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SYSTEMATICALLY EXCLUDED AND IGNORED

ADDRESSING INEQUALITIES FOR WOMEN IN THE HIV RESPONSE

> *"Stop stealing our voices or ignoring us."*
>
> **Interview participant 6,**
> White British woman living with HIV

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HIV HAS CHANGED. Thanks to extraordinary scientific advances, many people living with HIV can take one pill a day with minimal side effects, live well and have a normal life expectancy.[1] We now know that people on effective HIV treatment can't pass HIV on,[2] and people who do not have HIV can take medication that can prevent them acquiring it.[3] Some progress has been made in shifting norms and stereotypes about HIV, thanks to robust efforts to address stigma and discrimination. As the new HIV Action Plan for England is developed, there is significant progress to celebrate and on which to build.

AND YET, FOR TOO MANY WOMEN, HIV HAS NOT CHANGED. THE FAILURE TO CENTRE WOMEN'S EXPERIENCES HAS BEEN A STEADFAST FEATURE FROM THE EARLIEST DAYS OF THE HIV RESPONSE. THIS MUST CHANGE.

In 1992, a group of 54 women stormed the stage at the 8th International AIDS Conference in Amsterdam, forming the International Community of Women living with HIV (ICW),[4] and issued 12 clear demands, many of which continue to resonate and have yet to be realised today. These included asks for support for the development of self-help groups and networks, realistic media portrayals, funding for services, respect and support for choices about reproduction, and decision-making power and consultation on all levels of policies and programmes.[5]

In 2009, activists in the UK formed the Sophia Forum as a national policy and advocacy charity dedicated to advancing the rights of women living with HIV in the UK, recognising these same issues persisted and were not being prioritised in the UK HIV response.[6] Through peer-led research, policy influencing and the WISE UP+ advocacy programme for women living with HIV and advocacy to increase access to pre-exposure prophylaxis (PrEP) for all who need it,[7] Sophia Forum has been at the forefront of progress for women in the HIV response.

In 2018, Sophia Forum collaborated with the Terrence Higgins Trust (THT) to produce the 'Invisible No Longer' report,[8] and worked with Public Health England to produce the first ever Spotlight data report on women and HIV in the UK.[9] Based on the first ever national surveys of women living with HIV and women who felt HIV prevention was relevant to them, 'Invisible No Longer' provided a solid foundation of research to enable more action to be taken to address women's needs and realise women's rights in the HIV response. The report argued that for too long women had been invisible in policy, programmes, research and services related to HIV. While women had been standing up and speaking out, they were too often unseen and consequently unheard. This research could have been a turning point.

'Invisible No Longer' had five key asks:[10]

1. Achieve gender parity in the UK HIV response, ensuring equitable investment, priority and attention to women in HIV prevention, research, data and services.
2. Ensure that HIV research addresses specific knowledge gaps around HIV and women and supports the full participation and meaningful involvement of women.
3. Prioritise reducing late diagnosis of HIV among women, better explore the use of innovative HIV testing approaches and improve rates of HIV test offers and uptake in different settings.
4. Improve data collection and disaggregation on HIV and women, ensure local level data is available and include sexuality data for women in national reporting.
5. Invest in HIV support services that meet women's needs holistically and enable women to not just live well but to thrive, including peer support and support for mental health and gender-based violence.

Seven years on, all these asks remain relevant, and while some progress has been made, none have yet been fully achieved - we still have a long way to go to achieve gender parity.

> *"I think, to be heard, to be listened to, given options and choices, you know, I think that's the important one really, is to be heard."*
>
> **Interview participant 9,** Asian woman living with HIV

The national HIV Action Plan for England 2022-2025 has an overarching ambition to achieve zero new HIV transmissions, AIDS- and HIV-related deaths in England by 2030. While it did recognise persistent inequities, it did not provide a roadmap to specifically address women's needs and did not reference gender at all.[11] HIV is also not recognised as a women's health issue and is not included in the national Women's Health Strategy.[12]

In 2024, as development of a new HIV Action Plan for England began,[13] Sophia Forum and Gilead Sciences partnered to explore the landscape of women and HIV and understand the priorities of women living with HIV, women accessing HIV prevention and professionals working to provide HIV services. This summary presents key findings from that research, as well as recommendations to inform the development of an HIV Action Plan and HIV services that are fit for purpose for women in all our diversity.

Women living with and affected by HIV are not invisible. They are not hard to reach. The requests and recommendations made in previous publications which would have made a significant difference to women affected by HIV have not been acted upon adding to the stark inequalities we now see.[10,14] Women have repeatedly asked for change but have been systematically excluded and deliberately ignored, something confirmed by the women and professionals we spoke to for this report.

Our challenge to the UK's HIV response and the HIV Action Plan for England 2025: listen to women.

It's time.

SUMMARY OF RECOMMENDATIONS

Overarching aim

To secure urgent action to address the inequalities women experience in relation to HIV at every level, through adopting a gender transformative approach to achieve gender equity in HIV prevention, testing, diagnosis, care and support and promote gender parity in HIV research and data.

Definition: Gender transformative approach[15]

A gender-transformative approach in programming implies that promoting gender equality — the shared control of resources and decision-making — and women's and girls' empowerment are central to an intervention and programme. It means that while working to meet the main objectives of the programme, the approach also helps challenge underlying, harmful gender norms and stereotypes in the process. In the context of sexual and reproductive health for example, a gender-transformative approach entails not only improving women's access to key services including maternal healthcare and family planning services, but also helping communities understand and challenge the social norms that perpetuate inequalities between men and women. It also involves engaging men and boys in ways that address their sexual and reproductive health and rights while supporting women's and girls' sexual and reproductive health and rights including their decision-making in the process.

1 Prioritise women in national and local HIV strategies and structures.

a. The Government should ensure that the specific, evidenced needs and priorities of women living with or affected by HIV are represented throughout the next HIV Action Plan. Government should also conduct and publish an impact assessment for the Action Plan recommendations as they relate to women.

b. A named national champion for women and HIV should be appointed to ensure accountability and progress in reducing health inequalities and gender inequities and drive the implementation of gender transformative approaches at all levels. Similarly, leads for women and HIV should be appointed at the local level to support Integrated Care Systems (ICSs) and local authority-level services.

2 Address the systemic evidence and knowledge gaps around HIV and women.

a. Funding bodies providing resources for research and related activities must prioritise projects that address evidence gaps for women living with HIV.

b. Women with lived experience must be included and given the opportunity to participate meaningfully in the design, development and delivery of all research. This includes but is not limited to the development of medicines, evaluation of services and epidemiological studies and research led by academia, industry, third sector and government organisations.

c. The UK Health Security Agency (UKHSA) and other bodies responsible for the collection and provision of routine health system data should routinely consult with women affected by HIV and HIV community organisations serving women in order to improve their systems and outputs.

d. A programme of mandatory HIV awareness training for all current and trainee healthcare staff and providers of HIV support services should be implemented to ensure all staff have updated knowledge about HIV and the issues facing women living with and affected by HIV.

3 Apply a gender transformative approach to eliminate the inequalities in access to HIV prevention and testing faced by women and address the intersecting inequalities driving late diagnosis.

a. Opt-out or routine HIV testing should be integrated into more services and settings accessed by women. These include but are not limited to primary care, contraception services, routine health checks, termination of pregnancy services, women's health hubs and colposcopy services.

b. All providers of sexual health, HIV testing and HIV prevention for women should have the necessary training and skills to achieve good uptake, including on sex sensitive conversations and cultural sensitivity: see the example below for what this can look like.

c. HIV pre-exposure prophylaxis (PrEP) should be available in settings outside specialist sexual health services, supported by community outreach to inform more women about PrEP.

d. In line with the proposed British Association for Sexual Health and HIV (BASHH) guidelines, healthcare professionals should offer HIV prevention tools including PrEP to all those who request it and all people who seek HIV prevention services regardless of sex, gender identity, ethnicity or sexuality.

e. In settings not implementing opt-out testing, the offer of HIV testing and HIV prevention for women should be made to everyone, and not be restricted based on the bias or assumptions of care providers.

EXAMPLES: An example of a training module for healthcare workers aimed at tackling HIV stigma and discrimination has been developed by the NHS and can be found here.

4

Ensure that women living with HIV have access to comprehensive and appropriate HIV treatment, care and support services that adhere to the British HIV Association Standards of Care.[16]

a. The NHS and ICSs should scale up the implementation of flexible and integrated models of care for women living with HIV such as GROWS, the Sunflower clinic and CliniQ – see the examples below.

b. Funders, commissioners and providers must ensure that all HIV services provide access to a range of tailored support in different formats for women as standard.

c. Peer support, especially models designed for women such as the GROWS programme of gender-specific HIV and peer support education and training, should be sustainably funded and made available to all women living with HIV. In recognition of inequalities in funding access for women-led and focused organisations, resources should be invested in ensuring the availability and sustainability of those organisations.

d. Services accessed by women living with HIV that are not HIV-specific should be informed, inclusive and welcoming for women living with HIV.

EXAMPLES: Integrated models of care for women living with HIV.

GROWS: Women with HIV (GRowing Older Wiser and Stronger) is a programme to support women ageing with HIV. It was initially developed as one of Fast Track Cities HIV London Improvement Fund's 12 funded-projects, and was a collaboration between Sophia Forum, Positively UK, NAM aidsmap and University College London. GROWS aims to reduce inequalities for women ageing with HIV by providing peer-led support, accurate and accessible information, and networks and spaces to help improve outcomes for all women.[17]

Sunflower clinic: The Sunflower clinic is for all women living with HIV (cis and trans) who have their care at the Lawson unit in Brighton and Hove. It offers support, information and education around HIV treatment, contraception and fertility, pregnancy, sexually transmitted infections, cervical smears, menopause, bone and heart health, domestic violence, substance use, sexual assault, social issues, and concerns around mental health. The clinic has a staff team including a health adviser, peer support worker from the Sussex Beacon, HIV consultant, family planning/reproductive health consultant and specialist nurse.[18]

CliniQ: CliniQ is a Community Interest Company that offers a holistic sexual health, mental health and wellbeing service for all trans people, partners and friends. They are a trans-led team, who offer a safe, confidential space for those who may not feel comfortable accessing mainstream services. CliniQ offers wellbeing support services, and a service at King's College Hospital offering sexual health services, HIV testing, PrEP, HIV care and support, cervical smears, hormone injections and hormone blood tests.[19]

All based on content from respective organisational websites.

