

about HIV transmission. They often feel invisible in the response to HIV in the UK and ignored or not taken seriously by healthcare staff.

There were average levels of knowledge of Treatment as Prevention (TasP) and Undetectable = Untransmittable (U=U) among women who responded to the Prevention survey: 66% of women had heard of U=U and 63% had heard about TasP. Four in 10 women who had a partner living with HIV had used TasP as a method of HIV prevention. Knowledge was higher among women living with HIV, with nearly all (96%) of women who responded to our Experiences survey knowing about TasP and U=U.

A large proportion (83%) of women who responded to the Prevention survey had ever taken an HIV test. However only half (51%) of women were offered information about sexual health and HIV prevention when they last took an HIV test and significant barriers to testing for women remain. More women were tested in routine checks than for any other reason. Respondents expressed clear preferences for more HIV testing than is currently occurring to be done at home, in community settings and at the GP.

Over half of women (58%) said nothing would prevent them getting an HIV test. However, barriers to testing remain: 18% of women felt that sexual health services were not easy to access, including challenges with inconvenient opening times, distance between home and clinic, and difficulties making appointments. One in 10 women felt awkward asking for an HIV test and the same number were worried about judgemental staff.

## Conclusion

Our aim in this project was to make women visible in the HIV response in the UK. For too long, priorities have been shaped by an epidemiological approach that defines people by transmission routes, and makes invisible the breadth and diversity of women

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and women's experiences. Our findings demonstrate significant unmet need, from prevention services that recognise and respect the diversity and fluidity of women's sexuality, to support services that meet women's needs across intersecting issues such as violence, mental health and immigration. Women's voices are not heard and their experiences and needs are not sufficiently recognised, prioritised and met.

This report calls for women to be invisible no longer. Gender equity in research, funding, data, services and support is a minimum ask and is long overdue.

It is clear that many women are living well and thriving with HIV. In 2018, this should be true for all women living with HIV. To get there, we need to see targeted investment and genuine commitment from researchers, government organisations, commissioners, service providers, decision-makers and the HIV sector as a whole. In some cases, existing services, interventions and studies provide a framework for success that can be replicated and scaled up. For other issues, such as violence, there is an urgent need to prioritise and listen to women's experiences.

Women are diverse. In this project, we focused on women as a group because this gendered response has been lacking in the UK HIV response to date. But beyond gender, women's experiences are shaped by intersecting identities and factors that must also be recognised. Trans women, lesbian and bisexual women, women of different ethnicities, and women with experiences of migration, sex work, drug use, homelessness, mental health problems and disabilities all face compounded challenges, intersecting discrimination and magnified invisibility.

We hope this report will lay a foundation for women's visibility in all our diversity, and for research, data, services and support that are designed to meet women's diverse needs.

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# Women and HIV Invisible No Longer

A national study of women's experiences of HIV  
Executive Summary

April 2018

Women living with and affected by HIV have so far been mainly invisible in the narrative and response to HIV in the UK, despite making up a third of all people living with HIV and a quarter of new HIV diagnoses in 2016. We know little about what it means to be a woman in the UK living with HIV. We do not know enough about what women's needs are or what interventions are in place to meet these needs. There is little focus on defining the risk of HIV for women, on HIV risk perception among women, or on HIV prevention efforts. This must change. Women living with and affected by HIV want to talk and want to be heard.

Women and HIV: Invisible No Longer was a one-year project jointly led by Sophia Forum and Terrence Higgins Trust aiming to explore women's needs and experiences and support making these more visible. The project was co-produced with women living with and affected by HIV and draws on their experiences to understand what HIV means for women in the UK. It looked at existing evidence and generated new

data to provide an overview of the situation for women in the UK living with or vulnerable to acquiring HIV.

Gender equity in the response to HIV is essential, but we are currently far from achieving it. Equal attention to women's needs and experiences in HIV prevention, services, care and support is long overdue.

There isn't one story or one solution and every woman and every experience is important. Women living with and affected by HIV are diverse in age, ethnicity, nationality, gender identity and sexuality.

This project did not seek to provide answers to the multitude of interacting and overlapping issues that women living with and affected by HIV face. Instead it aimed to help shape the future research, policy and service agenda to ensure that greater focus is given to the gaps in knowledge and needs of women living with, at risk of, or affected by HIV.

Read the full report at [www.tht.org.uk/invisiblenolonger](http://www.tht.org.uk/invisiblenolonger)

Sophia Forum promotes and advocates for the rights, health, welfare and dignity of women living with HIV through research, raising awareness and influencing policy.

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## Methodology

This project used mixed-methods including:

- a literature review
- an online ('Experiences') survey of women living with HIV
- an online ('Prevention') survey of women who have ever been concerned about HIV
- participatory workshops
- stakeholder interviews
- a mapping of services available for women living with and affected by HIV.

In total, data from 310 online surveys was taken forward for analysis and 32 women attended the workshops.

## Visibility and diversity

The majority of stakeholders interviewed as part of this research felt that overall there had been a disproportionate focus on men who have sex with men (MSM) in the HIV response with one stakeholder suggesting that the sector had 'taken its eye off the ball' when it came to HIV and women. For effective policy and programmes to be targeted at women, sufficient epidemiological data is needed. A substantial amount of national HIV epidemiological data is broken down by gender which is welcome. However, more needs to be done to highlight the interpretation of this data.

When it comes to the national response to HIV, all women are by default assumed to be heterosexual. There is a lack of understanding of the diversity of sexualities of women living with and at risk of HIV, as well as a lack of targeted information and interventions to support the sexual health needs of lesbian and bisexual women and women of other sexualities.

