



Women and HIV Invisible No Longer

A national study of women's experiences of HIV



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The following colour coding is used for quotes throughout the report to show their origin

Experiences survey respondent

Prevention survey respondent

Stakeholder interview and service mapping



Florence Obadeyi

Foreword

Florence Obadeyi and Jane Shepherd

*Peer Researchers, **Women and HIV: Invisible No Longer** project*

As women living with HIV, we know what we want. We always have. For decades we have been a collective voice in the HIV response – advocating for services and mobilising for change; pushing and pulling to get women's needs and priorities acted upon. But the results are disappointing and the minute our backs are turned or we pause to rest, we slide off the agenda.

The HIV services that exist are rarely designed with women in mind, or include and consult with women, in all their diversity, on their priorities and needs. We are often expected to use services designed and dominated by groups that we are unable to relate to. A decade of government disinvestment has meant many of us have lost our HIV support services, our women-only spaces, advice centres, counselling and mental health services, disability support, local authority support for housing, our domestic violence support services. The list goes on. The safety net gets more and more threadbare.

We need a return to telling, hearing and documenting our stories – bearing witness to our experiences. It doesn't matter if it is through interviews, dance, spoken word or art – the more participatory, the more transformative and powerful our stories become.

Through storytelling we can celebrate our agency and resilience, and acknowledge and embrace our differences. We can challenge dominant narratives and expose the intersectional nature of our lives.

As women living with and affected by HIV we are not a homogenous group and to treat us as such results in services that do not fit our needs and, worse, do not reach those for whom the safety net already has massive holes.

This makes research projects such as Invisible No Longer so exciting and necessary. Exposing the data gaps for women affected by HIV opens up possibilities to start seriously addressing women's needs. It opens the door to more research, more stories, more evidence and interventions that are rooted in our diverse experiences.



Jane Shepherd

Rt Hon Maria Miller MP

*Chair, **Parliamentary Women and Equalities Committee***

I welcome this timely report from Terrence Higgins Trust and Sophia Forum. In the centenary of votes for women and the tidal wave of activism and bravery that we have seen from women across the world over the past year - gender equality is again at the centre of people's minds.

I am immensely proud of the world-leading efforts of the UK in combatting HIV since the start of the epidemic. Great strides have been made and we are now at the point that the possibility of ending new HIV infections in the UK could be a reality.

But this report rightly sets out that we cannot, and should not, leave anyone behind in the progress that we make in addressing HIV. There have been incredible female activists who have stood up, and continue to fight for the rights of women living with HIV. But women have too often been the silent partner when it comes to HIV. This must change.

The issues raised in this report are familiar to me in many ways – time and again women's issues are not prioritised and addressed.

This report sets out a clear rallying call to researchers, academics, government organisations, clinicians and charities. To work side by side with women living with or affected by HIV, to enable women to support themselves, to empower women to thrive with HIV.

Together, we will see equality for all women affected by HIV.



Rt Hon Maria Miller MP

Acknowledgements

The *Women and HIV: Invisible No Longer* research project was jointly carried out by Terrence Higgins Trust and Sophia Forum and was funded by the Terrence Higgins Trust Lighthouse Fund.

Our biggest thanks go to all the women living with and affected by HIV who took part in this research by attending workshops and completing the research surveys. Your voices and experiences made an enormous and important contribution to this project and without you it would not have been possible.

We would also like to extend a special thanks to the peer researchers of this project - Florence Obadeyi and Jane Shepherd.

We would like to thank the members of the Invisible No Longer Advisory Group who provided guidance and expertise throughout the project: Claudia Carvell, Valerie Delpech, Chenai Mufanawejingo, Luisa Orza, Irene Parker, Juno Roche, Kelsey Smith and Shema Tariq.

The research would not have been possible without the organisations that supported the project's workshops: Body and Soul, Herts Aid, HIV Scotland, The LGBT Foundation, NAZ, and Terrence Higgins Trust's offices in Scotland and Wales.

In addition, we are grateful for the time and effort of individuals who were interviewed as part of this research and who shared their experiences.

We would like to thank the organisations who responded to the service mapping survey and provided us with valuable information on existing services.

Public Health England has been supportive throughout this project in providing us with useful data and insight on HIV surveillance in the UK.

We would also like to thank Terrence Higgins Trust staff and members of the Sophia Forum Board of Trustees for their expertise and leadership at different stages of the project.

Thank you also to photographer Charlotte Haddon and all the women who were part of the project photoshoot.

The following individuals formed the project team for the research and the writing of the report: Emma Bell, Fiona Hale, Longret Kwardem, Debbie Laycock, Jane Lennon and Jacqui Stevenson.



Executive Summary

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.

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.



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 abuse 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 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 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.

Recommendations

For research

Researchers and funders should examine the gaps in knowledge that still exist in the UK around HIV and women and take steps to ensure a proportionate focus of HIV research is on women.

The study team recommends further research is needed to specifically explore the experiences of girls and women under the age of 18 living with HIV and the transition of young women to adulthood.

Researchers should take steps to actively increase meaningful participation of women in HIV research, working directly with women living with HIV to ensure that proposed research will facilitate participation.

The eligibility criteria and recruitment processes for HIV clinical trials should be reviewed to ensure maximum participation of women.

Public Health England (PHE) and the British HIV Association (BHIVA), working with service providers and women living with HIV, must as a matter of urgency, examine why women are being diagnosed late with HIV and make recommendations to ensure rates of late diagnosis in women reduce substantially.

Researchers should actively explore the links between HIV and mental health and make recommendations to HIV service providers and mental health service providers with regards to the mental health needs of women living with HIV.

Researchers should undertake work to better understand the vulnerabilities and causal link between violence, gender and HIV in the UK.

As a matter of urgency, Public Health England and researchers should examine why rates of HIV testing are declining in sexual health services and make recommendations on how HIV testing for women can be increased in these, and other preferred testing settings.

For data

Public Health England should ensure that all HIV reports that it publishes include clear and comprehensive analysis of all relevant data for women as a group, as well as disaggregation by ethnicity and other relevant factors.

Public Health England, working with women living with HIV, should release a Spotlight Report on women affected by HIV in the UK.

Public Health England, as part of a Spotlight Report on women, should conduct a full gendered analysis of the factors which put women at risk of HIV in the UK.

Public Health England, Public Health Wales and Health Protection Scotland should ensure that local commissioners and provider organisations have the gendered data they need to understand local burden of HIV in women.

Public Health England, Public Health Wales and Health Protection Scotland should include sexuality data for women living with and affected by HIV in publically available HIV data and reports.

Until data on sexuality is publically released, data descriptors should focus on the known route of transmission (e.g. heterosexual contact) rather than making an assumption on the sexuality of the woman.

Public Health England, Public Health Wales and Health Protection Scotland should ensure that better quality data is collected on HIV support services

For services

Investment should be directed at creating opportunities for women living with HIV to participate in service design and delivery at local levels, and encourage women living with HIV to reach senior positions in HIV policy making, commissioning and service provision at regional and national levels.

Commissioners and service providers should ensure sustainable access to women only spaces and peer support for women living with HIV as a vital part of HIV management; using the National Standards for Peer Support in HIV to guide service provision.

Service providers should explore the support needs of family members and partners of women newly diagnosed with HIV, as well as ensuring the support needs of women themselves are met.

HIV and mental health services need to offer better screening and access to a range of mental health interventions tailored to women living with HIV.

NHS England, NHS Scotland and NHS in Wales must work with women living with HIV to increase accurate knowledge and awareness of HIV among health and social care practitioners and accelerate actions to eliminate HIV stigma and discrimination from health and social care settings.

HIV service providers should 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.

HIV and women's support organisations should ensure that all of their services are identifying and meeting the needs of women living with HIV who have faced, or face, violence or trauma.

Service providers should work with women living with HIV to design interventions that enable women to enjoy the sex life and healthy intimate relationships that they want

Reproductive health, HIV and other relevant services should ensure that women living with HIV get appropriate timely information and support on reproductive health so that they can make fully informed decisions.

Commissioners and service providers need to recognise that women with unresolved immigration decisions need additional support as a matter of urgency, and ensure that these needs are met.

Service providers should assess how they can directly support, or refer, women living with HIV on low or no incomes to services that will help ensure their basic needs are met.

Prevention efforts should include a focus on ensuring women are informed about and have access to a comprehensive package of prevention methods, including condoms, and invest in social interventions to support women to feel confident in asking partners to use condoms.

Policy makers and advocates in Scotland, Wales and England should increase focus and activity on ensuring women are informed about Pre-exposure prophylaxis (PrEP) and able to access it, if it is right for them.

Service providers and clinicians must ensure adequate information is provided to women and their partners to fully understand Treatment as Prevention (TasP) and U=U and enable partners to enjoy a sex life free from anxiety and fear. This should occur when a woman is living with HIV, or if a woman is in a relationship with someone living with HIV.

HIV and sexual health service providers and charities should consider the needs of women who are in relationships with people living with HIV and ensure that they receive non-judgemental services.

Service providers should work with women to pilot testing schemes, including exploring the use of HIV self-testing and testing in community settings

HIV and sexual health service providers should work with women who do not identify as heterosexual to understand their needs, ensure that quality resources are available on HIV and that current HIV and sexual health services are reflecting the needs of this population of women.

Introduction

Invisible No Longer

Even though women make up a third of all people living with HIV and a quarter of new HIV diagnoses, women living with and affected by HIV have so far been mainly invisible in the narrative and response to HIV in the UK. We know little about what it means to be a woman in the UK living with, or at risk of, HIV. We do not know enough about what women's needs are or what interventions are in place to meet these needs. This must change. Women 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 that aimed to contribute to this change. The project was co-produced with women living with and affected by HIV and draws upon their experiences to understand what HIV means for women in the UK. It drew on 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, as well as identifying areas where gaps in our knowledge remain.

The project did not seek to provide answers to the multitude of issues that women 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.

Definition of women within scope of this project

This project is focused on all women aged 18 and over, of all identities and experiences. It is inclusive of cis and trans women, of all sexualities, all ethnicities, and regardless of pregnancy or whether or not a woman has children.

Women and HIV in the UK

Women in the UK remain significantly affected by HIV. In 2016, a total of 28,479 women were living with HIV and receiving care - 31% of all people living with HIV in the UK - and almost a quarter (24%) of new HIV diagnoses in 2016 were in women¹. With advances in medicine, we are now seeing the first generation of people ageing with HIV - with more women living with HIV than ever before. These women are diverse in age, ethnicity, sexuality, gender identity and where they live in the UK.

Women accessing HIV care in the UK in 2016

93.4% access care in England

4.3% access care in Scotland (1,214 women)

1.6% access care in Wales (457 women)

0.8% access care in Northern Ireland (219 women)

42.9% of newly diagnosed women were aged 35-49

25.9% were aged 25-34

20.4% were aged 50 or older

10.8% were aged 24 or under

46.1% of new HIV diagnoses in women were among women of black African ethnicity

31.8% were in women of white ethnicity

5.7% were in women of Asian ethnicity

16.3% were in women of other ethnicities

50.9% of newly diagnosed women were born in Africa

26.1% were born in the UK

93.4% of new diagnoses in women were likely due to heterosexual contact

3% were due to injecting drug use

2.1% were due to vertical transmission

1.5% were due to other routes

*Data source: Public Health England

1 Public Health England, October 2017. National HIV surveillance data tables. www.gov.uk/government/statistics/hiv-annual-data-tables

Diversity and intersectionality

Women's experiences of HIV are as diverse as women themselves. By focusing on women as a whole, we are responding to a specific gap in the evidence base on HIV in the UK. Little is known about the interactions between HIV and gender and the impact of this on women's experiences in the UK. Some experiences are common across women, while others will differ. In this report, we present both overarching themes, and the differences in experiences reported by different women within these themes.

In addition to gender, overlapping identities and intersecting discriminations and experiences all shape women's experiences regarding HIV, including socioeconomic status, class, ethnicity, sexual orientation, gender identity, and immigration status. The concept of intersectionality helps us to both understand and respond to complex and multifaceted identities². The themes explored in this report highlight the intertwined factors that influence women's lives and experiences.

Trans women, lesbian, bisexual, asexual and queer women, migrant women, women who do, or have done, sex work, women who have been or are homeless, women who have been imprisoned, young women, older women, women who have children, women who choose not to have children, women who are unable to have children, women who are asylum seekers or refugees, and women of many different ethnicities, have all added their voices to this study to make their experiences visible. This report offers an insight into the diversity of different women's experiences with the recognition that this is only the start - recommendations throughout the report indicate where more work is needed.

Some women in our research raised the issue that there were some groups of women who were even more ignored, more invisible. Indeed the current epidemiological approach in the UK means we focus very specifically on women who are African, women who use drugs and women who are pregnant - but women can be all these things, or none of them, and are always so much more.

'It is not so much being a woman living with HIV - it is being a white woman who does not use drugs. I feel very isolated at times because there are not many stories I can relate to as I am a minority group. The message needs to be put out there that HIV does not discriminate against sex, colour, race etc.'

Some of the issues explored in this report will also apply to men living with HIV, or to women who do not have HIV. We did not set out to conduct a comparative study, so do not comment directly on this. Instead, we offer a focused study on women living with or vulnerable to HIV. The first of its kind in the UK.

The *Invisible No Longer* report shines a spotlight on women as an often neglected group, challenging assumptions and showing where gaps in our knowledge remain. It is aimed at those individuals who can make change happen - policy makers, funders,

commissioners, service providers and academics - as well as women affected by HIV. We hope that by setting out clear recommendations for policy, services and future research we can move towards women becoming fully visible in the UK's response to HIV.