5

Increase knowledge and awareness of HIV among all women.

a. Existing national and regional campaigns, outreach and direct interventions should be developed and delivered in partnership with women in all their diversities including trans women.

b. Local interventions and campaigns should be aimed at and designed with populations of women affected by HIV and community organisations in the local area using local HIV surveillance data to inform and measure their implementation.

c. All interventions and campaigns should be informed by local HIV new and late diagnosis data and local community organisations to ensure they are meeting the needs of people and addressing HIV in that area.

BACKGROUND AND CONTEXT

WHO IS THIS REPORT ABOUT?

This report speaks to the priorities and experiences of women in all our diversity, including women living with HIV, transgender and gender-diverse people, lesbians, bisexual women, sex workers, women with disabilities, women who use drugs, refugees, migrants, women living in detention and other closed settings, women from racial and ethnic minorities, and young women.

When the term 'women' is used, it is used inclusively to reflect all diverse identities women hold.

The most recent HIV surveillance data (2023 data, published in 2024) produced by the UK Health Security Agency (UKHSA) highlights continuing and persistent inequalities for women particularly in terms of access to PrEP, testing and rates of new and late diagnosis.[20] As we move towards the goal of eliminating new HIV transmissions in England by 2030, these inequalities are feeding into a worrying trend of widening gaps in outcomes and underscore the need to address the drivers of inequalities in order to move towards equalities in outcomes.

The HIV evidence base for women in the UK is limited, itself an indicator of the unequal attention and priority given to this population in the HIV response. The 'Invisible No Longer' study (2018) found over half (58%) of the women surveyed had experienced violence in their lives. Nearly one third (31%) had avoided or delayed accessing required healthcare in the past year due to fear of discrimination. Two thirds (67%) were not satisfied with their sex lives and two in five (42%) said that HIV impacted their decisions on whether to have children. Despite this, half of women living with HIV (49%) described their quality of life as 'good' or 'very good', while a further 38% called it 'acceptable'. On HIV prevention, 42% of respondents felt that barriers prevented them from accessing HIV testing.[10]

Recognising the scale of the challenge, Gilead Sciences and Sophia Forum came together to develop and deliver a project that aims to bring women's voices to the fore again, to ground the data in lived experience and gain an in-depth insight into the inequalities that exist for women today.

WOMEN AND HIV: INEQUALITIES AT A GLANCE

PREVALENCE

33% of all people seen for HIV care in England in 2023 were women[21]

PREVENTION

46% of all new HIV diagnoses in 2023 in England were among women[21]

YET ONLY **3%** of those using PrEP in 2023 in England were women[22]

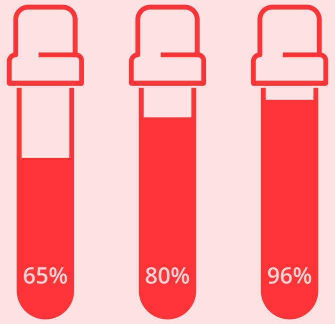
TESTING

Uptake of HIV testing in sexual health services is:

ONLY **65%** among women

COMPARED TO **>80%** among heterosexual men

and **96%** among gay, bisexual and other men who have sex with men (GBMSM)[20]



LATE DIAGNOSIS*

The proportion of women diagnosed late is **42%**[23]

TRANSMISSION

Of the 15,800 people living with transmissible levels of HIV **4,400** were women compared to 2,900 that were heterosexual men[23]

STIGMA

Women are more likely to keep their HIV status private compared to men: **14%** vs **9%**[24]

WIDER INEQUALITIES

10% of people living with HIV are unemployed. Unemployment was highest among people who identified as trans, non-binary or in another way (18.8%), women (14.3%), people of Black African ethnicity (13.5%), and other minority ethnicities (12.7%)[24]

U=U Overall, awareness of the concept of U=U was very high with 9 in 10 (92.3%) people living with HIV aware. Across demographic groups, awareness was highest among young people (98% in 18 to 34 year olds) and lowest among women at 88%.[24]

1 IN 9 (11.8%) people were afraid to attend healthcare services in the last year due to concern that someone may learn their HIV status[24]

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*A late HIV diagnosis is defined as having a CD4 count below 350 cells per mm^3 of blood within 91 days of diagnosis and no evidence of a recent infection.[23]

AIM

This report aims to build on existing evidence and advocacy efforts, shining a spotlight on the inequalities women experience and providing an insight into the impact on women's lives. The report also sets out a path towards greater equity for women in HIV prevention, testing, treatment and care in the UK.

Without prompt, targeted and dedicated action, the gaps will get wider, and more women will be affected by unequal access, poorer support and care that does not meet their needs. The inattention and inertia that has characterised the response to gendered inequalities in HIV policy, services and research in the UK must be overcome.

METHODOLOGY

LITERATURE REVIEW

A literature review was conducted as a first step to examine previous publications on HIV, inequalities and services in the UK. The review focused on UK literature. It included strategy, policy documents and reports as well as quantitative and qualitative research.

Findings from the literature review informed the development of discussion guides that were used in the interviews (described below). The evidence gathered is further used in this report to put this research and our findings into context.

INTERVIEWS

We undertook a series of interviews with women living with HIV, women with experience of HIV prevention and PrEP, and professionals with experience of working with and delivering health services for women. The professional interviews included HIV consultants, sexual health leads, local authority sexual health commissioners and third sector organisation representatives. Interviews were semi-structured and followed an interview guide. Interviews with professionals were conducted by Incisive Health on behalf of Gilead Sciences, and interviews with women with lived experience of HIV or PrEP were conducted by Sophia Forum. Interviews were conducted over the phone, using Zoom, or face-to-face, according to interviewee preference. All interviews were audio-recorded, transcribed, anonymised and analysed thematically (using Dedoose software for the lived experience interviews).

WORKSHOPS AND FEEDBACK

Initial findings and draft recommendations were shared and discussed at an in-person workshop with a range of stakeholders including: women affected by HIV; community organisation representatives; NHS and local authority commissioners; clinical leads; public health experts and HIV policy professionals. The feedback received was used to adapt and refine the recommendations. The final recommendations were validated in an online workshop with the women living with HIV who had been interviewed to ensure they resonated with the experiences that they had shared.

PARTICIPANTS

Fifteen women participated in lived experience interviews:

- 12 women living with HIV and three with experience of PrEP.
- Seven women were Black African, four Asian and four White British.
- Ten women lived in London, and five outside London.
- Two participants identified as trans women.
- Of the twelve women living with HIV, seven were long-term diagnosed, and five more recently diagnosed.
- Two women were diagnosed late, seven received a timely diagnosis, and for three women this is unknown.
- Women interviewed represented a diversity of socio-economic experiences, purposively sampled to ensure a range of views and experiences.
- Three women acquired HIV through vertical transmission.

Six professional interviews were conducted, with a total of seven participants: three interviews with four third sector organisation employees (one interview included two participants), one sexual health and HIV consultant, one sexual health and gender identity physician, and one public health commissioner.

SUMMARY OF FINDINGS

CHANGES PARTICIPANTS ARE CALLING FOR

Interview participants were invited to share changes they believe would make a difference to the lives of women living with HIV and to describe the priorities they would share directly with politicians and health service leaders. Responses to this question helped shape the recommendations made in this report.

> “I’d want them to know that HIV is a stigmatised condition, and you need to have a lot of support around you, from services and from family and friends, and that a lot of women don’t receive that. A lot of women are maybe in relationships that are not necessarily healthy, that women are often juggling many jobs or childcare. Women often suffer also from poor mental health from chronic conditions, and they’re doing all this with HIV, and this often prevents them from accessing services they need. Don’t you think it’s time that you actually built in women living with HIV’s needs into all your services that you do a kind of… an audit of how accessible your services are to women living with HIV. Yeah, and I’d like to see in all healthcare services, I’d like to see all the staff undergo HIV awareness training.”
>
> **Interview participant 11,** White British woman living with HIV

Issues that women prioritised included: greater access to PrEP in more settings to ease barriers; integration of HIV testing into regular testing and health checks; services and support including access to Legal Aid for women who have experienced gender-based violence; well-funded, non-judgmental, holistic trans healthcare services; and funding for awareness campaigns and for services including psychological support.

Women wanted health service leaders to know that more research into treatment and side effects in women and improved access to new developments was needed – for example, support for breastfeeding and greater access to innovative treatments and prevention technologies. Women also flagged better integration between services, including improved communication between GPs and HIV clinics. Better integration of broader care was highlighted including mental health services and prescription complementary therapies, providing a bigger range of options for managing pain. Access to both peer support and psychological support were called for, with support that is diversified to meet different needs and preferences and tailored to meet changing needs across the life course. Increased funding for services would support the diversified and sustainable services women need. Women living with HIV called for women to be recognised as a diverse and unique group, with complex lives and experiences, and for services and support that reflects this. Parity of services, support and care across the whole country, and not just in London, was also highlighted. Women called for efforts to improve HIV knowledge and training across the healthcare workforce and better coordination with GPs and other providers.

