made since the introduction of PrEP.

Mental health impacts of not being able to access PrEP

Respondents to our community survey reported significant personal impacts as a result of being unable to access PrEP – of the 555 people providing further open text responses, almost half (48%) reported mental health related issues whilst trying to access PrEP, including stress and anxiety.

Almost half (48%) of respondents who provided further information reported mental health related struggles whilst trying to access PrEP, including stress and anxiety

Respondents reported issues and barriers at each step of their PrEP journey. Access required individuals to be highly motivated and persistent. In some cases where our respondents reported experiencing a smooth service during PrEP initiation, they still far too often experienced barriers and issues around accessing repeat prescriptions.

MATTHEW'S STORY

Matthew started taking PrEP in the summer of 2021, where his clinic initiation experience went relatively smoothly, and he left the clinic with three months' supply of PrEP. But it was his ability to get a supply to continue taking PrEP, after that initial consultation, that left him frustrated. With only an online option to access a repeat PrEP prescription, Matthew was promised a phone call within 72 hours to organise his next prescription of PrEP.

“ I tried 4 different times to use the online appointment system, and each time I didn't get a call back from the clinic

With two weeks left before running out of PrEP, Matthew rang the clinic, and then had to visit the clinic and “argue at the counter to get an appointment”. Matthew ended up having to borrow PrEP from a friend, in order to access a continued supply of PrEP. “I sent a detailed complaint, but the response felt dismissive”. Since this experience, the clinic has changed the system so that up to six months of PrEP can be dispensed at one time.

Workforce challenges and demand

Staffing issues were at the forefront of the concerns experienced by clinicians, with nearly half of clinical respondents (47%) feeling that their clinic did not have sufficient workforce levels to meet current need around PrEP. 28% of clinicians specifically mentioned challenges in maintaining appropriate staffing levels in their clinic.

Local authorities in Northamptonshire, Middlesbrough and West Midlands all reported a need to cap their PrEP services. Meanwhile, several local authorities reported the creation of PrEP waiting lists, with 4 of those authorities reporting waiting lists of 2 months or more. The longest waiting list was in Cambridgeshire, which reported a waiting list of 5-6 months.

Nearly half of clinical respondents (47%) felt that their clinic did not have sufficient workforce levels to meet current need around PrEP



Such waiting lists or caps are unacceptable as they mean that people who need PrEP are unable to access it. This will also mean additional and preventable HIV transmissions, undermining the national goal of ending all new transmissions by 2030, and reducing these by 80% by 2025.

The lack of data about the quality of PrEP services

The lack of comprehensive and consistent demographic data about those accessing PrEP services makes it impossible to improve equity and redress health inequalities. 10% of clinicians reported that their clinic does not capture demographic data. Similarly, 16% of local authorities reported that they did not hold any data on patient age, gender, ethnicity, or sexual orientation.

This is problematic because accurate data about patient demographics is vital in order to effectively target groups at risk of HIV transmission and promote PrEP services to these groups. There is a need to improve data and data collection from people accessing PrEP services or trying to access services. Experience and satisfaction data should be used to ensure that services can be targeted for support where improvements are needed.

Not PrEPared: Barriers to accessing HIV prevention drugs in England

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