'As women living with HIV, we don't have male privilege, many of us don't have cis privilege and many of us don't have white privilege and that needs to be considered in the trials and support out there, our accessibility needs are very complex. I'm glad that this research is being done as it makes me feel as though we're moving away from a one-size-fits-all approach in the mainstream HIV discussions.'



² Gender & Development Network think pieces, November 2017. Intersectionality: Reflections from the Gender & Development Network <http://gadnetwork.org/gadn-resources/2017/11/20/intersectionality-reflections-from-the-gender-development-network>

Methodology

This project used mixed research 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 acquiring HIV
- participatory workshops
- stakeholder interviews
- a mapping of services available for women living with or affected by HIV.

Peer researchers

Peer research is a participatory approach, where members of the community play an active role in the research process. Shared experiences and the freedom of being with peers can allow research participants to relax and open up, increasing the quality of information gathered.

We recruited two volunteer peer researchers as part of this research. Training introduced researchers to peer research, groupwork methodology and facilitation skills.

The inclusion criteria for a peer researcher in this project was that the individual must be a woman living with HIV aged 18 or over, and living in the UK. After completing training, peer researchers co-led the participatory workshops research stream. They also had the opportunity to be involved in all other stages of the research process from survey design, to data analysis, to final report content and recommendations, as well as dissemination of findings.

Advisory Group

To support the project, and ensure it was delivered effectively, a Project Advisory Group was set up to provide guidance and expertise. The Advisory Group was made up of eight members who represented experience and expertise relevant to the project, and included women living with HIV, researchers, clinicians, service providers and advocates. A full list of advisory group members can be found in Appendix 1.

Literature reviews

A key part of the project was to undertake a mapping of what is already known with regards to women and HIV in the UK, where gaps in knowledge exist, and identify possible issues and themes that could be explored in more depth using quantitative and qualitative data collection. Altogether 374 academic articles, national

governmental organisations' policy documents, local governmental organisations' policy documents/websites, and third sector reports/websites were reviewed as part of the literature review. Findings from the literature review were used to determine the priorities and areas of focus for the primary data collection, and key findings are integrated into this report.

Stakeholder interviews

We conducted a number of telephone and email interviews with individuals working in specific areas of the HIV response or with specific groups of women. Individuals were selected for interview based on where further information and in-depth knowledge was required, as indicated by the literature review. A full list of stakeholders interviewed can be found in Appendix 2.

Online surveys

We developed and used two surveys with very different focus and target participants.

One survey ('Experiences') was open to women living with HIV aged 18 and over and living in the UK. It aimed to elicit information on the experiences of women living with HIV. The survey focused on: money matters, HIV testing and diagnosis, social care and support needs, access to services, immigration and its impact on care, mental health and wellbeing, sexual wellbeing, reproductive health and choices, freedom from violence and abuse, taking part in HIV research, and any other key issues that participants wanted to share. The survey was piloted with women living with HIV to ensure that it was clear and that the language was appropriate.

A second survey ('Prevention') was open to any women aged 18 and over, living in the UK not diagnosed with HIV but who had experienced concern about HIV. This survey aimed to understand women's experiences and views of HIV prevention interventions. It focused on sexual health screening, HIV testing, HIV prevention, access to services and any other key issues that participants wanted to share. The survey was piloted with the Project Advisory Group and three Sophia Forum Trustees.

Both surveys (hosted on Survey Monkey) were available online and information about each was disseminated through social media and a range of sexual health, women's, and HIV organisations and networks. The Project Advisory Group was also active in reaching out to their contacts.



Participatory workshops

Survey results were supplemented by six 95-minute workshops that used participatory methodology to gather additional qualitative information.

Experiences workshops

We held five workshops for women living with HIV. The peer researchers designed the workshop content and structure to include reflection, group discussion and a chance for all to participate. A final activity was included to capture experiences of resilience and agency and act as a counterbalance to sharing negative stories. Organisations fed back on the workshop content and identified women living with HIV who were accessing their services, inviting them to participate. A peer researcher or the project co-ordinator facilitated the workshops.

Four activities were used in these workshops:

- 1. Sticky Fingers** – each woman drew her hand on a piece of paper and was asked to reflect on five things in her life that were difficult, writing one on each finger. This activity was used to explore how living with HIV impacts on health and wellbeing.
- 2. Circle of Support** - each woman wrote down services she has used to address her 'sticky fingers' and why. Women also wrote down services they needed that either didn't exist or they couldn't access.
- 3. Green Fingers** – each woman drew her hand on a piece of paper to look at the five things in her life that she does or has that are important in helping her live well with HIV, writing one on each finger.
- 4.** Finally each woman was invited to share what she would like to see change with regards to women and HIV.

Prevention workshop

We held one workshop to explore in more detail the sexual health and HIV-related experiences and needs of women who do not identify as heterosexual. The workshop was hosted by the LGBT Foundation, who advertised on social media and other networks to recruit women who have not been diagnosed with HIV but who have ever experienced concerns about HIV. This workshop was co-facilitated between a project staff member and a staff member of the LGBT Foundation. Three main activities were used in this workshop:

- 1. Sticky Fingers** – each woman drew her hand on a piece of paper and was asked to reflect on five things in her life that were difficult, writing one on each finger. This activity was used to explore how sexual health and HIV-related experiences impact on health and wellbeing.

- 2. Circle of Support** - each woman wrote down services she has used to address her 'sticky fingers' and why. Women also wrote down services they needed that either didn't exist or they couldn't access.
- 3.** Finally each woman was invited to share what she would like to see change with regards to women and HIV.

Service mapping

We carried out a mapping exercise through an online survey for HIV service providers to find out what services exist for women living with HIV and at risk of HIV in the UK. We asked about all services aimed at women (whether statutory services or services funded through voluntary funding).

The survey was circulated to 49 organisations via the English HIV Providers Forum. Nine organisations responded to the survey: one in Scotland and eight in England. These are only a fraction of the number of HIV organisations who provide services in the UK and the survey results therefore do not provide a comprehensive picture of currently available services. The results do however provide examples of interventions already in place for women affected by HIV.

Interpreting findings

Following the data collection and initial analysis of results, we held a data summit, which brought together project staff and peer researchers to discuss and reflect on the data collected. Attendees identified key themes, grouping themes that emerged across the different data sources, and noting important themes that emerged from only one data source. Finally, we developed the concise list of themes which form the basis for this report.

Limitations of the research

Workshops were held by HIV support service providers and participants were recruited by HIV and sexual health charities. There is therefore a likely bias against women who are currently not accessing HIV support services – either because they do not need these services, or they cannot access them (or do not know the service exists). Women living well with HIV – of which there are many – are therefore likely to be under represented in the workshop data in this research.

The Experiences and Prevention surveys were only available online. Women who could not access or complete the online survey for whatever reason are absent from the survey responses.

The research only focused on England, Scotland and Wales. Northern Ireland was not included in the scope of the research as neither Terrence Higgins Trust nor Sophia Forum work in Northern Ireland.

We also decided to focus only on women aged 18 and over. We believe that there is not enough focus in the HIV response on girls and young women under 18 affected by HIV. However, it was felt that issues affecting girls and young women under 18 were very different and would widen the scope of the research beyond that which was manageable. Ethical issues also arise with participation of minors. The study team recommends further research is needed to specifically explore the experiences of girls and women under the age of 18 and the transition of young women to adulthood.

We are clear that this research only conveys the experiences of those women who were involved. Each woman's experience is extremely valuable and helps improve our understanding of how HIV affects women and contributes to ensuring women are more visible. Rather than providing a conclusive picture, the aim of this project was to use new and existing data to challenge assumptions, show where gaps in our knowledge remain and identify where further attention is needed.





Participant demographics

342

women
participated
in the
research

310

survey
responses

32

women
attended
6 workshops

The demographic information provided by women in our research highlights the importance of considering diversity and intersectionality throughout our findings³. For instance, all of the eight women who reported being (or having been involved) in sex work in the Experiences survey had other long-term health conditions (including autism and bipolar disorder). Among those who reported partner or community violence were trans women, non-heterosexual women, women who had used drugs, women who had been incarcerated, and some women who had experienced immigration detention.

In the Prevention survey we found that women who had experienced homelessness, drug use, prison or sex work were overwhelmingly from sexual minorities, and more women with a disability were from sexual minorities than heterosexual. Disability also intersected with homelessness, drug use, prison and sex work. Of the eight women who responded as having done sex work in the Prevention survey, one had been homeless, four had used drugs and four were living with a disability.

³ The concept of intersectionality helps us to both understand and respond to complex and multifaceted identities. Gender & Development Network think pieces, November 2017. Intersectionality: Reflections from the Gender & Development Network <http://gadnetwork.org/gadn-resources/2017/11/20/intersectionality-reflections-from-the-gender-development-network>

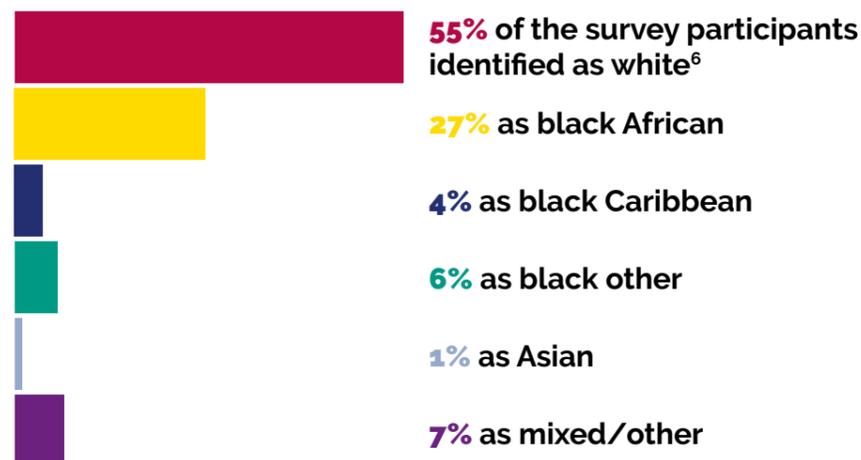
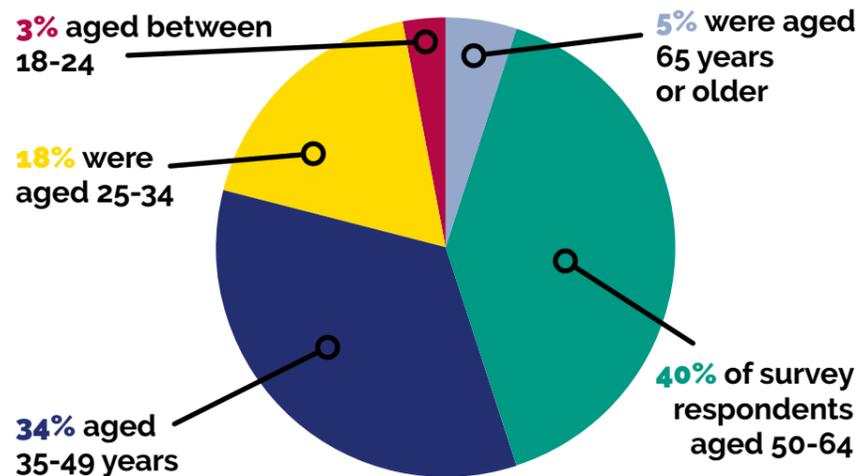
Online surveys

In total, data from 310 surveys were taken forward for analysis⁴.

The Experiences survey

A total of 185 responses to the survey were received with 159 valid surveys taken forward for analysis⁵.

Responses came from women of all ages and ethnicities.



Just over half (56%) of survey participants were born in the UK with the remaining 44% born overseas. The majority (92%) lived in England with 32% resident in London. Altogether, 5% were resident in Scotland and 3% resident in Wales.

In total 41% of women who responded were UK nationals, 9% were European nationals, 23% had indefinite leave to remain, 8% had discretionary leave to remain, 11% were asylum seekers awaiting a decision, 4% were refugees and 4% were on a student visa.

⁴ Note that not all women who completed the survey answered all of the demographic questions.

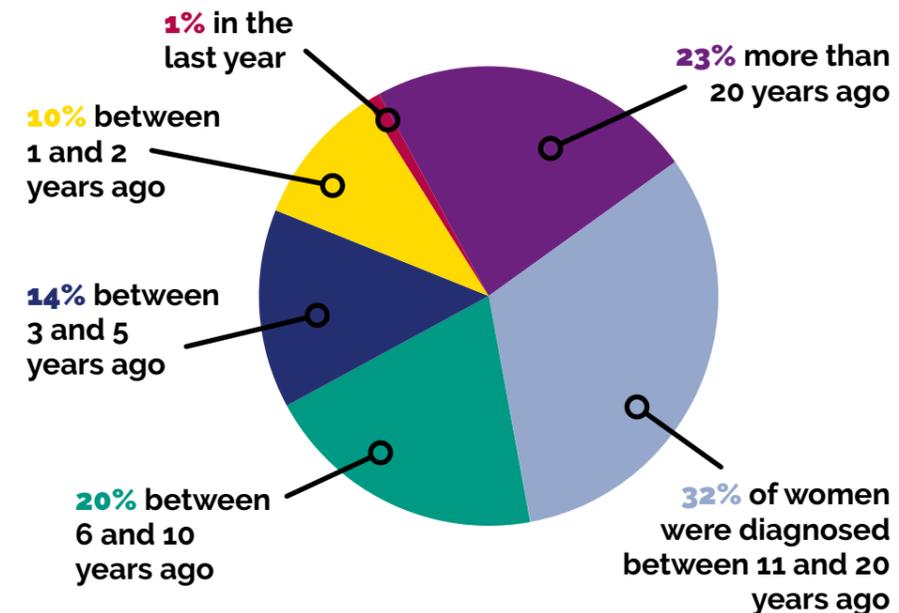
⁵ 26 responses were excluded as women were either not living with HIV, were under 18 years of age or were not living in the UK

⁶ Our research provided more options for ethnicity than are shown here but we have used the PHE categories for ease of reading. Additional breakdown from our research is available on request.