> “I think it has to be individualised, personalised care, for sure, because every person, woman’s experience is different, and this journey in their life is different. So it has to be bespoke to that. I think it has to be definitely around, peer support has to be offered. I think that’s really important for women as well. I think treatment advocacy is really important. I think as well, and mental health support, I think is really important, whether it’s counselling, and I think all of that is really important, and knowing as and when people want to get it they can access that, because people want different things at different times, because when your life changes, things happen.”
>
> **Interview participant 9,** Asian woman living with HIV

Women also called for more research on HIV treatment in women to provide better evidence on dosages and side effects, more support for families of women living with HIV including adult children, more support and services for women experiencing violence and its consequences, and more support tailored to young people. Finally, women identified the need for general HIV education and broad information campaigns to update knowledge and awareness among the general public and encourage more women to test for HIV and consider their HIV prevention needs.

> “I’ve sometimes felt invisible. I felt frightened and worried and lonely. That should not be the case, and I feel very vulnerable. So yeah, that’s how I’ve experienced it. There’s certain things I feel they could do to improve, and one is educating the whole public about it. They had in the 80s, the tombstone. They should have one now about living with HIV, but also that it can affect basically anybody you know.”
>
> **Interview participant 8,** White British woman living with HIV

When asked the same question, professionals’ requests included: more research focused on women’s experiences with HIV, particularly regarding pregnancy, menopause, and overall health outcomes; sustainable funding and support to maintain and grow new community spaces to reach marginalised groups; greater capacity in gender services to help address the issues of HIV and people’s ongoing wellbeing, as gender services are often a setting where trans people can feel safe; greater accountability to women in policy, including through dedicated resources and greater priority on women’s needs in the next HIV Action Plan; and a long-term plan for HIV and HIV care, recognising that people will need to be supported to live well with HIV beyond 2030.

WELLBEING AND QUALITY OF LIFE

Women described a range of factors influencing their wellbeing and quality of life including a sense of meaning and purpose in life, financial stability, secure housing, good social support and networks, feeling a sense of ownership, leaving behind difficult or unhealthy relationships and finding contentment. Managing HIV treatment effectively, including through strong adherence and minimising side effects, also positively affects wellbeing.

Conversely, a number of issues and experiences negatively affect wellbeing and reduce quality of life. This includes factors directly related to HIV such as family challenges and breakdown of relationships, the burden of daily treatment, side effects, and the impact of HIV on life choices and opportunities, such as not having children. Some women described a lack of family support, due to not sharing their HIV status, or having done so and receiving a negative reaction, or further due to migration causing physical dislocation from support networks. For example, one participant described struggling with limited physical mobility as well as other physical and mental health issues, with very few social support resources due to migration rupturing her social networks.

Stigma

The intersecting impacts of HIV stigma, racism, anti-trans stigma and other forms of oppression and exclusion also negatively impacted the wellbeing of some women we spoke to.

Professionals also highlighted how they see the impact of different forms of stigma on the women they interact with, particularly in relation to mental health. They perceived the biggest limiting factor in the lives of women affected by HIV was stigma, whether it was internalised, externalised, perceived or objective. One participant went on to say that the idea of 'quality of life' was subjective, and the feeling of self-worth is a privileged mindset that some women living with HIV are not able to access due to their culture or circumstances, which makes quality of life difficult to measure, or improve at scale. How quality of life is understood and experienced is complex and varies across individuals, and attention should be paid to the individual's own perception of their quality of life and wellbeing, beyond clinical markers.

Mental health

Women identified stress, anxiety and trauma as impacting their mental wellbeing. A sexual health clinician identified that integrated mental health support systems within care frameworks would help women's ability to engage with care, as charities are currently picking up this essential aspect of care. Access to mental health support can vary between locations, and even where there is dedicated support, it may not cater to the needs of women.

Intersectional experiences and discrimination also impact on wellbeing. Professionals highlighted the need for more research and targeted support to address wellbeing and quality of life for trans people. Trans people are generally more stigmatised, both in wider life and in health and care settings, and adding HIV to this only exacerbates the issue. Further, trans people can already have mistrust of the system, which mirrors what a lot of people experience through HIV care and can lead to compounding challenges.[25]

Managing multiple conditions

Other health issues also affect wellbeing, including managing pain and multiple co-morbidities, with pain posing a significant challenge for multiple women we interviewed. Many participants were dealing with multiple other health issues, some more impactful than HIV. Navigating multiple treatments, appointments, symptoms and care is a significant practical and psychological burden, compounded by the complexity of navigating several secondary care providers and the requirement to coordinate and advocate for yourself.

Some participants described the impact of trauma and addiction, while others described challenges due to menopause, often with limited access to information and support. Participant 13, an Asian trans woman who is using HIV PrEP, described a range of complicated physical health issues that impact her ability to manage PrEP, and its side effects. Importantly, some participants did describe good health and this having a positive effect on their wellbeing.

> “Currently, my health [does impact my quality of life], which is maybe related to HIV, maybe not. They're the inflammatory issues. So they do degrade the quality of life somewhat, yeah, I would say that's the one thing that does. Also, I've got arthritis of the knee, so that's been a massive shift in my quality of life because I was always very active. I still remain active, but it means daily life comes with a degree of pain..”
>
> **Interview participant 11,** White British woman living with HIV

The extent to which HIV influences wellbeing is difficult to unpick and quantify. For some, there was a positive impact due to regular access to healthcare and check-ups, as well as the benefits of community and peer support. For others, HIV posed a barrier to relationships, whether due directly to feared or realised discrimination, or to the additional burden of considerations of whether to talk about HIV and if so, how and when, which discouraged some women from making connections. The psychological impact of uncertainty weighed heavily on some women.

> “[HIV does impact me] psychologically, definitely. And I think it does physically in terms of the tiredness, but it is obviously very difficult to separate off, low energy levels with all the factors involved in you know, you’re getting older, menopause, stuff like that. I’m doing a lot of physical work, working full time, and it’s hard to know what relates to the HIV and what doesn’t, so I would say it definitely affects me psychologically and possibly physically as well. And if anything goes wrong with me, I’m always wondering, is it the HIV, like I had some issues with neuropathy. You’re always wondering, you know, is it that, or if you get something, would you have got that if it wasn’t for the HIV? You know, when I get a cold or something, it does tend to go on for quite a while, so I need a lot more rest than I used to.”
>
> **Interview participant 3,** White British woman living with HIV

Individual experiences were varied. A Black African woman who took part in an interview felt that HIV had only had a limited impact on her life, only really affecting her experiences around pregnancy, birth and breastfeeding, whereas another participant felt she had missed out on her childhood and education due to the wide-ranging physical impact of HIV including a stroke and reduced mobility, as well as the psychological impact of feeling different.

Sex and sexual pleasure were rarely highlighted, though one participant described its importance to her, as well as her belief that it is not spoken about and addressed enough.

Caregiving and care responsibilities

Caregiving and providing support to others impacted women in several ways. This included participant 6, who is White British and living with HIV, who had prioritised caring for her husband over her own health and wellbeing, and participant 5, who is Black African and living with HIV, who had assumed financial responsibilities for family members, and a number of other participants have young children and/or ageing parents. It is important to understand caregiving responsibilities as both current and implied – for example with ageing parents, and as encompassing both practical care, financial responsibility and other types of care, including for adult children.

> “I did before last year, I had [caring responsibilities] for my mother, who was diagnosed with Alzheimer’s in 2020 and I was her main carer until she went into a home shortly before she died, but I was her carer for about the last three years, so that was quite major. And did you know leave me quite depleted.”
>
> **Interview participant 3,** White British woman living with HIV

Socio-economic factors also influence wellbeing, both positively, with some participants reporting secure housing, employment and economic status, and negatively, with others describing the impact of insecure housing, poverty and the impact of the cost-of-living crisis.

In the validation workshop, discussions focused on the need to make some fundamental changes to the way services are delivered to make them more person centred and that this requires leadership. There was consensus around needing to do more to address stigma in healthcare settings and to involve women in the development and delivery of their care.

THE CASE FOR CHANGE: WELLBEING AND QUALITY OF LIFE

The 2022-2025 HIV Action Plan for England stated that the Government would “optimise the quality of life of those living with HIV.”[26] However, the experiences shared in this project illustrate and underscore data from the Positive Voices survey which reported little change in the quality of life and wellbeing of people living with HIV or their experiences of HIV-related stigma between 2017 and 2022.[24]

Whilst this report highlights the specific issues facing women living with or affected by HIV, the urgent need to provide person centred services that support quality of life and wellbeing are well documented. The BHIVA Standards of Care state that “people living with HIV should receive care that takes account of and enhances their wellbeing beyond their physical health and life expectancy.”[27] Actions 18 and 19 in the HIV Commission both focus on the need to better integrate and co-deliver services,[27] and the HIV Action Plan committed that “commissioners and service providers design and deliver culturally competent HIV and related health services.”[11]

Similarly, addressing stigma in healthcare settings came through as a key factor in women’s wellbeing and numerous reports call for, or commit to, addressing HIV stigma in healthcare settings through training and education.[16,26,27,28] However, as is clear from the findings of this report, improvements are not coming fast enough or at all.

Whilst there are some good examples of progress such as integrated care models or HIV training programmes, they are too few meaning most women cannot benefit from them. The systemic changes we are calling for to address inequalities in quality of life and wellbeing for women require strong leadership and greater accountability at national and local level. Prioritising these recommendations and driving progress will bring significant benefits to women affected by HIV and to the UK’s chances of reaching the 2030 goals.

RECOMMENDATIONS THIS SECTION SUPPORTS: 1a, 1b, 2a, 2b, 2c, 2d, 3b, 4a, 4b, 4c.