There must now be a readjustment of the resources, time and focus invested in the HIV response. Women must receive equal focus in the HIV response in the UK.

## Living well with HIV

Women's experiences of living with HIV, and the impact it has on their lives, varies widely. Half (49%) of respondents to our Experiences survey said that quality of life was good or very good at the moment,

while almost 14% deemed it to be poor and 38% 'acceptable'. It also changes over time. A third (30%) of women said their quality of life had got better since their HIV diagnosis, while 23% of women said it had got worse.

All women in our research (regardless of how long they had been diagnosed) reported that receiving an HIV diagnosis had a negative impact on them. The right support after diagnosis was vital.

Three-quarters (75%) of women in our Experiences survey were offered counselling, advice or information after their diagnosis. However, a third of women (29%) did not have anyone to turn to for support straight after diagnosis. There were also particular concerns regarding the high number of women (42%) who felt they had been diagnosed late. Altogether 27% of women felt that there were missed opportunities to test earlier for HIV.

Women living with HIV have specific support needs related to HIV as well as needs related to wider health and social issues. Women reported that not everything 'was about HIV' and yet HIV can make it harder to access support for other issues. Many women from our research were either unable to access the kind of support they needed or did not feel this support met their needs.

Peer support was mentioned frequently in the Experiences survey and workshops as a positive form of support and there were calls for more of it to be available.

Our research reveals high levels of unmet need and poor mental health among women living with HIV. Many women described anxiety, depression and stress linked to living with HIV. Almost all of the women living with HIV who participated in Experiences workshops reported mental health issues. Responses to the Experiences survey show mental health is a major issue: 42% of women have had a mental health diagnosis since being diagnosed with HIV. In total 33% felt they had an undiagnosed mental health issue. The qualitative feedback illustrated that a number of women had more than one mental health issue. Nearly half (46%) of women would like support with managing their mental health but cannot access it.

Stigma (including self-stigma, perceived stigma and discrimination) continues to play a role in the lives of women living with HIV. Many women in our research both feared and experienced exclusion and negative treatment as a result of their HIV status. Nearly a third

(31%) of women had avoided or delayed attending healthcare (including HIV services) in the past year due to worries about how they would be treated because of their HIV status.

The link between HIV, gender and violence is recognised globally, but has been under-addressed in the UK. Our research shows evidence that women living with HIV are experiencing violence and action is needed now to address it. Over half (58%) of women in our Experiences survey had experienced some form of violence or abuse including violence due to their HIV status. Only one in five women who had experienced violence were able to access the support they needed. Experiences of violence and abuse in healthcare settings increased after women were diagnosed with HIV. A total of 29% of women said that the violence or abuse they had experienced in health services was because of their HIV status.

About a third (29%) of women in our Experiences survey were sexually active and 54% felt that HIV had affected their sex lives. Only one in three (33%) women was satisfied with their sex life and 40% were not satisfied with their sex lives. Many women living with HIV who participated in our Experiences workshops also reported issues with intimacy, fear of sexual relations, and low libido.

HIV is also impacting on women's reproductive choices. Our research found that two in five (42%) women felt that HIV had affected the decisions they made on whether to have children. Over half (62%) of respondents to our Experiences survey had children and a quarter (27%) of women wanted to have children or have more children.

Challenges related to immigration can affect women's ability to cope well with HIV. From our Experiences survey, of the 53 women who answered the questions on immigration, a third (32%) of women felt that their immigration process and/or immigration status had affected their ability to manage HIV. In particular, women asylum seekers and refugees living with HIV faced multiple challenges. For instance, of the women in the Experiences survey who were seeking asylum or had refugee status, half had another long-term health condition, six out of eight were not working and not receiving benefits, the same number rarely had enough money to cover basic needs and seven had experienced violence (some from multiple sources).

Nearly half (45%) of women living with HIV who responded to the Experiences survey were living below the poverty line. One in six (17%) women living

with HIV never or rarely had enough money to cover their basic needs, with a further two in six (43%) having enough money most of the time but not always. Even those women who generally felt they could cover their basic needs had financial worries related to HIV. Women felt that HIV can also be a barrier to obtaining and maintaining employment.

## HIV Prevention

Little effort has been made to define who women at risk of HIV are. 'We do not know which women are at risk of HIV' is an often heard answer in the HIV sector but it is no longer an acceptable excuse for the lack of focus on HIV prevention for women. In our research a number of stakeholders interviewed identified a need to re-examine how people at risk of HIV are described, and to do more to identify risk factors that put some women at risk of acquiring HIV.

The sexual health and HIV prevention needs of women who are not heterosexual or who do not fall into an 'at risk' group are not understood by health services. There is a particular lack of understanding of women's sexuality, relationships and sexual fluidity when it comes to HIV prevention and service providers.

Most women in our research felt informed to some degree about HIV. Over 90% of Prevention survey participants felt they were very well or quite well informed about how HIV is transmitted and 96% felt that they were very or quite well informed about how to protect themselves from HIV. Nearly one fifth of women (18%) reported that in the past five years there had been times when they had wanted to use an HIV prevention method, but had not felt able to.

Condoms were reported as the most commonly used HIV prevention method (used in the past five years by three quarters of women), but there was a wide range of women's experiences of using condoms and some women specifically mentioned that negotiating condoms with their partner is a problem. Very few women had recently used female condoms.

Pre-exposure prophylaxis (PrEP) access for women is relatively recent in the UK, and uptake has been limited. While awareness of PrEP among women who responded to our Prevention survey was high – 74% of women had heard of PrEP, no women had used it.

Our research showed that women who are in relationships with partners who have HIV often worry