A total of 97% of women identified with the gender they were assigned at birth, with 3% (four women) identifying as trans women.

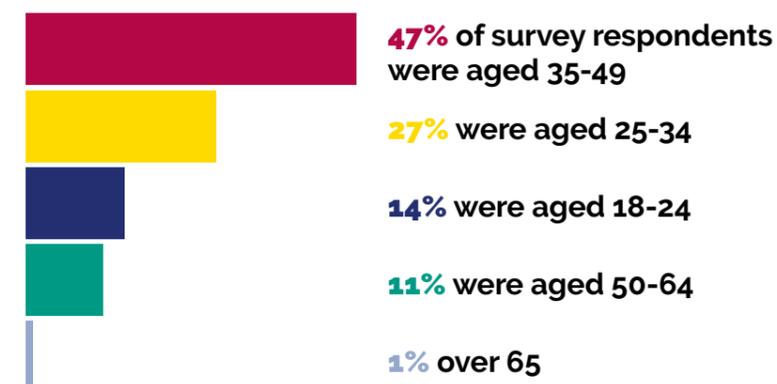
The majority of survey participants (89%) identified as heterosexual/straight, five women (3%) as bisexual, four women (3%) as pansexual, two women (1%) were questioning and one woman identified as aromantic (1%). Altogether three participants (2%) responded that they did not define their sexuality and two women (1%) preferred not to say.

Survey participants varied in terms of when they had been diagnosed with HIV.



The Prevention survey

There were 172 respondents and 151 valid responses taken forward for analysis⁷.



A large proportion (86%) of survey participants identified as white⁸, 5% black African, 3% as Asian, 1% as black Caribbean and 5% as other. Altogether 144 women (97%) identified with the gender they were assigned at birth, with four women (3%) identifying as trans. One woman preferred not to say.

⁷ Seven women were excluded as they were living with HIV, five were not women, eight were not living in the UK, one was under 18 years of age.

⁸ Our research provided more options for ethnicity than are shown here but we have used the PHE categories for ease of reading. Additional breakdown is available upon request.

The majority (86%) of participants were born in the UK - 95% were UK nationals, 2% were European nationals, 1% had discretionary leave to remain, 1% was on a work visa and 1% responded as 'other'.

Nearly a third (29%) of respondents lived in London, 10 women lived in Scotland, five in Wales and two in Northern Ireland.

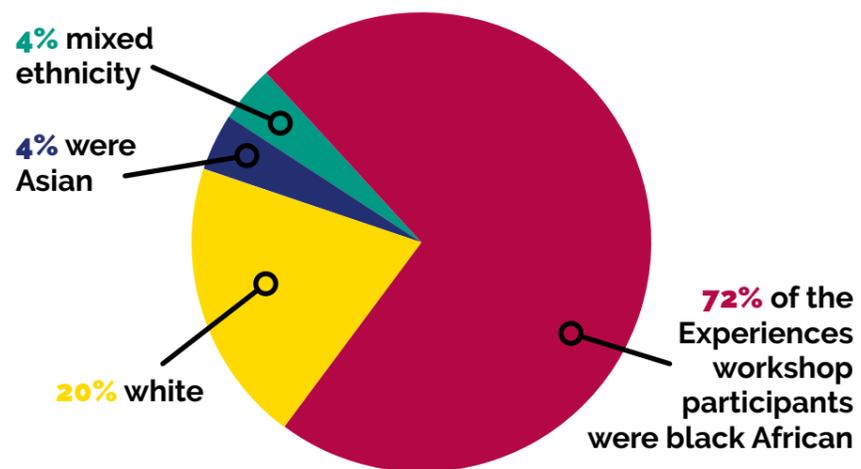
94 women who participated in the survey identified as heterosexual:



Experiences workshop

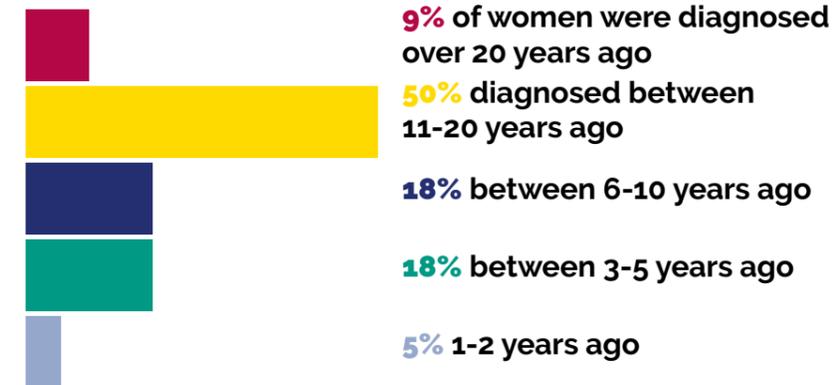
A total of 26 women attended the workshops which were held in London (two workshops), Cardiff, Glasgow, and Hertfordshire.

Of those who were happy to share demographics 52% were aged 35-49, 28% aged 50-64, 16% aged 25-34 and 4% over 65.



Altogether 65% of the participants were born in Africa, 26% in the UK and 9% elsewhere in Europe.

All of the participants identified with the gender they were assigned at birth.



Prevention workshop

The workshop was held in Manchester and was attended by six women. Demographics were collected for five out of the six women who participated.

Altogether three women were under the age of 25, and two women were aged 25-35. Three of the participants identified as white, one as black African and one as Asian. One participant was a trans woman. All participants were born in the UK.



Visibility and Diversity

The need for gender equality in the UK's response to HIV

'Sometimes it feels like women are ignored as the discussions around HIV are often dominated by gay men, and while they are a very important group, women are too. I want to highlight this.'

Our research identified that women are indeed invisible in much of the UK's response to HIV. The result is that there is a clear and present barrier to effectively understanding and meeting women's needs when it comes to HIV.

A unifying theme among stakeholders interviewed in this research was the reflection that the leadership of the HIV and AIDS response since the start of the epidemic in the UK has been too male dominated. There has been a rich history in the UK of women's participation and leadership yet there have been too few senior leaders who are women and, even less so, women living with HIV.

While this has started to change in recent years, some stakeholders felt that there was a need for greater investment in the meaningful leadership of women living with or affected by HIV. The valuable work women do as leaders in their communities - providing support to peers, challenging stigma and leading community initiatives, should also be more visible and valued.

Very few stakeholders interviewed as part of this research were able to cite women and HIV-specific resources (for HIV prevention or focused on women living with HIV) that they can call upon to support their work. This gap was reflected in the literature review, which found a complete lack of focus on women and HIV in policy resources, limited focus on women by HIV and sexual health charities, and a clear over-representation in HIV-related academic studies and clinical resources on men who have sex with men (MSM). Even where resources were focused on black African communities, gender was rarely disaggregated. Where there was a focus on women living with, or at risk of, HIV the emphasis was often on women who are pregnant, and in relation to vertical transmission specifically, so focused on the infant rather than the woman.

The majority of stakeholders interviewed as part of this research felt that overall there had been a disproportionate focus on 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.

'Women can be termed "hard to reach" yet no efforts have been made by providers and policy makers to involve women in solution finding.'

Differing suggestions were given as to why this was the case with some suggesting it is due to a focus on incidence as the only evidence of HIV burden or due to (in the case of HIV prevention) a lack of clarity on the risks of HIV for women. Many interviewees felt that it was easier to identify MSM at risk of HIV, easier to identify HIV-related need and easier to target interventions at this group – and prove impact.

'[I] find that as a woman and person you are overlooked and you become a statistic. [I] realised women are marginalised because we are not in the majority. We are not gay men. Why are our issues not being addressed?'

Women who participated in our surveys also highlighted this gap and commented on not feeling visible or involved in the response to HIV.

'I don't think we are seen as an important population in the UK because we are small in comparison to men living with HIV. I often see stories from the male perspective in the spotlight, but rarely women. I think that sharing stories from women living with HIV from multiple backgrounds could be empowering for women living with HIV to show that we are resilient and beautiful in our own unique ways.'

This is not to diminish the contribution of lesbian, gay, bisexual and trans (LGBT+) activism in ensuring access to treatment and care for people living with HIV or to detract from the importance of a continued focus on ending new HIV infections in MSM and ensuring that all men living with HIV are supported to live well. This important work must continue. But there must now be a readjustment of the resources, time and focus that is invested in the HIV response. We have a good understanding in the UK of what interventions work for MSM and where the main challenges are in tackling HIV in this community. This has meant that in MSM the number of HIV diagnoses have decreased by 21% in 2016 in the UK⁹. This is good news. We now need to ensure that women receive equal focus in the HIV response to ensure these gains are replicated within all communities.

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 welcome¹⁰. However, more needs to be done to highlight the interpretation of this data. Public Health England has not to date produced a women focused report as part of their series of HIV *Spotlight Reports* and the current structure of PHE's annual HIV report is not conducive to understanding how women are affected by HIV. Support is also needed to ensure that local stakeholders have the data they need to meet the needs of women. One stakeholder interviewed in this research wanted more data available at the local level to ensure that local commissioners and service providers better understand how women are affected by HIV in their area.

⁹ Public Health England, October 2017. National HIV surveillance data tables. www.gov.uk/government/statistics/hiv-annual-data-tables

¹⁰ To note: currently no data for trans women are available but PHE and Clinic Q have worked together to include a two-step gender identify demographic question in routine surveillance data that will allow greater focus on trans women in the future.

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

Recommendations

Investment should be directed at creating opportunities for women living with HIV to participate in service design and delivery at local levels, and encourage women living with HIV to reach senior positions in HIV policy making, commissioning and service provision at local, regional and national levels.

Public Health England should ensure that all HIV reports that it publishes include clear and comprehensive analysis of all relevant data for women as a group, as well as disaggregation by ethnicity and other relevant factors.

Public Health England, working with women living with HIV, should release a Spotlight Report on women affected by HIV in the UK.

Public Health England, Public Health Wales and Health Protection Scotland should ensure that local commissioners and provider organisations have the gendered data they need to understand local burden of HIV in women.

Only heterosexual women exist in HIV 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.

The prevailing view, as reinforced by a stakeholder interviewed in this research, is that *'if the transmission route was sexual, of course the woman is heterosexual'*. This view needs to be questioned. PHE labels women likely to have acquired HIV through heterosexual contact as being heterosexual, and this carries over into services. Yet our own research has indicated the breadth of sexualities of women living with HIV with 10% of women who completed our Experiences survey not identifying as heterosexual. This chimes with information from Positively UK in their report – *Women Know Best*¹¹, where 23% of women living with HIV who attended a national women and HIV conference identified as bisexual.

¹¹ Positively UK, 2015. <http://positivelyuk.org/women-know-best/>

Very little research has been carried out in the UK aimed at understanding HIV risk in lesbian, bisexual and gay women. A study in the US in 2009¹² found that some women who have sex with women engage in behaviours that could place them at risk of HIV. Yet epidemiological data is not collected on the sexuality of women diagnosed with HIV in the UK. We were unable to find any national data on the number of women living with HIV who do not identify as heterosexual and little focus was found on these communities during the literature review.

A 2016 article published by the Sophia Forum also reinforced our findings. They state that 'the sexual health concerns of lesbian and bisexual women have often been invisible although studies conducted around the world show that lesbians and bisexual women face multiple vulnerabilities to sexually transmitted infections (STIs) including HIV'¹³.

Very little information and interventions exist to support the sexual health needs of lesbian and bisexual women and, where it does, this is often confined to the work of focused charities eg, the LGBT Foundation which was one of the first organisations in the UK to provide specific information on HIV to women who have sex with women¹⁴.

Recommendations

Public Health England, Public Health Wales and Health Protection Scotland should include sexuality data for women living with and affected by HIV in publically available HIV data and reports.

Until data on sexuality is publically released, data descriptors should focus on the known route of transmission (e.g. heterosexual contact) rather than making an assumption on the sexuality of the woman.

12 Women's Institute at Gay Men's Health Crisis, 2009. HIV Risk for Lesbians, Bisexuals & Other Women Who Have Sex With Women, www.gmhc.org/files/editor/file/GMHC_lap_whitepaper_0609.pdf

13 Daly F and Strachan S, 2016. Facing the facts: lesbian and bisexual women's vulnerability to HIV <https://sophiaforum.net/index.php/2016/02/01/facing-the-facts-lesbian-and-bisexual-womens-vulnerability-to-hiv/>

14 Beating Around the Bush was the first e-resource of its kind produced in the UK for lesbian and bisexual women. <http://lgbt.foundation/who-we-help/women/sexual-health>

Women's participation in research

'It's important that there is greater understanding of the needs of women living with HIV.'

As a third of people living with HIV in the UK, and as a diverse group in terms of age, experiences, ethnicity, migration, sexuality and reproductive choices, there should be a broad, rich evidence base on women and HIV in the UK. Instead, women are under-represented in clinical research¹⁵ and the social research base is limited. In order for women to become fully visible in the UK's response to HIV, women need an equal footing in the evidence base that influences commissioning, policy and service delivery. Our study demonstrated the will to participate in research when there are opportunities to do so and when that research is accessible and meaningful to women.