HIV PREVENTION

> “There has been a blind spot historically when looking at prevention efforts in women.”
>
> **Interview participant,** Sexual Health and Gender Identity Clinician

Effective HIV prevention requires knowledge about HIV and an acknowledgement that preventative actions are relevant to the individual and worth taking. For some of the women we spoke to, their vulnerability to acquiring HIV was related to things they did not know, such as the sexual activities of their purportedly monogamous partners, complicating the possibility for preventive action, as did HIV acquisition through rape. However, women frequently highlighted how nothing had ever made HIV seem relevant to them, and that their knowledge about HIV prior to diagnosis had been very limited and often very outdated. This feeling was echoed by the professionals we interviewed who highlighted that materials and education are often targeted at gay and bisexual men and other men who have sex with men (GBMSM), and women are not represented sufficiently, which would be necessary to drive uptake in women and awareness in professionals.

> “Someone else, a man, has determined what an at-risk group looks like.”
>
> **Interview participant,** Former Women’s Activities Officer at an HIV charity

This failure to ensure that everyone is informed about HIV, despite presumptions about their risk status, complicates access to prevention and has profound effects on women and their wellbeing.

> “I was aware of it, but it wasn’t something I was worried about, and it wasn’t something that I had in depth knowledge about either. It was just, you know, [it was just] one of those sexually transmitted diseases.”
>
> **Interview participant 16,** Black African woman living with HIV

The importance of HIV prevention for people living with HIV should not be forgotten. A lack of knowledge of progress in HIV prevention, especially of U=U, among the women interviewed was evidenced. This negatively affects women directly, delaying access to testing and treatment, whilst limited knowledge also permeates women’s social and family networks, limiting the support they can access and the safety they can expect when talking about their HIV status.

Professionals described how they had seen the value of effective community engagement to support improvements in HIV prevention for women. Engaging with communities and building trusting relationships is essential to overcome taboos and open up the conversation for women who are part of these cultures or religions. This can be supported by making HIV conversations more mainstream, integrating them into various healthcare settings like pharmacies, dentists and antenatal care settings to normalise them. Participants spoke about making testing and access to PrEP more mainstream by moving access to these services into the community, to reduce the stigma around accessing prevention or testing for PrEP.

> “I think we need to be a bit more innovative, creative and flexible, in the sense that we need to make access more diverse... let them go into spaces that people feel free going into, and then let’s make it a normal conversation.”
>
> **Interview participant,** Co-director of a peer-led support and advocacy network

Effective HIV prevention services should recognise the importance of addressing mental health, the complexities of linkage to care, and the necessity for dedicated resources and accountability in policies aimed at improving the lives of women living with HIV. The limited involvement of primary care providers in HIV prevention was highlighted as an important gap to address, because they are a major part of people’s lives and the number one point of contact in the health system for many women.

When asked about their HIV prevention choices, most women talked about condoms, highlighting challenges in using these, especially as they grew older, and male partners who thought of condoms only as contraceptives became reluctant to use them as they thought they were no longer necessary. For some women, prevention didn’t feel relevant as they were not having sex, which reflects personal choices but also indicates the lack of support and information made available to them to realise their right to a full and healthy sexual life. Participant 17, a Black African woman living with HIV, was aware of U=U and using this strategy with her partner, and others talked about feeling comfortable with it and having support from their clinics. For others though, HIV was seen as a barrier to dating and relationships, linked both to concern about consequences but also reticence and discomfort in having to talk about HIV with potential partners.

Three women interviewed for this project were currently accessing or had previously accessed HIV PrEP. Participant 18, an Asian trans woman using PrEP, first learned about it at a community meeting for trans people and followed up at a clinic. Participant 14, a Black African woman using PrEP, was interested in an effective HIV prevention option she could control, and also first heard of PrEP in a community setting and then attended a sexual health clinic, where she described a good experience of accessing information and support. For all participants, the decision to access PrEP was based on a combination of awareness of potential for HIV transmission, current sexual activity and comparison with other prevention options, balanced by concern regarding potential side effects.

Participant 13, an Asian trans woman using PrEP, described regularly accessing sexual health screening where HIV and PrEP were routinely discussed, and she also received support for gender transition. She currently takes PrEP episodically but is experiencing challenging side effects, especially stomach cramps and diarrhoea, so she is considering a return to taking every day as she used this regimen previously without problems. Initially, she accessed PEP after experiencing sexual assault, and subsequently learned about, and decided to take, PrEP. Her decision-making over PrEP, including whether to take it and how to take it, has changed over time depending on other circumstances in her life, including how sexually active she is and her experience of side effects. She described feeling supported in this process, with no challenges with access or information, and a good experience at clinic with screening and prescribing of three-month supply of PrEP.

Similarly, participant 18, an Asian trans woman using PrEP, described her experiences of accessing PrEP through a sexual health service for trans people as positive, with a good, efficient and friendly service that is sensitive to and able to meet her needs. Appointments are quick and efficient, and she has not experienced side effects.

Participant 14, a Black African woman using PrEP, had previously accessed PrEP but decided against using it after the first couple of weeks, as she found it challenging to remember to take it every day, and the relationship she was in that had led her to consider her HIV prevention options had broken down.

Professionals suggested that the low uptake of PrEP among women stems from a lack of awareness, education, and representation in media or national HIV campaigns, and advocated for a more inclusive approach in healthcare services. Professionals highlighted significant inequalities in providing access to PrEP for women, influenced by cultural taboos, stigma, and discrimination within healthcare settings and within their communities. Key issues also included the lack of targeted information, and system barriers such as the need for multiple clinic appointments that are impractical for most women given the challenges of travelling to clinics, finding cover for caring responsibilities and time away from work, education or other responsibilities. Concerns about interactions with other treatments, or hormone therapy for trans women, can also complicate access to and uptake of PrEP, and need to be sensitively addressed and fully understood by clinicians providing care.

> “There are communities where having sex outside of marriage is considered taboo, and so why would you be promoting PrEP? ... so there are some conversations that need to be had first, before we even get to the point of why we’re having PrEP.”
>
> **Interview participant,** Co-Director of a peer-led support and advocacy network

These barriers are compounded by challenges resulting from the focus of early research and initial rollout and research of PrEP on GBMSM, which meant that nobody else outside of this group viewed themselves as candidates for PrEP, and since then efforts have not been intentional enough to reposition PrEP for other groups.

> “[Women] are not the only group, but they are a group that we have spectacularly failed.”
>
> **Interview participant,** Public Health Commissioner at local authority level

One participant suggested that women in general do not have PrEP in their minds as something within their sexual health prevention ‘toolkit’ in the same way that they might consider condoms or the contraceptive pill, and a reframing of PrEP is needed to achieve this. However, a clinician highlighted that clinicians unfamiliar with PrEP needed to ensure they were educated on how PrEP works for women and have the time to have a conversation with women. Additionally, the preconception that PrEP is primarily a prevention resource for GBMSM is not limited to women (or other groups) themselves, with one participant saying that some clinicians are still hesitant to prescribe PrEP outside of GBMSM:

> “[Clinicians have] got a box of who fits the criteria, and they’re nervous of coming out of that box.”
>
> **Interview participant,** Consultant physician in Sexual Health and HIV

Evident across these experiences is the value of services which provide accessible and sensitive information on HIV prevention options, and access to a range of tools and options that reflect the diversity of women’s needs and preferences. Professionals advocated for expanding PrEP services beyond sexual health services, to be accessible in a wider range of settings. Other suggestions to improve PrEP experiences for women included promoting greater general awareness of PrEP, so that it is easier for PrEP users to inform their partners about their prevention choices and for them to feel comfortable. Participant 14, a Black African woman using PrEP, had struggled with the size of PrEP tablets and the need to take them daily; participant 13, an Asian trans woman, echoed this and was interested in alternative forms of PrEP.

> “I already take so many tablets, so even if some of them are reduced, I would be happy.”
>
> **Interview participant 13,** Asian trans woman using HIV PrEP

During the workshop there was acceptance that expanding access to PrEP through a wider range of services was crucial to addressing inequalities, but that more work was needed to tackle disparities in existing sexual health services. It was also highlighted that women had not been prominent or involved enough in past interventions and campaigns and that more effort was needed to change this and ensure women are seen in HIV prevention.

THE CASE FOR CHANGE: HIV PREVENTION

The principle of greater involvement of people living with or affected by HIV (GIPA) is a long-standing one; UNAIDS published their first policy paper on this topic in 1999,[29] and there is a recommendation for GIPA in both the HIV Commission report and BHIVA’s Standards of Care.[27,28] With current HIV prevention measures and services not sufficiently catering for women’s needs, putting women at the centre of their design and implementation would provide an opportunity for real improvement.

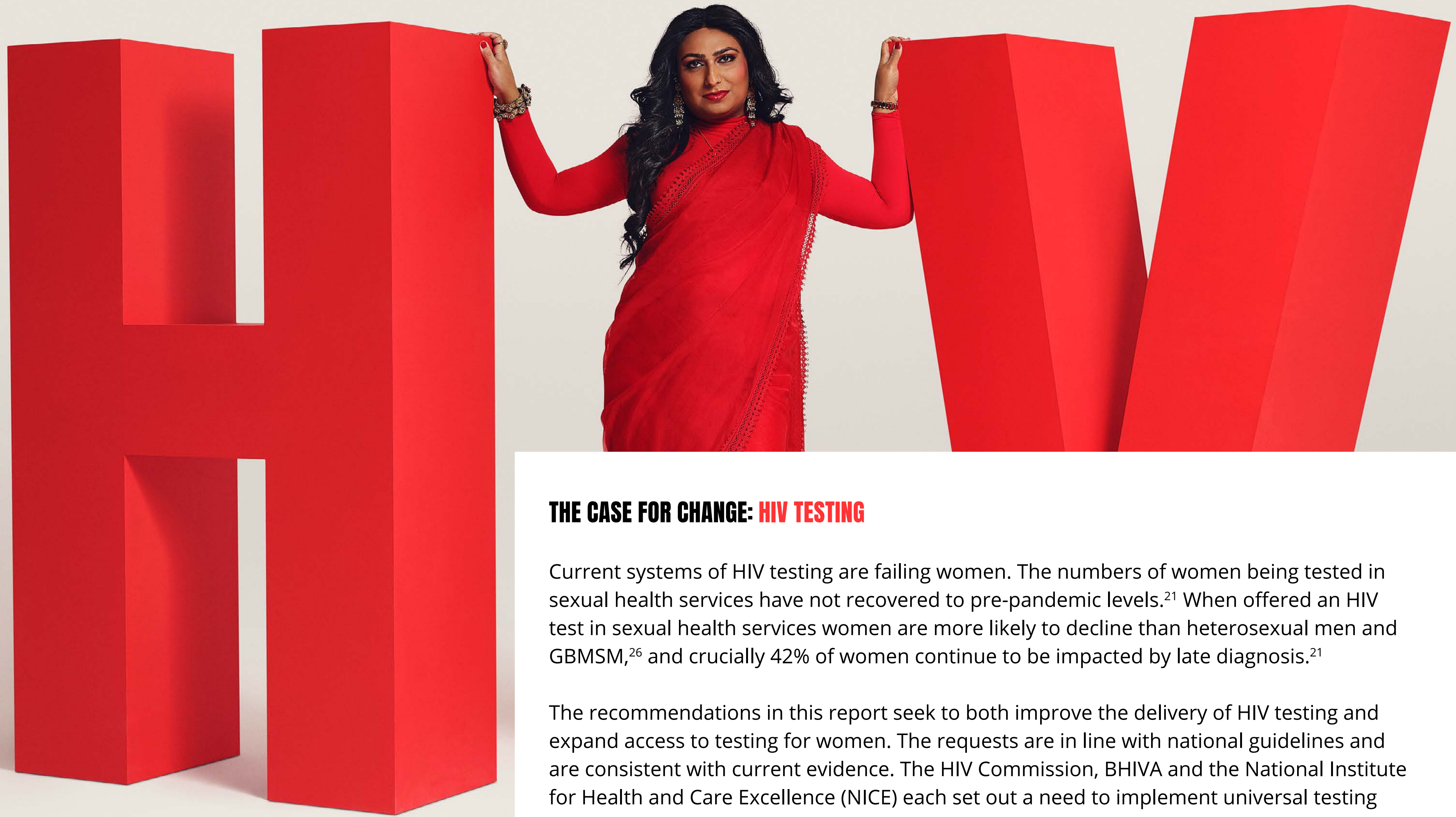
This report reminds us that enabling people living with HIV to engage with care and treatment is also central requirement for successful HIV prevention. Therefore, ensuring that women have equitable access to all HIV prevention interventions will be essential to ending new transmissions and is reflected in almost all the recommendations in this report impacting on HIV prevention in some way.

The disparities women experience in relation to PrEP are particularly stark. The data is clear, PrEP is not reaching the women that need it.[20] An important meta-analysis that reviewed the barriers and facilitators to HIV PrEP in the UK highlighted that the majority of the scientific literature focuses on men who have sex with men and that more research is needed to ensure that underserved populations are included and prioritised.[30]

Professionals interviewed here called for PrEP to be made available in more settings beyond sexual health services, especially those that are primarily women-facing and have the potential to reach underserved populations. This is an ask that has been made previously in both the HIV Commission report and the ‘PrEP Insight Project’ report, commissioned by the English HIV and Sexual Health Commissioners Group (EHSHCG), as well as 2022 ‘Not PrEPared’ report, published by the National AIDS Trust with other community organisations.[31,32] The meta-analysis also highlighted a number of studies which set out the potential benefits of extending PrEP delivery to more settings especially primary care. The need to change the way in which PrEP is delivered to women was recognised in the Government’s ‘Roadmap for meeting the PrEP needs of those at significant risk of HIV’, which committed to exploring opportunities for PrEP service delivery in reproductive health services with the aim to improve access to PrEP for women.[33]

However, providing PrEP in more settings alone is not sufficient. UKHSA data indicates that even in sexual health services women are less likely to have their need for PrEP identified and women whose needs are picked up are less likely to start PrEP.[21] The forthcoming updated BASHH/BHIVA guidelines are a welcome step in moving towards a more equitable approach. However, this report identifies specific gaps in the training and skills of staff delivering HIV prevention services, something also highlighted in the ‘Not PrEPared’ report,[32] which also cited a specific requirement for training to tackle the barriers that are created by outdated eligibility criteria and assumptions about women’s need for PrEP.

RECOMMENDATIONS THIS SECTION SUPPORTS: 1a, 1b, 2a, 2b, 2c, 2d, 3a, 3b, 3c, 3d, 3e, 4a, 4b, 4c, 5a, 5b, 5c.



HIV TESTING

Few of the women interviewed had ever requested an HIV test, describing how HIV had not felt relevant to them or not been suggested to them as something to consider. Participant 3, a White British woman living with HIV, described requesting a test and being made to feel like she was wasting resources or part of the 'worried well', which put her off further testing. That HIV testing had not been made available routinely or as part of health checks or standard blood tests was highlighted as a gap and an area for action. Offers of HIV testing were made infrequently and often accompanied by an indication that it was not something to be concerned about, as doctors implied that it was incredibly unlikely that some women we spoke to would be diagnosed with HIV. Women described missed opportunities for normalising testing by integrating HIV tests into routine care, encouraging uptake of services, and addressing risk perceptions – not just for diagnosis.

The only women in our sample that talked about routinely accessing HIV testing were those currently using HIV PrEP, whose prevention needs had been identified and were being met. For women living with HIV, outside of maternity services HIV testing had not been routinely available, and in some cases specific barriers had been enacted making it harder to access, such as restrictive eligibility criteria. Often, the specific HIV prevention needs experienced by women were not clear, and this, coupled with institutional barriers, led to many cases of late diagnosis and serious ill health. Professionals described the need for open, non-judgemental and regular conversations about sex in general between clinicians and patients to allow for conversations about HIV prevention to take place and ensure clinicians have a better understanding of an individual's risk.

Discussions on HIV testing in the workshop centred around the importance of training for healthcare workers to address stigma and limited understanding of HIV risk. Attendees also discussed that to normalise HIV testing, routine testing approaches should be introduced in more settings outside of sexual health services, especially in those with a focus on women's health such as reproductive health services, abortion services and women's health hubs.

THE CASE FOR CHANGE: HIV TESTING

Current systems of HIV testing are failing women. The numbers of women being tested in sexual health services have not recovered to pre-pandemic levels.[21] When offered an HIV test in sexual health services women are more likely to decline than heterosexual men and GBMSM,[26] and crucially 42% of women continue to be impacted by late diagnosis.[21]

The recommendations in this report seek to both improve the delivery of HIV testing and expand access to testing for women. The requests are in line with national guidelines and are consistent with current evidence. The HIV Commission, BHIVA and the National Institute for Health and Care Excellence (NICE) each set out a need to implement universal testing approaches in areas of high and extremely-high HIV prevalence in a range of settings, including abortion services and primary care.[28,34,35] The BHIVA testing guidelines also recognise the need for appropriate education and training for staff to successfully deliver HIV testing.[35]

In 2021, the HIV Action Plan pledged to scale up HIV testing in line with national guidelines and as part of that there was a specific commitment to focus on populations and settings where testing rates must increase.[26] Funding to implement opt-out testing in emergency departments came alongside this pledge and has been an excellent example of the impact that routine, universal testing can have on inequalities. This approach has been successful in disproportionately identifying HIV among women and people of Black ethnicity.[36]

However, in sexual health services in 2023 testing rates among women had not returned to pre-pandemic levels.[21] Introducing the recommendations presented for HIV testing would reduce rates of undiagnosed HIV and late diagnosis for all – something that is fundamental to achieving health equity for women and essential for reaching the goal of ending new HIV transmissions.

RECOMMENDATIONS THIS SECTION SUPPORTS: 1a, 1b, 2d, 3a, 3b, 3e, 5a, 5b, 5c.

DIAGNOSIS

Participants in this report had been diagnosed at different stages of the HIV epidemic, and in different contexts regarding access to care and treatment. Many women described missed opportunities for earlier diagnosis with HIV, with serious implications for their health and wellbeing. The experience of receiving an HIV diagnosis was often shocking and frightening, representing a rupture from a former life and conception of self. For some women, the diagnosis carried further meaning and complications, whether as a permanent consequence of sexual violence, or revealing a husband or partner had been dishonest about their sexual activity.

> “So, the diagnosis was at the health clinic, at the GU clinic, we'd gone the week before to get tested, and I insisted we had to have all the tests. Another thing my husband had said was that he would go and get all the [tests] to save me anxiety, that he would go and get all the tests done, and if he was clear, I didn't need to go. But I said, no, we both go. We both go together, but, I mean, we were tested separately. I then, at the time, thought that was the time that he got the diagnosis of HIV. Then later, just with conversations, he happened to slip up, and some of the things the medical people said, I realised they knew his diagnosis before. Yeah, we weren't receiving the diagnosis together. We weren't receiving this diagnosis on the same day.”
>
> **Interview participant 8,** White British woman living with HIV

Limited knowledge about HIV and carrying stigmatising views further complicated the diagnosis experience. Firstly, as diagnosis was often late, with serious health consequences, and secondly, because despite all the advances made in HIV treatment and care, diagnosis for even recently diagnosed women had conjured up images of tombstones and life sentences. Some women described simply not ‘hearing’ or understanding when HIV was suggested as a possibility, while others shared the same from their clinicians and healthcare providers – HIV testing was presented to them as ruling out a very unlikely possibility, so the positive result was unexpected and unprepared for. Receiving an HIV diagnosis had physical, emotional and psychological implications, complicated by women's lack of knowledge about HIV, experience of physical ill health at the time of diagnosis, and often a lack of support. Professionals identified the need to ensure that women are provided with support when receiving a diagnosis, including safeguarding support which might further empower and support women to seek additional services.