'I want to be involved in all forms, consultation, policy etc. I do not want assumptions made about me or just being generalised as I believe I am unique in my own way and my contributions impact service delivery.'

Two thirds (68%) of women in the Experiences survey had been involved in some kind of research prior to filling in our survey and women across all of our research streams expressed a desire to be more involved in HIV research that affects women. A specific part of our project aimed at understanding women's experiences of being involved in HIV research and how women's participation can be improved.

Responses on why women want to get involved in HIV research overwhelmingly focused on the desire to improve the lives and knowledge of women living with HIV.

'I wouldn't be alive if people didn't do them [surveys] in the past.'

When asked what discouraged women from taking part in research, responses included if the research was particularly time consuming, if they had concerns about lack of confidentiality and anonymity, or if there was no follow-up after the research.

Several women also expressed concerns regarding access to research: both physical (the time and place need to be convenient) and the language used. Others said they would be discouraged if they felt they were just a token woman and some shared comments that showed the need for emotional support for women involved in research, both during and after participation.

15 A recent review of patients starting ART through randomised controlled trials in the UK found women were under-represented. Smith C et al. 2016. Starting first-line ART as part of a randomised controlled trial (RCT): demographic differences in recruitment and long-term response. www.bhiva.org/documents/Conferences/2016Manchester/AbstractBook2016.pdf

'Most surveys I have found upsetting, but can get my head round my situation.'

Feedback from stakeholder interviews identified that women often find it difficult to participate in clinical trial research because of eligibility criteria (including requirements to use two forms of contraception and avoid pregnancy for a specified period)¹⁶. We may therefore be unaware of how antiretroviral therapy (ART) efficacy is affected by body size, metabolism, pregnancy, hormone replacement therapy, and hormonal contraception.

Tips for researchers based on the experiences of women living with HIV:

- Consider from the very start how you will facilitate women's participation in research.
- Work with women living with HIV directly to decide how women's participation can be facilitated.
- Ensure the research focus is clear and relevant to women.
- Build women's participation into budgets and consider offering a financial or equivalent incentive to women who get involved.
- Some women need childcare cover to participate – include costs in budgets and make clear to women that this cost can be covered.
- Invest in recruitment to ensure women are proportionately represented among participants.
- Ensure women understand that any research will be confidential and anonymous.
- Be accountable to women, ensuring those who take part in research know how the research will be used and to what effect.
- Ensure that emotional support is provided for women involved in research, both during and after participation.
- Ensure women's meaningful involvement in research at each stage – for instance, involve women in the data interpretation stage and when disseminating results.

Recommendations

Researchers should take steps to actively increase meaningful participation of women in HIV research, working directly with women living with HIV to ensure that proposed research will facilitate participation.

The eligibility criteria and recruitment processes for HIV clinical trials should be reviewed to ensure maximum participation of women.

Researchers and funders should examine the gaps in knowledge that still exist in the UK around HIV and women and take steps to ensure a proportionate focus of HIV research is on women.

¹⁶ At the global level one systematic review in 2016 found women accounted for 19.2% of participants in studies of HIV antiretroviral treatment, despite being half the global population of people living with HIV: Curno MJ et al. 2016. A Systematic Review of the Inclusion (or Exclusion) of Women in HIV Research: From Clinical Studies of Antiretrovirals and Vaccines to Cure Strategies. www.ncbi.nlm.nih.gov/pubmed/26361171

Women living 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.

49%
good or
very good

38%
acceptable

14%
almost
poor

QUALITY OF LIFE AT THE MOMENT

'I am in a committed relationship and we have recently had a child. I have supportive family and friends. I have a good job that I enjoy. I generally feel positive about life.'

'I have lots of interests and I don't see myself as having a separate HIV life. I like the arts, theatre, galleries, holidays, dinner with friends, gigs, travel. I have a wonderful husband. Five sisters. Close-knit girlfriends.'

'My life is not over like I thought it was when I was first diagnosed, yes my life is different now and will never be the same but I look at it as a rebirth, I've grown into something wiser and stronger and I feel I now have the knowledge and understanding to move forward and help others.'

'Family, I feel happy around my family cos I can tell them I am well, they don't judge me, I feel free and it normalises HIV. I am comfortable.'

'At first my self-esteem was really low but now after going to groups and seminars to learn how to manage my diagnosis my mental health and wellbeing has improved slightly although I still have bad days when I pretend everything's fine.'

'When diagnosed with HIV you can never be the same as before - it is just years of learning to live and cope with the diagnosis that make it seem like it has not affected you. Some people tolerate it better than others but we live in [a] cycle of feeling hopeful and then not being sure. Particularly if you experience isolation and lack of mutually satisfying relationships, when children that took up most of your time and attention leave the home.'

'I don't always feel I can scream into the void about HIV. Yes, it is largely manageable but it isn't always easy and a lot of support systems are - no pun - full of upbeat positive people and I sometimes feel like I am Eeyore or a total downer if I rant and rave. Not sure who would help with this!'

'Just miserable, what's there to look forward to when everyone hates you because you're "diseased"?''

'I feel isolated and have settled to being a loner, it's difficult finding a partner or friends due to my HIV status.'

'Feel like HIV has taken over our lives and is extremely isolating.'

'Having HIV forever, no cure.'

'HIV is ruling my life.'

Experiences of HIV diagnosis

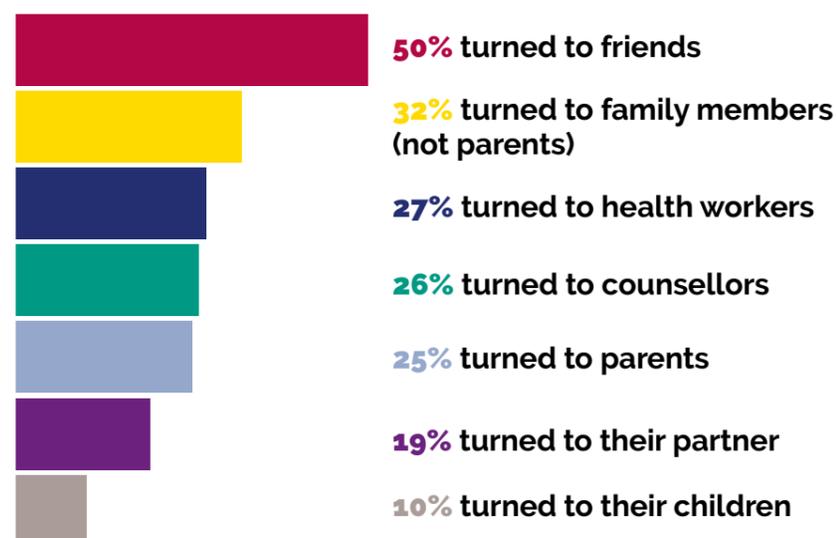
'Diagnosis felt like receiving a death sentence.'

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 is 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.

Support after diagnosis

Women's experiences of support post diagnosis varied. Women were more likely to have turned to someone for support if they were diagnosed in the last five years. Only 6% of women who had been diagnosed within the last five years were not offered counselling and support at diagnosis. This is in comparison to a quarter of women diagnosed more than five years ago who were not offered counselling and support. Women diagnosed outside the UK were much less likely to have received counselling post diagnosis.

Of those women who did get support after diagnosis*:



*Note: multiple answers could be given

Many women found these sources of support helpful and, for many, this initial support plus ongoing social support had enabled them to accept an HIV diagnosis.

'When I was diagnosed I was referred to Body and Soul. Then referred to Cascade for counselling. Nine weeks' counselling was really helpful. I could say everything and anything. About how afraid I was. Lack of confidence. That really helped me. I was referred to Food Chain. Attending their classes. Able to get six weeks' groceries to keep up my healthy eating. I learned about how to cook healthily. I attended Terrence Higgins Trust's Work Positive programme and did a placement at Stonewall and learnt to accept myself.'

In total 81% of women who were offered formal counselling, advice or information when newly diagnosed sought additional support post diagnosis, compared to just 42% of women who were not offered support straight after their diagnosis.

A number of women in our research called for more and better counselling and support around diagnosis.

'Specialist counselling is essential, I cannot say this strongly enough. This was never offered, although I could have asked for mental health support via my GP. I don't think that would have helped, it needs to be specialist and fully understanding of HIV and a rapid intervention.'

'The counsellor had no HIV counselling experience and no knowledge of HIV. She did find out as much as she could but a trained counsellor would have been more beneficial.'

Relationships with friends and family were a strong source of emotional and practical support for some women after diagnosis. However others did not have such a positive experience and friends and family became a source of stress.

'I wish I hadn't told some friends as they broke confidentiality big time.'

Peer support came out strongly from the Experiences survey and workshops as an important way of coping well with HIV after diagnosis – both support when newly diagnosed and ongoing support.

'What made me find my rollercoaster rails was meeting a group of approximately 25 women all living with HIV.'

'Peer support, if I had met another woman with HIV to reassure me at that time it would have helped. I became very isolated and shamed and didn't tell anyone, just the people at the GUM clinic.'

'I got information which didn't make sense at the time. I didn't want leaflets to take home for fear of disclosure. The healthcare professionals were very supportive and reassuring. The HIV social workers were available and supportive. I had wanted to see another person living with HIV to reassure me but couldn't.'

Women also worried about the impact of their diagnosis on their children, other family and friends and felt the need to protect them as well as the need to be discreet about their HIV status. Family and friends of women living with HIV were often an important source of support, and also needed support themselves. Women felt that family counselling would be helpful in coming to terms with an HIV diagnosis.

'My extended family told everyone in my phone contacts like it was a duty. I became a write-off. And they said she will be dead, prepare to take her home. An HIV diagnosis takes the whole family down with you. They didn't know what to do, didn't know their boundaries. With cancer, healthcare professionals sit with the family and tell them but with HIV it is difficult.'

Recommendations

Public Health England, Public Health Wales and Health Protection Scotland should ensure that better quality data is collected on HIV support services, including the degree to which the support needs of women are met.

Commissioners and service providers should ensure sustainable access to women only spaces and peer support for women living with HIV as a vital part of HIV management, using the National Standards for Peer Support in HIV to guide service provision.

Service providers should explore the support needs of family members and partners of women newly diagnosed with HIV as well as ensuring the support needs of women themselves are met.

Late HIV diagnosis

Within our research there were some particular issues and concerns related to the large number of women who felt they were diagnosed with HIV late.

Public Health England is clear that late diagnosis¹⁷ is 'the most important predictor of morbidity and premature mortality among people with HIV infection¹⁸. People diagnosed late are at increased risk of developing an AIDS-defining illness and continue to have a more than tenfold increased risk of death in the year following their diagnosis¹⁹.

Public Health England data²⁰ indicates that 48% of women diagnosed with HIV in 2016 in the UK were diagnosed late. This is an improvement on the rates seen over the past 10 years but is still far too high. Women still see some of the highest rates of late diagnosis (behind heterosexual men). In 2016, 60 women in the UK were diagnosed with AIDS when they tested positive for HIV.

Within our research 42% of women felt their HIV was diagnosed late – with diagnosis often occurring due to the appearance of symptoms related to their HIV infection. Overall, 27% of women felt that there were missed opportunities to test earlier for HIV.

'I had problems which were driving me mad. I kept asking for the doctors to check this out. They just gave me thrush remedies. It was not thrush, it took two years for me to find out it was HIV. They didn't look at me as a whole.'

Women who were not born in the UK were more likely to have felt that they had been diagnosed late. Asylum seekers and refugees were also more likely to have been diagnosed late.

Women diagnosed more recently (those diagnosed in UK only) were more likely to have felt they were diagnosed late: 52% of women diagnosed in the last five years felt they were diagnosed late compared to 37% of women who were diagnosed more than five years ago.

'GPs need to be recommending testing more, and recognising the signs of HIV. Much more could have been done for me earlier.'

Women who felt that they were diagnosed late were less likely to rate their quality of life as very good, were more likely to rate their quality of life as poor or acceptable, and were more likely to say that their quality of life had got worse since diagnosis.

There needs to be a much greater focus on understanding why so many women are diagnosed late with HIV and what more can be done to ensure that women are diagnosed more promptly.

Recommendation

Public Health England and the British HIV Association, working with service providers and women living with HIV must, as a matter of urgency, examine why women are being diagnosed late with HIV and make recommendations to ensure rates of late diagnosis in women reduce substantially.

¹⁷ Defined as a CD4 count <350 cells/mm3 when diagnosed.