Women received their diagnosis alone and often struggled to share it with friends and family, making diagnosis a lonely and isolating experience.

> “Okay, so I'm 52, I was diagnosed in 2017, towards the end of 2017. I had a CD4 count of 209 at that point, and I realised... something was up because I had very swollen lymph nodes. So that was how I came to be diagnosed. That took some time, because I wasn't in a group that they thought was at risk. So I was being tested for cancer of the lymph nodes and all the rest of it... And even when I was tested, well, I was given a blood test as part of the testing for cancer of the lymph glands and what was going on. And the consultant said, oh, we're going to test to all these things. And he made a point of saying, oh, there's HIV on the list, but obviously, you know, basically, you're not going to have that. And when he gave me the results, he said, I'm really surprised. You know, he was quite incredulous that that was what it was.”
>
> **Interview participant 3,** White British woman living with HIV

For many of the women we spoke to, while the experience of diagnosis was isolating, the impact of it was relational. Caring roles and responsibilities, implications for relationships and the impact of diagnosis on those around them were all prioritised, sometimes to the detriment of caring for their own needs.

> “So I was looking after him, and it wasn't till after he died. I mean, I didn't even have my own status as a patient. I was his wife, and I was positive.”
>
> **Interview participant 6,** White British woman living with HIV

Women also described the profound and lasting impact of good, empathetic care – a listening ear or kind gesture. One example was a nurse who brought a Bible with marked passages for participant 5, a Black African woman living with HIV, who received her diagnosis alone, required in-patient care, and was deeply concerned for and isolated from her husband. The possibility for good support to alleviate the immediate challenges of receiving an HIV diagnosis was clear in many women's accounts, but also frequently lacking.

Missed opportunities should be understood as including both earlier possibilities to diagnose HIV and missed chances to ensure the diagnosis experience is as supportive as possible. Support needs included how to talk about HIV with others in their lives, including adult children and partners. It was highlighted that trans people in particular express worry about the impact an HIV diagnosis might have on their future access to gender affirming care.

A diagnosis of HIV is not a single event. For women who acquired HIV perinatally (transmission of HIV during pregnancy, birth or breastfeeding), diagnosis, beginning treatment and learning about their HIV status could be distinct events with significant time passing between them. Participant 10, a Black African woman living with HIV, learned about her status aged 11, started medication at 10 but had been diagnosed at birth; participant 17, a Black African woman living with HIV, was diagnosed aged 3 and learned her status at 11 or 12. For these women, learning their HIV status was accompanied with confusion, anger and fear and a sense of a lack of ownership over their own experiences and information.

Barriers to diagnosis include individual level knowledge and awareness, medical staff bias (for example, GPs not suggesting an HIV test despite significant indicators) and issues around trust and knowledge in relationships. This was identified by professionals as a key change needed in HIV diagnoses. For example, participant 8, a White British woman, was in a 30-year marriage she believed to be monogamous, but her husband had multiple other partners and had received an HIV diagnosis some years earlier. She believed her care had consistently been substandard, and her ex-husband's needs prioritised over hers at the clinic they both accessed.

From the point of diagnosis, linkage to care varied for different women, and was sometimes complicated by poor health and other issues. When diagnosed late, many women experienced in-patient hospital care for a range of conditions and co-morbidities. Linkage to care was often helped by access to support, though this varied from individual counselling and immediate peer support to much later access to peer and community services. Professionals described the need for clinicians to provide supportive care that recognises the complexity of women's lives, including the responsibilities and competing priorities they were carrying.

Experiences of support at the point of diagnosis were mixed. Some women were not offered any support or counselling. Others benefitted greatly from HIV-specific support, including mental healthcare and counselling. Women identified differences in the availability of support between urban and rural areas, and long-term diagnosed women felt that more support was available in the past than now. Women receiving their care outside London talked a lot about a lack of options for wider support, especially peer support. They described services closing and fewer HIV support organisations resulting in unfeasibly long distances to the nearest peer support services that are tailored to the needs of women. Limited options introduced challenges, including accessibility, feeling like a particular service or support worker was a good fit, and partners or former partners accessing the same services, which introduced conflicts of interest and concerns about confidentiality and whose needs were being prioritised.

Navigating diagnosis as a migrant was a particular challenge for many women, with issues including limited social support, distance from friends and families, the burden and worry of legal immigration issues and financial challenges all compounding the difficulty of dealing with an HIV diagnosis.

Reflecting back, many women regretted the missed opportunities for earlier diagnosis, due to both increased ill health and a sense of 'wasted time', especially due to not fitting rigid risk categories. Participant 9, an Asian woman living with HIV, spoke positively about the impact of her HIV diagnosis, leading her to greater self-love, self-empowerment and bringing value to her life through creating opportunities to help others. For other women, links to wider traumas, the impact of missed opportunities and damaged relationships made the experience much more challenging.

Participant 1, a Black African woman living with HIV, described feeling isolated, alone and in fear of dying, while participant 3, a White British woman living with HIV, said her experience of diagnosis left her with ongoing trauma:

> "Well, [my experience of diagnosis] gives me a little bit of PTSD to be honest, remembering it. After the diagnosis, I still had to have tests for cancer because they needed to rule out that I hadn't got HIV and cancer, and I found everything out over the phone while I was in the middle of something else. I remember I was going to a job interview when I was phoned and told that they still wanted to test for cancer. It was all very traumatic, and obviously it was further complicated because my ex-husband hadn't been diagnosed with HIV when I was so then he obviously got tested and was also found to be HIV positive, and that added a whole other layer of complications. And was very difficult psychologically."
>
> **Interview participant 3,** White British woman living with HIV

Discussions in the workshop highlighted the significant capacity limitations in community organisations and the effect this has on women being able to access support beyond their medical needs, which is clearly essential. Geographical inequalities were also raised with a recognition that support services, especially those including a focus on women, were not available everywhere, especially outside London. There was a strong feeling that support services should form part of routine HIV services and be commissioned as such.

THE CASE FOR CHANGE: DIAGNOSIS

Despite the progress made in HIV treatment, the experiences shared here illustrate the huge impact receiving a diagnosis can still have. Women describe both the power of good care and support at the time of diagnosis, as well as the damage that can occur when this is lacking.

The value of peer support to help people to engage with services and improve initial clinical outcomes has been documented elsewhere and is recognised by the World Health Organisation.[37,38] The 'Invisible No Longer' report also recognised the specific issues that women may face when diagnosed and asked that HIV service providers "ensure that women living with HIV have adequate support to understand and overcome HIV self-stigma, as well as address cases of HIV stigma, discrimination and violence that women experience".[10]

There was consensus among the professionals and women with lived experience of the necessity of peer support, but concern remains around geographical disparities in access, and community services' ability to meet demand under current pressures. It is therefore crucial that national and local action is taken to ensure that all women have access to support that is appropriate and meets their needs.

RECOMMENDATIONS THIS SECTION SUPPORTS: 1a, 1b, 2b, 2d, 3a, 3b, 3e, 5a, 4b, 4c.

HIV CARE

Women reported mixed views on clinical services providing HIV care. While some felt their needs were being met, others described both service design and systemic issues within the NHS that pose challenges to their care. Funding crises in the NHS directly impact on access to and quality of care, while changes in HIV-specific services, with more care transferred to GPs and away from the HIV clinic, have introduced challenges. Broadly, women advocate for person centred care, personalisation to individual needs, and joining-up care to promote enhanced communication and reduce the burden to them as individuals to coordinate their own care. It was also highlighted that women's confidence in their care and ability to engage may fluctuate, and that this should be met with understanding and support, not judgment.

Support beyond the initial point of diagnosis was also valuable; participant 9, an Asian woman living with HIV, accessed counselling two years after diagnosis, and felt the time to process and go through her own journey of recognising her mental health needs and seeking support was invaluable.

Challenges accessing support included a lack of information and signposting, with individual women doing their own research to identify support which their clinic had not directed them to. Some women felt sidelined and let down by gaps in support available, especially where there were specific gaps for women while other people were able to access services. Participant 6, a White British woman living with HIV, described feeling sidelined and ignored while her partner was supported by both HIV and haemophilia organisations. Partners of those affected by the contaminated blood scandal were not supported until many years later when the possibility for compensation emerged and organisations adopted a new focus on the issue.

When considering the care they had received in relation to their HIV, the standards of care women described varied widely. While generally perceived as best in HIV services, women also experienced challenges within HIV clinics. Participant 9, an Asian woman living with HIV, highlighted the need to listen to patients and that women need to be assertive and self-advocate around issues like treatment options and side effects as they were often not heard.

> "I was rejected for my injectables… which I was a bit annoyed about, because they gave me some brush off excuse, and I wasn't assertive enough to go back. But I'm alright at the moment. But I think that's happening with a lot of women, older women, actually, and I don't know why, so I do want to make a point of that actually. I am quite assertive, though. Overall, I mean, I think the one time when they did change my medication and I was really, had really bad side effects, I had to really assert myself and say, I need to stop taking this because it's not working, because they would ignore you. And I think that happened with some of the women I've supported as well, the symptoms, diagnosis, their side effects, are ignored or not listened to. And even for me as an articulate woman, you know, you really have to say, excuse me, this treatment is not working for me."
>
> **Interview participant 9,** Asian woman living with HIV

Care coordination

Disconnects between HIV care and other services, including gender services, introduce challenges to providing the holistic care that women need. Both women living with HIV and professionals highlighted the challenges this creates and called for systemic change to provide services that are more able to meet women’s needs. These changes included recommendations to provide care in more community settings and moving away from HIV care being solely located in sexual health services.