¹⁸ Public Health England, HIV in the UK, 2016 report www.gov.uk/government/uploads/system/uploads/attachment_data/file/602942/HIV_in_the_UK_report.pdf

¹⁹ ibid

²⁰ ibid

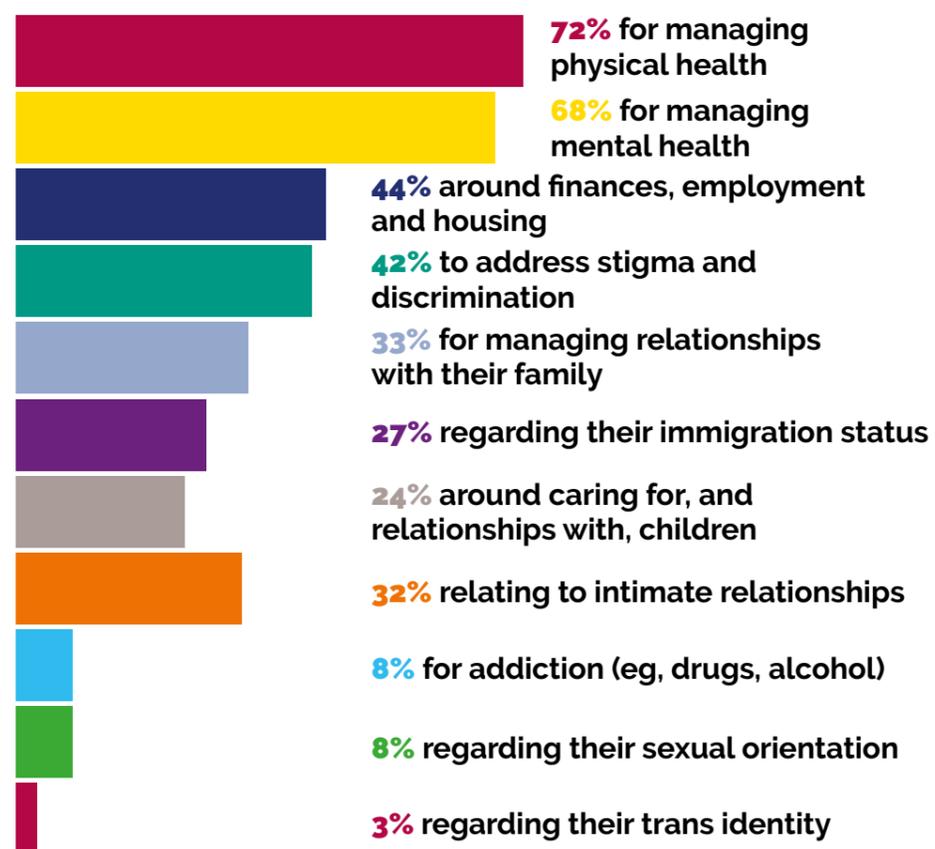
Support needs

'Most of us are single parents, trying to balance work, kids and disease. It's hectic without support or respite.'

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.

We asked women living with HIV about their support needs including what support they had accessed, what had met their needs and where the gaps were.

Women have accessed support services*:



*Note: multiple answers could be given.

Many women had their needs met by the support they accessed but others did not. The most positive response was for support for managing physical health, where 63% of women said their needs were met or somewhat met.

The lowest response was for help with intimate relationships where nearly half (45%) of women had not had their needs met and 17% only had their needs somewhat met from the support they accessed. Support with addiction was also low with 50% of women reporting that they had not had their needs met.

'Doctors or governments don't understand. They think because medication is available all is sorted. But our health is on a rollercoaster! Just because you are undetectable does not mean you are always well.'

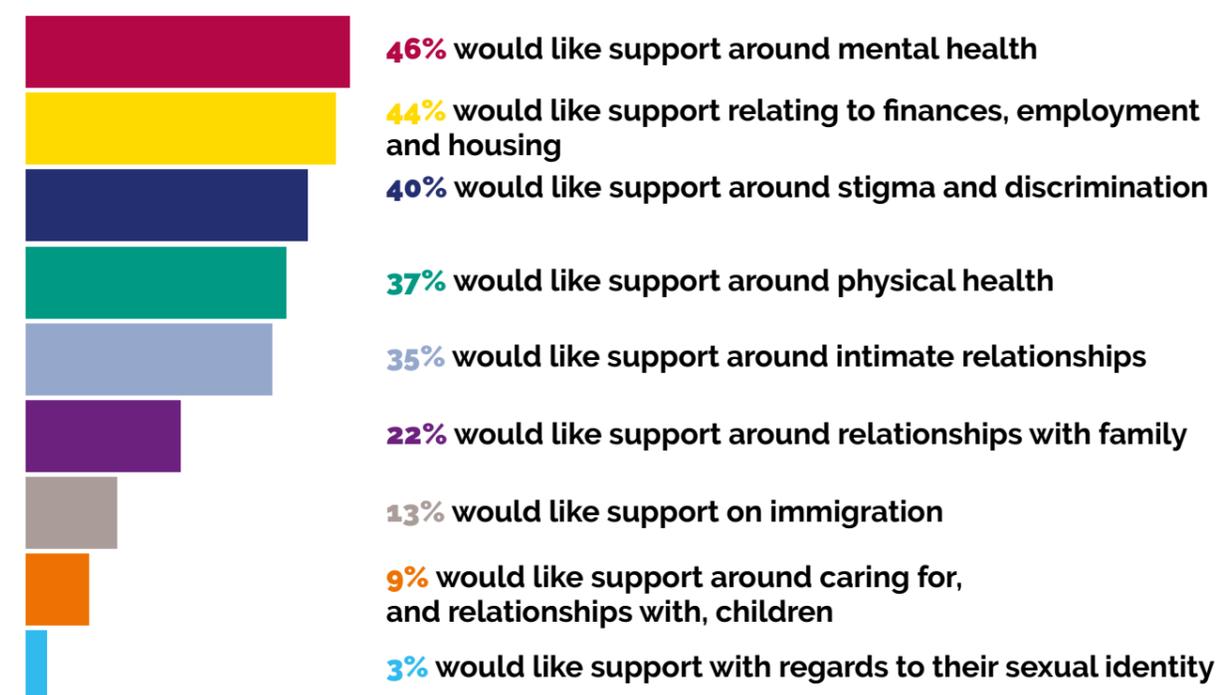
Women in the Experiences survey that were diagnosed in the last five years reported higher levels of support accessed but lower levels of satisfaction.

'Although general advice is available it is difficult to get specific advice related to our situation.'

Altogether, 43% of respondents thought that compared to five years ago, the support available now is less, 11% thought it was the same, and 12% thought there was more support available now - 34% were not sure. Black African women overwhelmingly thought (compared to women of white ethnicity) that there was less support available now compared to five years ago.

'Cuts to social and welfare services means that often women have to prioritise meeting basic needs and survival rather than HIV.' [survey mapping]

A lot of women wanted support in different areas of their life but could not access it.



Responses around support needs also showed the intersectionality of women's lives and complex needs.

[I have] debilitating chronic pain - especially in the morning and I am unable to care or cook for myself and my daughter, take my daughter to nursery, go shopping etc. Sometimes I cannot lift basic items and have to entice people to help out with everyday stuff. I use money meant for other essentials to offer people gifts to help out or go shopping. Sometimes I have the shopping in the car for days and can't get it out so can't eat. [I am] worried about my child starting school soon and how we will both cope.'

Peer support

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

'Having women living with HIV working as peer mentors in clinics ...when a woman becomes newly diagnosed it might be helpful to talk to a woman living with HIV to talk her through things like treatment, CD4 count, viral load, and personal stuff like sex and relationships after HIV. A woman living with HIV who has had a child/children or is pregnant can also be an inspiration to a newly diagnosed woman who may want to have a child/children in the future.'

Comments from our research underscored the need for peer support to be tailored for women and accessible at times that fit in with women's lives.

'I want it to be for women only, women led, developed by women living with HIV, offering child care, financial assistance for travel, and holistic.'

'[I wanted] formal referral to an HIV positive support network that I could identify with. Appreciate this is a big ask, but I felt very isolated being in a room with other "peers" who were peers because we shared the same virus but I could not relate to them. I needed someone like me, or similar.'

'With peer support groups, it's important to talk about our challenges but it would be good to also talk about the progress and positive changes that we've seen. I've been put off by support groups in the past where it feels like we're all re-traumatising ourselves (by sharing our experiences) without much movement towards healing/closure.'

Women also said they wanted support with setting up independent peer groups to support each other in geographical areas where no such services exist. Women want to reach out and support others.

'My life is not over like I thought it was when I was first diagnosed, yes my life is different now and will never be the same but I look at it as a rebirth I've grown into something wiser and stronger and I feel I now have the knowledge and understanding to move forward and help others.'

HIV, ageing and the menopause

When asked about what support services women would like to access, there were a number of responses in our Experiences survey about ageing and the menopause.

'Advice and counselling regarding menopause, including early menopause as result of diagnosis, and cervical health screening and support.'

There has traditionally been a lack of information on menopause and HIV and low take up of hormonal treatments in women living with HIV. Data from the PRIME Study reveal a high level of menopausal symptoms in women living with HIV²¹, and yet in the study's focus groups, women reported a lack of knowledge about the menopause and concerns about interactions between menopause and HIV treatments²². Things are starting to change. NAM have now published a leaflet on the menopause²³, BHIVA, British Association of Sexual Health and HIV (BASHH) and Faculty of Sexual and Reproductive Health (FSRH) guidelines include a new section on the menopause and HIV²⁴, and new draft BHIVA Standards of Care state that clinics need to provide information on menopause to women, and have pathways in place for its management²⁵.

In recent years there has been an increase in research on HIV and ageing and HIV is now recognised as a long-term condition. But more focus is needed on the interplay between HIV, age and gender. In a UK study of 100 people living with HIV aged 50 and over, female gender was associated with poorer quality of life, as well as anxiety, depression and concerns about memory²⁶. In the 2017 Terrence Higgins Trust HIV and ageing report, *Uncharted Territory*²⁷, women reported lower levels of wellbeing than men - 28% of women rated their wellbeing as 'very good' or 'good', compared to 41% of men. There remain many unanswered questions regarding the effects of HIV on women as they grow older - including the impact on menopause. Analysis in Terrence Higgins Trust's ageing report showed that women were more concerned about all aspects of growing older with HIV than men. Women were most concerned about the long-term effects of HIV and ART as well as how they would manage co-morbidities.

21 Tariq S, Rolland A, Burns F, Sabin CA, Gilson R, 2017. Menopausal status and symptoms in women living with HIV in the UK: results from the PRIME Study, 9th IAS Conference on HIV Science; 23-26 July; Paris 2017

22 J McGregor-Read, F Pettitt, F Burns, R Gilson, C Sabin, S Tariq and S Petretti. 2017. You're suffering all these things and you keep going backwards and forwards: experiences of the menopause among women living with HIV in the United Kingdom. BHIVA 2017 abstracts

23 Menopause and HIV, 2017 www.aidsmap.com/Menopause-and-HIV/page/3117291/

24 Waters L at al. 2017. BHIVA/BASHH/FSRH guidelines for the sexual & reproductive health of people living with HIV. Consultation document www.bhiva.org/documents/Guidelines/SRH/Consultations/SRH-guidelines-for-consultation-2017.pdf

25 Consultation www.britishtinfection.org/professional-affairs/consultations/

26 Catalan J, Tuffrey V, Ridge D, Rosenfeld D. 2017. HALL (HIV and Later Life) Team. What influences quality of life in older people living with HIV? AIDS Res Ther. 2017 Apr 11;14:22. doi: 10.1186/s12981-017-0148-9.

27 Uncharted Territory, 2017. www.tht.org.uk/-/media/Files/Publications/Policy/uncharted_territory_final_low-res.pdf



Mental health

'I believe that my HIV diagnosis and the four years after were very traumatic, I was diagnosed with reactive depression.'

Our research reveals high levels of poor mental health and unmet need among women living with HIV. A lot of 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 related issues. Nearly half (46%) of women would like support with mental health but could not access it.

Responses to the Experiences survey showed that poor mental health was a major issue. Altogether 42% of women had had a mental health diagnosis since being diagnosed with HIV. In total 33% felt they had an undiagnosed mental health issue, including women who already had a mental health diagnosis, indicating that some women potentially have more than one mental health issue. The qualitative feedback also illustrated that a number of women had more than one mental health issue.

There were examples of resilience in the face of mental health issues.

'I remained in an abusive relationship for four years following my diagnosis, the fear generated by healthcare professionals that I should not tell anyone else, and his enforcement of this and coercive control, affected my mental health and wellbeing. As soon as I was empowered to speak my truth HIV has helped my mental health as it has allowed me to live authentically, honestly and with empathy and compassion. My relationships in my family have improved and so has my financial situation.'

'I'll was very depressed in the beginning. Even now I feel not good enough sometimes. But mostly I don't even think about it.'

However some women described extremely difficult experiences, many related to significant trauma.

'It's been a very lonely and utterly terrifying experience for me since diagnosis.'

Over three quarters of the women in the Experiences survey (77%) had spoken to a medical professional about their mental health. Women were most likely to speak about their mental health to their HIV consultant (62%) or their GP (55%).

While over two thirds of women (68%) had accessed mental health support, over half (54%) felt that it had not fully met their needs. Nearly half of women (46%) stated that they would like support (or additional support) around mental health but that such support was unavailable to them.

'The support in the first week was good, but it's almost as if they think you don't need it after that, but you do, it's been terrifying for me and for my mother.'

Women diagnosed 20 or more years ago were more likely to have received a mental health diagnosis, whereas those women who were more recently diagnosed (in the past five years) were more likely to suspect they had a mental health issue that had not been diagnosed.

Linked to mental health, but much broader, loneliness and isolation were significant issues for women in our research, often linked to stigma of HIV and fears of sharing their HIV diagnosis with others. The section on stigma later in this report describes this in more detail.

'I'm lonely with this diagnosis. If I had cancer I could be more open.'

Responses to the Experiences survey also illustrated intersectionality of issues for many women regarding mental health and HIV. Seven out of eight respondents to the Experiences survey who identified as asylum seekers or refugees had spoken to a health professional about their mental health. Almost half would like support for mental health but couldn't access it. A total of 15 out of 16 respondents who are, or have been, homeless had spoken to a health professional about their mental health: nine had a diagnosed mental health issue, and six felt they had an undiagnosed mental health issue. Two out of four trans women felt HIV had an impact on their mental wellbeing.

The link between HIV and mental health, including in women living with HIV, is not sufficiently focused on in research and there is a clear unmet need in the support services women living with HIV want around mental health.

Recommendations

Researchers should actively explore the links between HIV and mental health and make recommendations to HIV service providers and mental health service providers with regards to the mental health needs of women, living with HIV.

HIV and mental health services need to offer better screening and access to a range of mental health interventions tailored to women living with HIV.

Stigma and discrimination

'HIV is not the problem, but the stigma brings this entire calamity to one's mind, body and soul. Before you know it you are broken.'

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.

'I feel stigmatised and ashamed, and resentful of having to live in secrecy and isolation.'

'Since being diagnosed I've withdrawn and have become more of a recluse. I don't have many friends as I don't want anyone to know my status. I keep my feelings inside. Everyday I worry about my family finding out about my status. I cry a lot when I am on my own. Just really scared of what people will think of me and all the excuses I make just to avoid situations and people.'

Altogether, 42% of women from the Experiences survey reported receiving support around stigma and discrimination, however just under half of them found that this support did not meet their needs. Two-fifths stated they would like help but that it was not available.

Women felt that low levels of HIV awareness and education among health professionals, schools and wider society fuelled HIV-related stigma.

'It is important not to have a culture of them and us. Which is quite prominent in some of the organisations I have dealt with.'

Our research on stigma focused particularly on stigma within health services. The way women are treated by health services (whether HIV specific or more broadly) is key to women's treatment outcomes and quality of life.

One in three women (31%) in the Experiences survey 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.

Women outside London were more likely to have avoided services because of their HIV status (35% compared to 23% of women in London).

A third (31%) of women had actually experienced negative treatment at a healthcare service due to their HIV status in the past year.

'For all the time I have been going to my HIV consultant, my blood samples have always had yellow 'danger of infection' labels stuck on them. I still fail to see the need for this, especially when I have had an undetectable viral load for over 10 years.'

Of the women taking part in the Experiences survey, 41% had been reluctant to return for an appointment or to a particular service due to the way they were treated by staff.

When asked about specific services, perhaps unsurprisingly the most 'friendly' was the HIV clinic which most respondents said was always (81%) or sometimes (15%) friendly. Women taking part in both surveys and workshops highly rated their HIV consultant and clinic as contributing to their ability to live well with HIV.

Over a third (36%) of women said that GPs were always friendly, however 17% said GPs were never or rarely friendly. Three quarters of women found dentists always (44%) or sometimes (29%) friendly, although some women found dentists rarely (10%) or never (4%) friendly. Women in London found dentists and GPs a little less friendly than women outside London.

There were comments from women about lack of trust in the ability of some GPs to effectively manage general health, confidentiality and HIV.

'GPs [are] badly educated and always shocked every time I mention it, have no awareness of HIV drugs - constantly prescribing things that cannot be taken with my antiretrovirals.'

'I feel there is a lack of info on hormone replacement therapy (HRT) and ART including dealing with trans women. I feel like anytime I go to GP it always feels almost thrown in - "could this be HIV related - speak to your clinic" or "I don't know what is meant to be normal for trans people with HIV" which is very frustrating and puts me off going to GP.'

These findings must be considered in relation to the findings outlined in the section on violence where women shared experiences of violence and abuse in healthcare settings. Of the 99 women who answered the question about violence and abuse in health services there was a large increase in women who had experienced this since being diagnosed with HIV: from 6% before diagnosis to 26% since. In addition, 29% of women said that the violence and abuse they had experienced in health services was because of their HIV status.

Our findings are in line with the 2015 UK Stigma Index²⁸ which provides evidence on the degree to which women living with HIV in the UK currently face stigma and discrimination. In total 378 women were surveyed as part of the Stigma Index. Women reported worrying about interactions, avoiding encounters and experiencing discriminatory treatment, including being gossiped about, sexual rejection and verbal harassment, due to their status.

The Stigma Index found that in primary healthcare settings, women continue to fear being treated differently to other patients, and 15% reported avoiding care that they required. Findings showed that 34% and 35% of all women worried about being treated differently to other patients at their general and dental practice respectively, and 15% had avoided seeking care in either setting when required. A similar trend was found in other healthcare settings with the exception of sexual health clinics. One in eight (12%) of women felt pressured by a healthcare worker to inform others of their status and a small number of participants also reported that a healthcare worker had discussed their status with others without their consent.

Recommendations

NHS England, NHS Scotland and NHS in Wales must work with women living with HIV to increase accurate knowledge and awareness of HIV among health and social care practitioners and accelerate actions to eliminate HIV stigma and discrimination from health and social care settings.

HIV service providers should 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.

²⁸ The people living with HIV Stigma Survey UK 2015, <http://stigmaindexuk.org/reports/2016/Women.pdf>

Violence against women and HIV

'Rape, physical and emotional abuse. I have changed town because people knew.'

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 abuse, 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 and abuse was able to access the support they needed. Experiences of violence and abuse in healthcare settings increased after women were diagnosed with HIV. Altogether 29% of women said that the violence and abuse they had experienced in health services was because of their HIV status. Half (49%) of women who experienced violence or abuse were unable to access support for this, and a third (31%) could only access 'some' support.

To try and better understand how HIV and violence are interconnected, we asked women about violence and abuse they had faced before and after their HIV diagnosis. We asked specific questions about different areas of women's lives and potential settings for violence and abuse (partner, family, community, health services, authorities) to build up as full a picture as possible.

Over half (58%) of women in our Experiences survey had experienced some form of violence or abuse.

Of the 99 women who answered the question about violence and abuse in health services there was a large increase in women who had experienced this since being diagnosed with HIV - from 6% before diagnosis to 26% since. Altogether 29% of women said that the violence or abuse they had experienced in health services was *because of* their HIV status.

Women also reported experiencing violence and abuse due to their HIV status from partners/spouses, from family and friends, in the community and from authorities. A total of 17% of the 100 women who answered the question regarding violence or abuse from a sexual partner or spouse had experienced violence that they felt was due to their HIV status. Of the 100 women who answered the question regarding violence in the community, 18% had experienced violence or abuse that they felt had been due to their HIV status. Of the 100 women who answered the question regarding violence or abuse from the police, in prison or in immigration removal centres, 5% had experienced violence that they felt was due to their HIV status.

What do we mean by violence?

Violence or abuse from a sexual partner or spouse could include: hitting, kicking, punching, threats (for example threatening to leave you), making you have sex when you don't want to, making you have sex without a condom or dental dam, blame, name-calling, making you feel stupid, stopping you from seeing friends, working or leaving the house, stopping you from seeking medical care for you or your children.

Violence or abuse from a family member/neighbour could include: refusing to share food/utensils, name-calling, blame, rejection, abandonment, physical violence such as hitting, kicking, or pulling hair, a member of the family or neighbour touching, kissing or making you have sex when you don't want to, female genital mutilation/cutting.

Violence or abuse in the community (including in the street, local shops, from neighbours, in the school playground) could include: gossip, bad words, rejection, avoidance, children being stigmatised or avoided, being attacked or beaten by a stranger, being touched or made to have sex with someone when you don't want to, being raped because of your sexual orientation or gender identity (homophobic rape), hate-motivated violence against trans women, any form of violence against sex workers by clients or strangers.

Violence or abuse in health services could include: rude or judgemental service providers, disclosing your status without your consent, making you take an HIV test without telling you or without asking for your consent, refusing to give you all the information about available services, forced/coerced abortion or sterilisation, making you wait until other clients have been seen, being refused a certain type of contraceptive, even when it is available, denial of care at hospitals.

Violence or abuse from the police, in prison or in immigration removal centres could include: police harassment, arrest without giving a reason, or because you are carrying condoms, lubricant or clean injection equipment, threat of, or actual, sexual violence or rape by police, prison/detention guards, military personnel, denial of medications and/or healthcare in prison or detention, disclosure of HIV status, refusal to provide services.

'My son is bullying me as he keeps shouting at me and threatening me if I don't do what he said to do.'

'Some people say that I had sex with a homosexual that's why God gave me HIV - people like me needs to be destroyed, we are poisoning.'

Half (49%) of women who experienced violence or abuse were unable to access support for this, and a third (31%) could only access 'some' support.

Results from our Experiences survey showed that there were shared experiences between women who identified with other issues that can be stigmatising or challenging, and violence and abuse. For example:

- Of the eight women who identified as asylum seekers or refugees, seven had experienced violence and only one had not. Most of these women (six out of eight) found that the experience or fear of violence had impacted on their ability to manage their health (in the context of HIV).
- Of the four women who identified as trans, two had experienced violence or abuse.
- Nine out of 11 women who had reported ever using drugs had experienced violence or abuse from partners, seven from family/neighbours, five from their community and five in health service settings.
- Of the eight women who were current or former sex workers six had experienced partner violence and six community violence.
- Among the 13 women who were currently or formerly homeless, 12 had experienced violence or abuse from partners, six from family/neighbours, six from the community, four in health settings and three from the police/authorities.

Issues of violence also came up in the Experiences workshops. There was one instance of a participant's partner threatening to tell everyone in the community of her HIV status. The participant said it felt like she could not leave him as she didn't know how to.

'Domestic abuse from partner - got refuge and was forced to be moved to a new city. I lost all former ties and friends and had to start again to keep safe. Difficult to manage as in the new city, no friends or social life.'

Our findings complement the limited amount of evidence that already exists around the links between violence, women and HIV. In a 2011 study of nearly 200 women attending an HIV clinic in east London, over half of women reported a lifetime experience of intimate partner violence (IPV)²⁹. A more recent study of people attending two large HIV clinics in the UK found that over 40% of women had experienced IPV. Almost all felt that asking about IPV in HIV clinics was appropriate³⁰.

29 Dhairyawan R., 2013. Intimate partner violence in women living with HIV attending an inner city clinic in the UK: prevalence and associated factors. <https://www.ncbi.nlm.nih.gov/pubmed/23217089>

30 F Rita, A Blume and R Patel. 2014. Are HIV-positive patients at increased vulnerability to violence from their partner? www.bhiva.org/documents/Conferences/2014Liverpool/AbstractBook2014.pdf

In addition, the 2017 World Health Organization's *Consolidated Guidelines on Sexual and Reproductive Health and Rights of Women Living with HIV*³¹ and the *Global Values and Preferences Survey*³² that informed it, show that violence across different settings was an all too common experience for women living with HIV.

In 2013 Sophia Forum published the findings of a study that found that many HIV support organisations were not routinely collecting data on gender based violence (GBV), and that not all organisations and HIV clinics had policies for responding to GBV disclosure. Of 30 GBV support organisations who responded to a survey, 11 felt they would know if a woman using their service had HIV, but only six routinely collect that information. Only 25% had written HIV policies and only 40% had protocols to follow if a service user disclosed HIV³³.

There is much to still understand about the link between HIV, gender and violence in the UK but it is clear that women living with HIV face violence and abuse and that not all women are getting the support that they need.

Recommendations

HIV and women's support organisations should ensure that all of their services are identifying and meeting the needs of women living with HIV who have faced, or face violence, abuse or trauma.

Researchers should undertake work to better understand the vulnerabilities and causal link between violence, gender and HIV in the UK.

31 www.who.int/reproductivehealth/publications/gender_rights/Ex-Summ-srhr-women-hiv/en/

32 Manjulaa Narasimhan, Luisa Orza, Alice Welbourn, Susan Bewley, Tyler Crone & Marijo Vazquez. 2014. Sexual and reproductive health and human rights of women living with HIV: a global community survey. www.who.int/bulletin/online_first/BLT.14.150912.pdf?ua=1

33 Sophia Forum. 2013. Violence as a cause or consequence of HIV for women in England: a feasibility study regarding a potential national investigation. http://sophiaforum.net/wp-content/uploads/2013/02/Finalweb_SophiaForum_HIV_GBVreport2013.pdf

Sex and intimate relationships

'I feel I've missed all the beauty of sex in my life as I was diagnosed really young, I was living in secrecy and isolation and now I'm a middle-aged woman that doesn't have sex because of health problems. Of course it has affected it. Completely.'

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 life³⁴ 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.

'Suddenly I was this, to him, this diseased person.'

'I've not been in a relationship for almost five years now which was before I got my diagnosis.'

Women described their fears of telling others about their HIV status and felt that this was directly impacting their ability to form intimate relationships.

'Living with HIV for life means ending up single because of the fear of disclosure.'

'I would love to have a relationship, get married, live together, but some people, if you disclose to them, they run.'

A third (32%) of women had accessed support around intimate relationships in the last five years (or since their diagnosis if more recent) but only one in five felt that this support had met their needs.

Women who felt that they were diagnosed late were far less likely to feel satisfied with their sex life, were more likely to feel that HIV impacts on their sex life, and less likely to access services to support a healthy sex life.

Our findings chime with the UK Stigma Index³⁵ which found that 35% of women living with HIV feared being rejected by a sexual partner due to HIV and 33% had avoided sexual encounters due to their HIV in the last 12 months.

³⁴ 'Satisfied with your sex life' was defined in survey as 'eg, number of partners you have and the type and frequency of sex you are having.'

³⁵ UK Stigma survey 2015 www.stigmaindexuk.org/reports/2016/NationalReport.pdf

Case study

The HIV charity Positively UK runs 'Between the Sheets', a one-day event for women with HIV to explore issues around sexuality and pleasure. The workshops provide an opportunity for women to talk openly about sex and pleasure in a safe environment. They aim: 'To learn, or re-learn, about our bodies and minds, and what turns us on. To discuss self-love and creativity as avenues to pleasure, and of course also to have much fun and laughter, in the spirit of sisterhood and friendship.' Between the Sheets events were started in 2012 by Sahir House in collaboration with Community Health in Liverpool, to offer women living with HIV a safe space to explore issues around sexuality, intimacy and pleasure.