Women and professionals called for better coordination between primary and secondary care providers and for better integration of HIV care with other care and services, recognising the complexity of women’s lives and healthcare needs especially when managing co-morbidities. Some women felt that earlier models of HIV care where the HIV clinic provided a broader range of services had functioned better for their needs, and hoped for a return to that model, particularly because not all GPs are knowledgeable about HIV or supportive of their needs as women living with HIV.

> “I would like to see it go back into a more holistic approach. I would like to recommend that actually, as part of this research, that it needs to go back in – particularly when you’re feeling that vulnerable and you’re that sick, yeah, well, you know, having to go to different places, if it’s all in one place, I think acceptability is greatly increased.”
>
> **Interview participant 9,** Asian woman living with HIV

> “I think, to me, to be honest, is if they could return all our care to our clinic, to our consultants, to our main hospitals. Because I feel sometimes the doctors don’t either have enough knowledge about the complexities of people living with HIV.”
>
> **Interview participant 5,** Black African woman living with HIV

Holistic care

There was a sense among some women that clinics are not meeting holistic needs, with no referrals to other services and a lack of follow-up on wider health and social issues discussed during appointments. Some women experienced problems with accessing their clinics, with communication (for example, lack of reminders sent for infrequent appointments which were then easy to miss) and with limited availability to meet with their named consultant. Pastoral care and support were limited, and some services were restricted to particular groups and communities with little availability for women. Navigating the system, identifying support and coordinating care across services was often left to women to manage for themselves, which was onerous and isolating. Women outside of London, described care of a good standard, but thought their clinicians were perhaps more cautious on new developments in HIV treatment or prevention, both past and current including PrEP, U=U and supporting women living with HIV to breastfeed. They spoke about hearing that women were receiving different advice or support in London leaving them with the sense that care was more up-to-date in London than outside.

Professionals called for greater attention to long-term health considerations, noting that more understanding is needed about the long-term health effects of antiretrovirals on women, including on bone health and menopause management. For women living with HIV taking medication, or those wanting to access PrEP, there is a lot of uncertainty around this issue.

> “There are worries about fertility, wanting to have children and then the double whammy of antiretrovirals and menopause, and the impact it [antiretrovirals] has on hormones – on the bones as well, and the severity of menopause.”
>
> **Interview participant,** Specialist Project Coordinator at a HIV charity

Systemic stigma

Outside of HIV-specialist services, women encountered ignorance, discrimination and poor care. Dental services were frequently identified as problematic, alongside primary care and secondary care providers. Participant 9, an Asian woman living with HIV, was asked how she acquired HIV by a doctor in front of students, while hospitalised, and again by a nurse at the GP surgery, experiences which she found stigmatising, and symbolic of a lack of knowledge which makes care hard to access. Participant 5, a Black African woman living with HIV, was similarly asked by a GP how she acquired HIV when seeking help with an unrelated health issue.

> “I found that question very intrusive, and I had examples of other people being asked the same questions, which are intimidating, and sometimes you feel like they are sitting there, you’re talking and they’re judging you. You know, because of the stigma that is attached to HIV.”
>
> **Interview participant 5,** Black African woman living with HIV

Stigma and discriminatory treatment were ongoing issues for many women and these experiences push women away from care. It is important to highlight that enacted stigma and direct discrimination were described in many accounts, across different services and across time periods. Importantly, in women’s accounts this was primarily enacted stigma – the actual impact of discriminatory and institutionally violent experiences driven by stigma. This is in contrast to self-stigma, which is an internalised feeling of shame or inhibition. The causes and solutions to these distinct types of stigma differ, and it is important to highlight that women focused on failures of care, unreachable services and inappropriate or poor treatment, not stigma itself.

> “I mean, I’ve had a really bad experience sharing my status with my GP, which my consultant at the clinic encouraged me to do. They didn’t pressurise me, they encouraged me. And after about a year, I did share my status, and I had such an ignorant response. [I’m no longer with that doctors, but] the GP actually asked me not to put any of his members of staff at risk. You know, it was, it was incredible. And I said, well, first of all, I’m undetectable, so even if I slept unprotected with members of your staff, if I so wanted to, that they wouldn’t be at risk. I’m not sure that he actually knew what undetectable meant. And then I said, and secondly, you should be treating anyone that comes in that’s having blood tests with the same precautions, because, you know. And he said, well, in theory yes, but in practice no. And I should have said, well, that’s your problem to fix, not my problem. I was so, I mean, I remember leaving the GP surgery and just feeling 1000 times worse, and very you know, basically, this is why I didn’t want to share this with my GP. It was just the awful experience that I thought it would be.”
>
> **Interview participant 3,** White British woman living with HIV

Professionals also highlighted the impact of stigma as a barrier for many women to access care and treatment.

Women described a shift in the way care is delivered, especially since the pandemic, with consultant appointments becoming rarer and consultations with other health professionals becoming routine. One woman described having her consultant appointments being transferred to the specialist pharmacist with whom she felt less able to discuss the wider issues of her care and so consultations become entirely focused on treatment. Women also reported changing needs over time with some women describing periods of disengaging from care or struggling with taking HIV treatment, and the need for continued supportive and non-judgmental clinical care during these periods.

Women identified enabling patient autonomy, providing full engagement and support, and offering services for newly diagnosed women, as well as tailored support at key transition points (for example, moving to adult services, menopause) and ongoing access to pastoral care as changes that would support better engagement with care. In addition, women spoke of needing more information and autonomy around treatment choices and more support with side effects and pill burdens, as they currently were not feeling heard or supported on these issues. Women wanted HIV clinics to prioritise continuous development and updates to provide full support to women, to reflect the diversity of their needs across the life course, as well as up-to-date scientific advances – including support around conception and breastfeeding, as well as transmission risks for partners.

Some women also described other factors impacting on their access to care, including racism, stigmatising assumptions, intersectional discrimination and not ‘fitting the mould’ for HIV care.

> “I think just being a woman is hard work for people. They just make assumptions, even with my colour on my skin, no matter how educated or whatever you are, you know, I’ve had that in my life all the time, where you’ve been discriminated on the basis of being a woman and a woman of colour.”
>
> **Interview participant 9,** Asian woman living with HIV

In the workshop there was consensus that overall HIV care was good but gaps exist. The delegation of commissioning of HIV services to local bodies (Integrated Care Systems) was discussed and there was agreement that this could represent an opportunity to better integrate or co-ordinate HIV care with other services; but it also raises concerns that the transition could lead to a reduction in quality of care and increased geographical disparities. Stigma and the barriers to care associated with it was also a strong theme and there was significant support for urgent change to address this issue.

THE CASE FOR CHANGE: HIV CARE

HIV services are not and have never been designed with women’s needs and priorities at the forefront. The experiences shared by the women here underline the challenges and inequity that remains for those living with HIV and echo many of the findings from the Positive Voices survey of people living with HIV.[24]

The standard of care that people living with HIV should expect is already set out in the BHIVA Standards of Care,[27] and the HIV Action Plan committed to tackling stigma and improving knowledge and understandings of HIV across the health and care system.[11] However, the experiences described in this report highlight how far away we are from achieving the goals and standards that must be met.

Women make up a third of those accessing HIV care services,[21] and the findings and recommendations of this report and the ‘Invisible No Longer’ report are specific to improving the accessibility, standards and appropriateness of services so that they better meet the needs of women.[10]

Prioritising women in the HIV response, and including women with lived experience at all stages of service design and delivery, is the first step towards achieving parity for women affected by HIV.

RECOMMENDATIONS THIS SECTION SUPPORTS: 1a, 1b, 2a, 2b, 2d, 4a, 4b, 4c, 4d.

SUPPORT

Adapting to an HIV diagnosis, living well with HIV and negotiating life's challenges are all made easier with the right support. Some women described having difficulty accessing support within family and friend networks, due to issues around HIV stigma, a lack of relevant knowledge and experience within their networks to provide HIV-related support, and in some cases the implications for sharing a current or former partner's HIV status if they talked about their own HIV with shared family and friends. Consequently, many women described valuing peer support, provided by individuals, through their clinic or through third sector organisation and professionals also reflected the urgent need for this holistic support for women across their life course.

Personal connections informed by shared experiences provided a more accessible type of support that women benefited from.

> “Peer support could help at that point, because looking back, it was more like I was dealing with an institution. That's how it is, but to have someone who has a face to it, because this was just doctors I'm talking about, you know, people that are sort of paid to do their work. But if there was, like a buddy, you know, to sort of call you up and talk to you, maybe I would have taken [treatment and engaging in care] earlier than it took me to.”
>
> **Interview participant 16,** Black African woman living with HIV

The important role of community support which can cater to each individual women's needs, including support provided by community organisations, was discussed in most professionals' interviews, and the need for funding and resources to sustain them was strongly emphasised. The professionals also discussed the wider support that women need as part of their HIV care to improve quality of life, in addition to their medical needs, including financial, emotional, and caregiving support.

Where it was available, peer support was greatly appreciated and had a significant impact on women's lives. Safe spaces and mutual support helped women to process their diagnosis and begin to live well, and some women described moving on to providing peer support to others and the value this brought to their own lives. However, women also talked about how their changing needs over time were not always met, for example, accessing peer support after taking up full time employment.

Some women described having to really push for access and limitations in what information is shared and connections made, while others struggled when shared experiences were assumed that were not relevant to everyone, such as having children. Some women had never been offered or connected to peer support and had to find services independently, while others appreciated their clinics or consultants having signposted them to peer support which was often critical to accepting their diagnosis and maintaining connections to care.