There is evidently a gap in the level of access that women living with HIV have to services and support on sex and relationships. But there is also a gap in understanding the complexity and underlying issues of why women living with HIV are not having the sex lives they want.

Recommendation

Service providers should work with women living with HIV to design interventions that enable women to enjoy the sex lives and healthy intimate relationships that they want.



Children and reproductive choices

'Women's reproductive health - listen, don't assume, check it out. We are not men. Our bodies are more complex. Pay attention.'

HIV is 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.

'It [HIV] is the biggest factor in me being undecided. I worry about pregnancy, giving birth, telling the child my status.'

Many women had sought advice around reproductive choices. This included advice on conception, termination of pregnancy, contraception and fertility. However, the advice had not always met women's needs.

'At some point I wanted to [have children] but my clinic asked me to see my GP for an artificial insemination kit which my GP had no idea about. The process was long and frustrating. I gave up.'

'I was disgusted that there's only two [fertility] clinics in the UK that take women living with HIV.'

Prevention of vertical transmission

Our literature review showed that there is a bank of evidence regarding prevention of vertical transmission. However this was very much focused on the child - on how to prevent HIV transmission and how to ensure the child is healthy.

The UK has good guidelines on HIV testing in pregnancy (for example, what to do if someone refuses a test), a robust antenatal screening programme, and some of the lowest transmission rates in pregnancy. There are also good national pregnancy surveillance programmes in the UK with Public Health England also including a section on vertical transmission in annual HIV reports³⁶.

Pregnancy, motherhood and HIV

There was a feeling from some stakeholders interviewed during this research that there is currently a lack of research on the experiences of women who were diagnosed with HIV during pregnancy and women living with HIV who become pregnant. One stakeholder commented that 'we have some information on

³⁶ Note that data on pregnancy comes from National Study of HIV in Pregnancy and Childhood (NSHPC). www.ucl.ac.uk/nshpc

pregnancy outcomes (outcomes for the baby), breastfeeding and family planning but not the actual experiences and views of women, nor early motherhood and retention in services post pregnancy.' However, this is starting to change with a number of researchers in the UK focusing in depth on the data around pregnancy and women living with HIV. Additional research is looking at antenatal bookings as it has been shown that women living with HIV tend to book later to attend antenatal care and that this is associated with poorer outcomes. The forthcoming BHIVA Pregnancy Guidelines will, for the first time, have a section on post-natal care of women living with HIV, focusing on how to support women post-pregnancy.

In some cases there remains a lack of nuance on national 'norms' and HIV. Breastfeeding is one example. Although actual cases are now very low, HIV can still be transmitted via breast milk. Clinical guidelines recommend that women living with HIV do NOT breastfeed and instead use formula milk³⁷. National AIDS Trust³⁸ has found a lack of consistency in the ability of women living with HIV to access free or affordable formula milk. This must change.

Feedback from the Experiences survey showed how having a child had impacted on women and their lives and relationships in different ways, with one woman saying that having a child had made her 'want to keep well for as long as possible'.

For some women living with HIV who have had a child who has subsequently tested negative for HIV (including at the 18 months mark) there was a continued worry that the child might acquire HIV even after a negative test result was known. Some women in the Experiences workshops would like the opportunity for ongoing testing for children to alleviate the anxiety of the mother.

Sharing information about their HIV status was an ongoing issue for some women with children.

'I'm a lot more cautious and scared of other parents' opinions/ignorance.'

'Having them helps me to cope to help them. They are encouraging me to find a partner, even though I tell them I want to find someone but I have to tell them everything about me and I don't feel that I can.'

Having children was a huge part of some women's lives and living with HIV can impact on decisions around this.

Recommendation

Reproductive health, HIV and other relevant services should ensure that women living with HIV get appropriate timely information and support on reproductive health so that they can make fully informed decisions.

³⁷ BHIVA Clinical Guidelines for the Management of HIV Infection in Pregnant Women, 2014. Note also that the 2018 consultation version for the updated version of these guidelines recommends the same.

³⁸ NAT Policy Briefing: Access to formula milk for mothers living with HIV in the UK, 2017 www.nat.org.uk/publication/policy-briefing-access-formula-milk-mothers-living-hiv-uk

Immigration and HIV

'Being in detention is not good especially with HIV. I had harrowing experiences and abuse and violence from the experience (detention) and could not report it to the police or anyone until this year and it has been very traumatising for me, affecting my ability to live well and manage HIV.'

Challenges related to immigration can affect women's ability to cope well with HIV. From our Experiences survey³⁹, 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.

Some women felt that immigration was a bigger problem than HIV for them, while others worried about periods of waiting - not knowing what was happening with their immigration application.

'My problem right now is not even the HIV. It is the immigration status. Not knowing what is going to happen to me is killing me. I cannot make any plans, I cannot move forward or backward. My life has stopped and I don't know what to do.'

Women asylum seekers and refugees living with HIV often faced multiple challenges, again highlighting the importance of intersectionality in our findings. 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 rarely had enough finances to cover basic needs, seven had experienced violence (some from multiple sources), half had received a mental health diagnosis, and a quarter had avoided health services due to fear of the treatment they might receive due to their immigration status.

Women in the Experiences workshops talked about how delays in immigration decisions being made, being unable to work and, in some cases, being classed as having no recourse to public funds, was linked to poverty, poor mental health, homelessness, a loss of skills and confidence which affected general health, wellbeing and women's ability to manage HIV.

'Immigration impacts on everything, "everything goes back". HIV medication means I need to eat properly but I can't do that without money. Food Chain were helping eg, providing fresh fruit and veg - but recent cutbacks means there is less support now. [I am] living off others.'

³⁹ 41% of women who responded to the Experiences survey were UK Nationals, 9% were European nationals living in the UK, 7% had discretionary leave to remain, 23% had indefinite leave to remain and 4% were on a student visa.

Some women felt that there were fewer services supporting them as women with no recourse to public funds and that not being allowed to work had led some to destitution.

'With no recourse to public funds and no right to work you are stranded - no food and homeless. Special assistance is necessary as feeding is vital for medication. Allow people without immigration status to work, they prefer to work than collect benefits. Not being allowed to work with no right to public funds is inhuman.'

A number of women in the Experiences survey (14%) had actually avoided or delayed attending services that they felt would have helped them with managing HIV because of their immigration status.

However some women identified services and support that helped them manage their health and HIV while going through the immigration process. These included peer support, sharing coping strategies with other women who have been through the immigration process, and church groups. For a few women, attending multiple support groups relieved immigration-related isolation and helped some to cope with and manage HIV.

'The length of time one waits for an immigration decision, by the time it comes through and you are allowed to work you lose focus and cannot work. [There is] stress and lack of support to cope with life after you have received leave to remain. We are not coping when we are alone. That is why we attend all those support groups moving from one to the other. If there is a new one, we will attend because they help us to cope. If we stay at home alone we can't.'

In 2016, HEAR Equality and Human Rights Network produced a guide to the rights and entitlements of disabled (which includes living with HIV) asylum seekers, refugees and refused applicants in the UK which can help to provide clarity to both service providers and women themselves who are living with HIV⁴⁰.

We were unable to find national data on the immigration statuses of women living with HIV. What is clear from our research is that for some women living with HIV, immigration issues are having a severe impact.

Recommendation

Commissioners and service providers need to recognise that women with unresolved immigration decisions need additional support as a matter of urgency, and ensure that these needs are met.

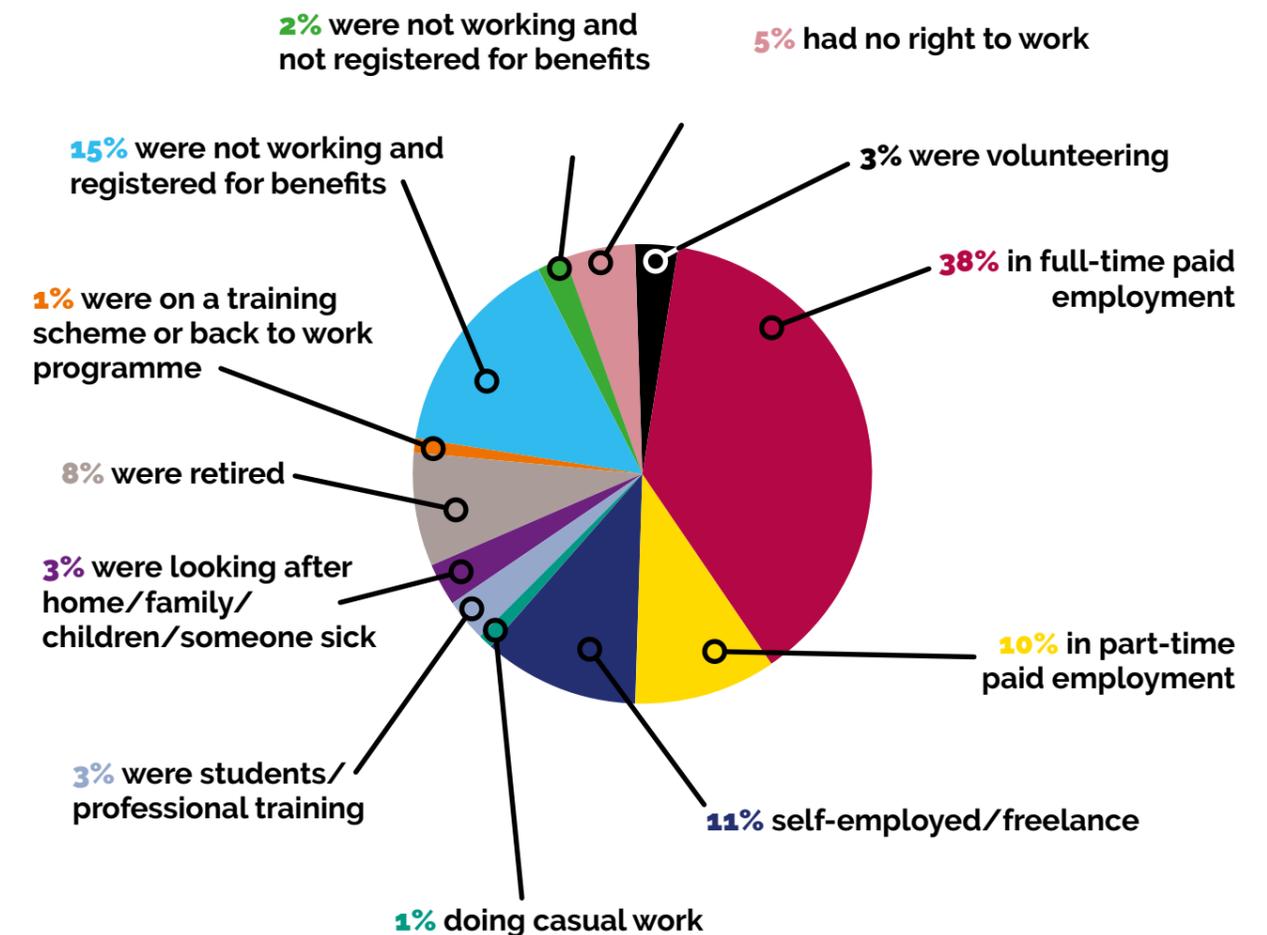
⁴⁰ HEAR Equality and Human Rights Network, 2016. A guide to the rights and entitlements of disabled asylum seekers, refugees and refused applicants in the UK <https://hearequality.org.uk/equalities-and-human-rights-resources/>

Money, employment and HIV

'It has impacted in some ways as I am constantly buying fresh healthy foods and sometimes the daily stress of keeping my status a secret makes me depressed so sometimes I end up spending unnecessarily to make myself feel better.'

Nearly half (45%) of women living with HIV who responded to the Experiences survey were living below the poverty line⁴¹. 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 could also be a barrier to obtaining and maintaining employment.

Employment status of Experiences survey respondents



⁴¹ www.cpag.org.uk/content/uk-poverty-line

Women in London were more likely not to be working and registered for welfare benefits, and were more likely to struggle to cover basic expenditure.

'I can't balance my bills and food. The benefits system does not provide enough which means I am always short and need to top up which I find very stressful. I have tried the CAB and they told me to go on the internet and apply for credit. I am not computer literate and am stranded. My child has been sent back from uni because we didn't know how to apply for UCAS properly and we owe lots for her accommodation. It is all in my head. Sometimes we just move but we are dead already.'

Over half (54%) of women had someone else to support financially, indicating that there may be wider challenges for women struggling to make ends meet not just for themselves, but for dependents.

Women also felt that HIV acts as a barrier to employment. Women reported fears around confidentiality and telling employers that they are living with HIV. There were also comments from some women that HIV affected their confidence regarding their careers.

'I worry about being outed and sacked from my job. I was dismissed from the NHS when they discovered my illness, I worked in an administrative role.'

'For work, having to disclose on, for example, application forms discourages applications for work - it is difficult.'

'I was stuck in underpaid jobs for all my life as I was diagnosed at a young age. Fear kept me low so I didn't have the courage to go after a better paid job.'

Women also felt that as HIV is often a fluctuating health condition it can make it difficult to find suitable employment opportunities.

'Because of health issues I'm not able to confidently work and plan my finances as I would like to. For example there is always fear of the unknown - if you decide to work your benefits are stopped, and if you continue to work then fall ill along the way it is another problem to get back in the system again to get help. It's a long process and until it's approved again you will be struggling. As a result most HIV positive people go into depression.'

Women felt that sick leave policies do not cater to long-term health conditions such as HIV and that there was a general lack of understanding about managing HIV in the workplace.

Our findings support the UK Stigma Index, which showed that 14% of women had decided not to apply for, or had turned down, employment or a promotion due to their HIV status.

Women also spoke of how HIV impacted upon their receiving benefits.