> “It sort of opened me up to know that I'm not in isolation, and I've made friends that have become like my family, so I am able to talk to them about it and they've gone through similar experiences as I have in terms of medication, in terms of childbearing, in terms of behaviour of children, in terms of the struggles of coming to terms with medication… so it has helped me a lot.”
>
> **Interview participant 16,** Black African woman living with HIV

Some women had unmet need for support, either in the past or currently. In some cases, this was because a particular type of support was unavailable, such as psychological support. Where services were available, they might be restricted to short-term access or focus on specific groups or communities which limited access. Women also described personal barriers that delayed or prevented them accessing support, such as not feeling ready or being fearful, or being too ill to take up the offer, and suggested both time and encouragement, as well as proactive signposting and referrals, were needed to ensure women got the support they needed. The professionals we interviewed echoed this need for broad support, including that of financial and emotional support which they felt would help women in all aspects of their lives, including to remain on medication and retain linkage to care.

Some women described being offered little support, and although services for women have always been limited, they felt this was further restricted by assumptions being made about who might need support and what their support needs would look like – for example, that only younger women might need to access a particular service, or a woman with secure economic status would have no need to be signposted to services. For women living with perinatally acquired HIV, the experience of having their diagnosis shared with them much later than it was originally made, and often after starting medication, meant the experience was uniquely challenging and that accessing support could be too overwhelming. This was an example of a need many women discussed – for support in different forms to be actively offered on an ongoing basis, not just at diagnosis.

Additional improvements to support models were also suggested, including ensuring that specialist and expert advice is made available on HIV treatment, where peer supporters may not be experts and the loss of third sector organisations such as aidsmap has left a gap. Developing peer support models that are accessible outside normal working hours and other commitments, and address transport issues, would be valued. It would also be beneficial to provide support for individuals that can provide connections to different services, resolve issues (for example in housing or access to benefits) and provide equity of access to women's support groups. Women who provide peer support described feeling isolated and unsupported by clinics and provider organisations outside London. They described lack of funding and lack of coordinating organisations as a barrier to accessing support for this and highlighted that informal mutual support opportunities through workshops or events are routinely held only in London.

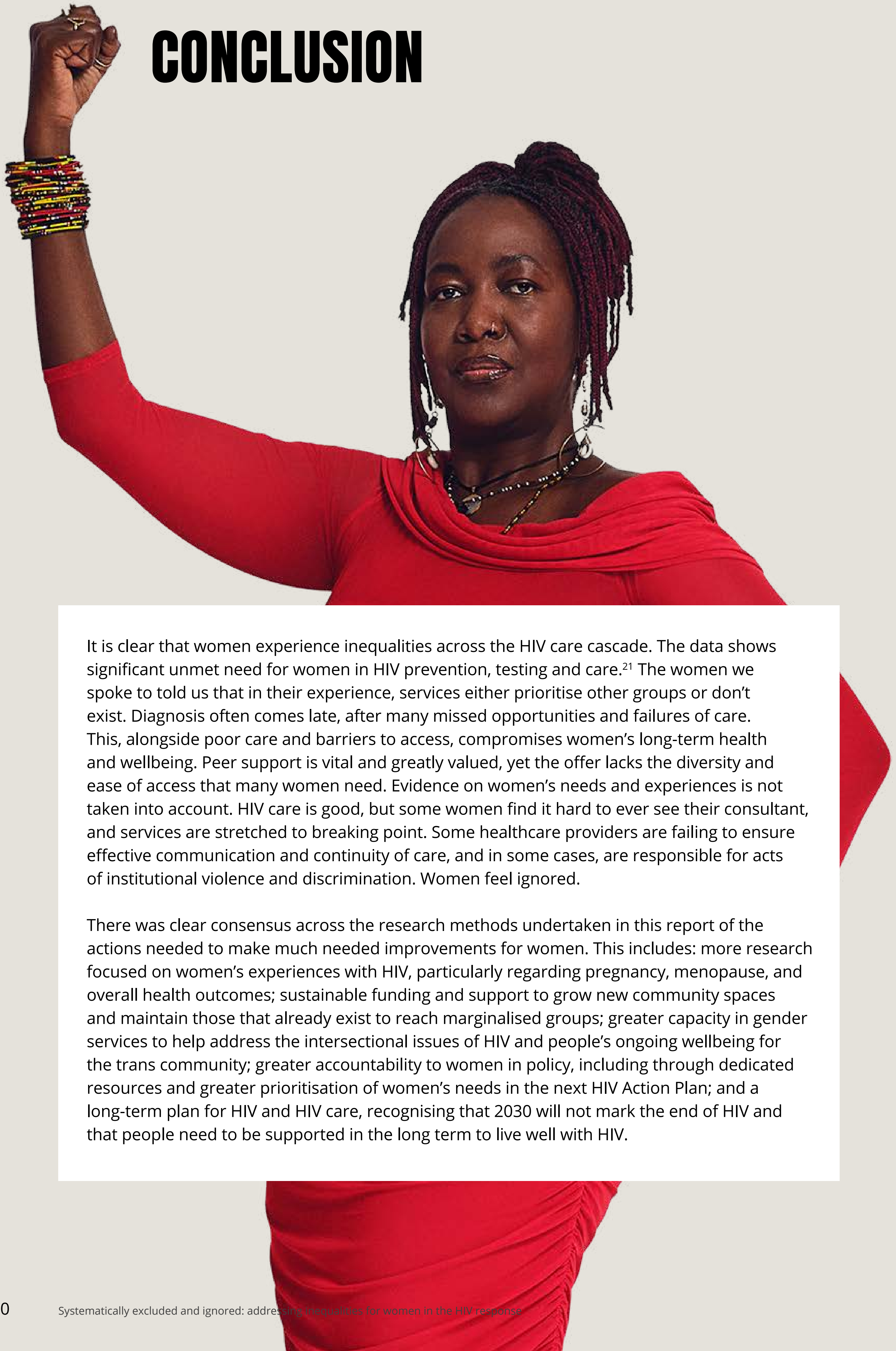
THE CASE FOR CHANGE: SUPPORT

The importance of support including peer support for women living with HIV was a central theme in this research and in the ‘Invisible No Longer’ report.[10] The National Standards for Peer Support set out the characteristics of good practice. These include the need to provide support in a range of settings using approaches that can benefit everyone, tailoring services to specific communities and ensuring that peer supporters have access to the necessary training and support.[37] Effective peer support has a significant impact on people living with HIV in general.[39] The BHIVA Standards of Care state that peer support “should be embedded in the clinical pathway to ensure everyone has access to peer support that is timely and meets the needs of the person”,[27] and the HIV Outcomes report, ‘Enhancing long-term health and wellbeing among people with HIV’, recommended that health bodies should provide support and funding for interventions involving peers and community members.[40] Still, we’re not seeing this consistently enough for women.

Health equity and the overall HIV response is dependent on people living with HIV having the support necessary to enable them to engage with services and that empowers them to advocate for themselves and their care. The recommendations in this report around delivering person centred care hinges on the availability of support that is specific to people’s needs. Given that women make up around a third of people accessing HIV care, providing women centred support should be prioritised and not been seen as a luxury or treated as an afterthought.

RECOMMENDATIONS THIS SECTION SUPPORTS: 1a, 1b, 4a, 4b, 4c, 4d.

CONCLUSION



It is clear that women experience inequalities across the HIV care cascade. The data shows significant unmet need for women in HIV prevention, testing and care.[21] The women we spoke to told us that in their experience, services either prioritise other groups or don't exist. Diagnosis often comes late, after many missed opportunities and failures of care. This, alongside poor care and barriers to access, compromises women's long-term health and wellbeing. Peer support is vital and greatly valued, yet the offer lacks the diversity and ease of access that many women need. Evidence on women's needs and experiences is not taken into account. HIV care is good, but some women find it hard to ever see their consultant, and services are stretched to breaking point. Some healthcare providers are failing to ensure effective communication and continuity of care, and in some cases, are responsible for acts of institutional violence and discrimination. Women feel ignored.

There was clear consensus across the research methods undertaken in this report of the actions needed to make much needed improvements for women. This includes: more research focused on women's experiences with HIV, particularly regarding pregnancy, menopause, and overall health outcomes; sustainable funding and support to grow new community spaces and maintain those that already exist to reach marginalised groups; greater capacity in gender services to help address the intersectional issues of HIV and people's ongoing wellbeing for the trans community; greater accountability to women in policy, including through dedicated resources and greater prioritisation of women's needs in the next HIV Action Plan; and a long-term plan for HIV and HIV care, recognising that 2030 will not mark the end of HIV and that people need to be supported in the long term to live well with HIV.

The aim of this report is to secure urgent action to address the inequalities women experience in relation to HIV at every level, through adopting a gender transformative approach to support achieving gender equity in HIV prevention, testing, diagnosis, care and support and promote gender parity in HIV research and data. To achieve this, we have set out the following five objectives:

1. **Prioritise women in national and local HIV strategies and structures.**
2. **Address the systemic evidence and knowledge gaps around HIV and women.**
3. **Apply a gender transformative approach to eliminate the inequalities in access to HIV prevention and testing faced by women and address the intersecting inequalities driving late diagnosis.**
4. **Ensure that women living with HIV have access to comprehensive and appropriate HIV treatment, care and support services.**
5. **Increase knowledge and awareness of HIV among all women.**

This report differs from almost all policy reports, action plans and guidelines by applying a gender lens to the UK's HIV response but the issues we highlight and many of the recommendations we have developed reflect or lead on from those published elsewhere.

We can no longer allow our ambition to be limited by what has been achieved in the past. We cannot look backwards. A truly ambitious and fit-for-purpose HIV response and Action Plan must ensure equitable access and outcomes for everyone and apply a gender transformative approach that addresses intersectional inequalities. It must commit to finally overcome the injustice of invisibility that has been enacted against women consistently since the onset of the HIV epidemic in this country.

HOW MUCH LONGER DO WOMEN HAVE TO WAIT?

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