'Assessors for benefits do not understand the needs of people living with HIV, so the assessment process is not suitable and requires us to say everything about HIV.'

Women reported a number of interventions that had helped them to get into or stay in work. This included support to help build their capacity and skills to seek employment.

WORK POSITIVE ✓

Terrence Higgins Trust runs the Work Positive programme⁴² which supports people, including women, who are living with HIV and unemployed to take positive steps back towards employment in a safe, supportive environment. It offers up to six months' part-time voluntary work experience at Terrence Higgins Trust or a variety of partner organisations, personal and professional development opportunities, confidence-building workshops, employment-ready workshops, mentoring, IT training, employment coaching, travel and lunch expenses, peer support and networking.

Not having enough money or a secure job can be a huge source of worry for women living with HIV, and it is often stigma against HIV that is impacting negatively on their employment status. This needs to be acknowledged, and legal and other support provided, as well as ensuring that employers are not able to discriminate in practice in the first place.

Recommendation

Service providers should assess how they can directly support, or refer, women living with HIV on low or no incomes to services that will help ensure their basic needs are met.

⁴² www.tht.org.uk/myhiv/Your-rights/Work/Work-Positive



Women's experiences of HIV prevention

'Little is known about which prevention interventions work for women and how women can benefit from PrEP: little is known about what factors influence risk, what works for women in terms of access, services and new innovations, and why women are less likely to be offered and to accept HIV tests in GUM clinics.'

This section focuses on the findings from our Prevention survey and workshop.

Defining the risk of HIV for women

'If you're a straight, white woman - it feels like you can't be worried about HIV. I've been lucky when I've gone to clinics and they have always listened to me and reassured me but I know it isn't the case for everyone.'

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.

Epidemiological data from Public Health England⁴³ shows that women newly diagnosed with HIV are of all ages, half are black African and a third of white ethnicity, and they live across the UK. PHE also estimate that over 1,300 women in the UK are living with undiagnosed HIV.

A report from the National AIDS Trust⁴⁴ highlights that gender is an important gap in the UK's approach to HIV prevention which must be addressed. A gendered perspective has never been truly integrated into the UK's HIV prevention response.

It is clear that more research is needed with women, in all our diversity, to better understand HIV risk perception and how this relates to the use (or not) of HIV prevention interventions. Epidemiological data needs to be used to better identify the circumstances or underlying behaviours that drive increased HIV risk, and how to reach women effectively with prevention interventions. There is an urgent need for more evidence - analysis of epidemiological data, academic research and intervention pilots - that can be used to inform policy and commissioning decisions around HIV prevention for women.

⁴³ National HIV surveillance data tables www.gov.uk/government/statistics/hiv-annual-data-tables

⁴⁴ National AIDS Trust, 2015. Preventing HIV in the UK Heterosexual Population. Note that this report was focused on heterosexuals, which reinforces the idea that when we look at HIV prevention for women we focus on heterosexuals only.

Recommendation

Public Health England, as part of a *Spotlight Report* on women, should conduct a full gendered analysis of the factors which put women at risk of HIV in the UK.

Knowledge and use of HIV prevention methods

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 HIV⁴⁵. 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.

A total of 84% of women who responded to the Prevention survey felt that they knew where to go to get advice and information on HIV prevention. A further 6% of women did not know and one in 10 (10%) women was not sure.

When asked about ways of preventing HIV, virtually all (99%) women had heard of condoms, 84% knew about using clean needles when injecting drugs, and 76% knew about the female condom as a way of preventing HIV.

Three quarters of women had heard about Pre-exposure prophylaxis (PrEP) (74%), and Post-exposure prophylaxis (PEP) (76%), with fewer women (66%) knowing about Undetectable = Untransmittable (U=U)⁴⁶ and Treatment as Prevention (TasP) (63%).

While knowledge of different ways of preventing HIV seemed high among survey respondents, when asked what methods women had used in the past five years the picture was different. The most common method by far that women reported using were condoms (used by 75% of women). Five women (4%) had used dental dams and only one woman had used female condoms. Six women (5%) had used TasP and five women (4%) had used PEP. No women reported using PrEP in the past five years.

Nearly one fifth of women 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. Reasons mainly related to condoms, with women feeling too awkward to use one, feeling pressure from a partner not to use one, or a partner refusing to use one.

⁴⁵ The Prevention survey was aimed at women who had ever been worried about HIV, not a general sample of women

⁴⁶ If someone with HIV is on effective treatment and has an undetectable viral load they cannot pass on HIV to others. This is often known as U=U (Undetectable = Untransmittable).

'I get exhausted trying to persuade some men to use them.'

Two women said that they had not used an HIV prevention method when they wanted to because they had consumed too much alcohol. For one woman it was due to a lack of confidence.

'Sexual health wasn't something I have always been confident bringing up.'

A quarter of women (25%, 32 women) reported using no HIV prevention method in the past five years. Of these, 12 women were sexually active and all but one married or in a stable relationship. All comments about why they had not used an HIV prevention method focused on being in a stable/ monogamous relationship.

The following sections look at women's experiences of specific prevention methods in more detail. We are clear that our prevention survey included a self-selecting sample of women who were aware of, and had at some point been concerned about, HIV. It would therefore be useful for additional research to be undertaken within a broader sample of women.

Condoms

'If my partner is happy to use them, there's nothing not to like. But having to negotiate can be a chore.'

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 29 women specifically mentioned that negotiating condom use with their partner is a problem. Very few women had recently used female condoms.

Many women reported that they found condoms easy to use, convenient, 'mess free', and easy to find as they were widely available. Most women felt that condoms were affordable.

Condoms as a method were seen as socially acceptable and 'everyone knows what they are'. Many women felt that condoms were, on the whole, reliable, were a recognised method for preventing HIV and were good because they gave 'immediate protection'.

One woman commented that she liked condoms because they were 'non-hormonal and chemical free'. Many women said that they used condoms because they also prevented other STIs and pregnancy.

However, some women did not like using condoms but still used them to protect against HIV.

'[I] detest them but use when appropriate.'

Some women felt that sex did not feel as good with condoms as it did without them, or that using condoms ruins the moment, undermines spontaneity, or lacks a sense of intimacy.

While, as above, some women found buying condoms easy and cheap, others did not like buying them, did not like *'shop assistants seeing what I'm buying'* and felt that *'GP surgeries don't have a system where one can collect them discretely'*. A small number of women found purchasing condoms expensive.

One woman who was also using the contraceptive pill felt that as the pill protected her from pregnancy there was less of an importance of using condoms and so she sometimes forgot to use one.

Some women felt that they were not always able to negotiate condom use with their sexual partner and a small number of women reported that their partner did not like using a condom.

Very few women had recently used female condoms. Two women said they liked to use female condoms as it put them in control. One woman would like to try using them but *'can never find where to buy them'*. Of women who had tried to use them, many felt that female condoms were fiddly, unpleasant or difficult to use, and *'a bit more of a technical faff than a male condom'*.

More research is needed into what alternative methods to condoms women want to use that protect them from HIV, pregnancy and STIs. The promotion of condom choice has been commonly aimed at men, but more also needs to be done to target and inform women about the choices of condoms available that work for them.

PrEP and PEP

PrEP access for women is relatively recent in the UK, and uptake has been limited⁴⁷. While awareness of PrEP in women who responded to our prevention survey was high – 74% of women had heard of PrEP, no women had used it.

Pre-exposure prophylaxis (PrEP) is the use of antiretroviral drugs before sex to reduce the risk of HIV acquisition. In women, a pill must be taken every day (or at least six doses per week), to be effective.

Access to PrEP differs across the UK. PrEP is available on the NHS in Scotland, through sexual health clinics, to anyone resident in Scotland who is clinically assessed as being eligible for it. PrEPARED Wales is a national PrEP pilot, making PrEP available to anyone who is resident in Wales and who is clinically assessed as eligible. In England, the PrEP Impact⁴⁸ trial is making PrEP available to 10,000 people over three years, as part of an implementation trial. At least 1,000 places on the PrEP Impact trial are ring-fenced for women (trans and cis), and heterosexual men. PrEP has also been available online through forums such as I Want PrEP Now⁴⁹.

Various reasons were given in our Prevention survey by some women for not using PrEP including it not giving protection from other STIs, worries about efficacy, potential side effects, not liking to take pills, having to plan in advance and not liking the idea of taking HIV medication when it is not needed. One woman asked *'do I really have to take it for a whole month before I can be protected?'*⁵⁰

PrEP has been largely seen as an intervention for gay men – in the media and in HIV advocacy and policy-making. Yet the potential of an individually-controlled, discreet method of HIV prevention is significant for women, especially women who find it difficult to discuss or agree condom use with partners. There have been some community initiatives to promote PrEP information to women, but more resourced action is needed urgently. Participants in our survey described the potential for PrEP, as well as questions and in some cases, misconceptions. This suggests that even among women who are concerned about HIV prevention, there are knowledge gaps that need to be addressed.

47 No one yet has full data on numbers of women accessing PrEP. In available estimates numbers of women are low.

48 <https://www.prepimpacttrial.org.uk/>

49 <https://www.iwantprepnw.co.uk/>

50 The answer to this is no – it's seven days, though previously some sources estimated it would take longer.

Women and PrEP

Sophia Forum has been leading efforts to improve PrEP access for women, and to ensure women who might need and want to use PrEP are aware of it. Advocacy efforts through United4PrEP and the UK Women and PrEP working group have focused on ensuring women are included in PrEP programmes and interventions. Sophia Forum also partnered with HIV i-Base to create a leaflet on PrEP for women⁵¹, and worked with CliniQ, the ATHENA Initiative and Forum Link to create <http://womenandprep.org.uk/> - a website designed by women for women to provide information on PrEP.

Post-exposure prophylaxis (PEP) is an emergency method of HIV prevention and should be used when there has been a significant risk of HIV transmission⁵². Of women taking part in the Prevention survey, 76% had heard of PEP but only five women had used it in the last five years. Of women who had used it one had found it 'a nightmare' to get it and another had 'heard terrible things but actually did not make me feel sick at all'. Four women who had heard of, but not used, PEP were concerned that it resulted in side effects.

Recommendation

Policy makers and advocates in Scotland, Wales and England should increase focus and activity on ensuring women are informed about PrEP and able to access it, if it is right for them.

⁵¹ 2017, <http://i-base.info/htb/33096>

⁵² www.hiv.gov/hiv-basics/hiv-prevention/using-hiv-medication-to-reduce-risk/post-exposure-prophylaxis

HIV Treatment as Prevention

Treatment as Prevention (TasP) refers to the 'impact of HIV treatment - when taken by an HIV positive person - on reducing the risk of transmitting HIV'⁵³. If someone with HIV is on effective treatment and has an undetectable viral load they cannot pass on HIV to others. This is often known as U=U (Undetectable = Untransmittable).

This has been proven by research including the PARTNER study⁵⁴ which found that no HIV transmissions occurred among the study group that had an undetectable HIV viral load. Using data from the Partners PrEP study⁵⁵ it was found that it can take up to six months for some people to become undetectable from when they start treatment.

'Partner is U, we have no issues. He takes meds daily - we accept all risks together. We actually don't think about it any longer other than daily reminder for meds.'

In this section we bring together data from the Experiences and Prevention surveys. Treatment as Prevention (or U=U) is an issue for women living with HIV, for women concerned about HIV and for women with partners living with HIV.

Our research showed that women who are in relationships with partners who have HIV worry 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 TasP and 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.

⁵³ <http://i-base.info/guides/testing/pep-pepse-and-prep>

⁵⁴ Rodger AJ et al for the PARTNER study group. Sexual activity without condoms and risk of HIV transmission in serodifferent couples when the HIV-positive partner is using suppressive antiretroviral therapy. *JAMA*, 2016;316(2):1-11. Full free access. <http://jamanetwork.com/article.aspx?doi=10.1001/jama.2016.5148>

⁵⁵ www.ncbi.nlm.nih.gov/pubmed/27070123 National Center for Biotechnology Information US National Library of Medicine 2016 Aug 15;72(5):579-84. doi: 10.1097/QAI.0000000000001019. HIV Transmission Risk Persists During the First 6 Months of Antiretroviral Therapy. Mujugira A1, Celum C, Coombs RW, Campbell JD, Ndase P, Ronald A, Were E, Bukusi EA, Mugo N, Kiarie J, Baeten JM; Partners PrEP Study Team 2016 Aug 15;72(5):579-84. doi: 10.1097/QAI.0000000000001019

For 41% of women living with HIV TasP had an impact on them or had affected their sex life, for nearly half (49%) however it had had no effect.

'U=U: Because it isn't widely known outside of HIV circles - it's not exactly flirt material to say "hey, so you heard of HIV, right? Well guess what - U=U!"'

Women who responded to the Prevention survey who knew or used TasP liked it because it allowed women to dispense with condoms and because it was a method backed by scientific research and they were 'confident in official statements that U=U'.

'My long-term partner is living with HIV and we have sex without condoms. His viral load is undetectable, but I still test annually. I'm not so worried about it now, but I was in the past. It's much easier now I can test at home.'

One woman in the Prevention survey also commented that her partner having an undetectable viral load had enabled them to have a child.

However, for some women in the Prevention survey U=U came with some questions and concerns.

'If viral load becomes detectable you may not know if your partner has not had a recent check-up.'

'Relies upon partner to be adherent.'

Ten women who responded to the Prevention survey were in relationships with a partner who was living with HIV. Most of these women (80%) worried 'a lot' or 'somewhat' about HIV. Of the HIV prevention methods used, four women used condoms, one woman condoms and PEP, one woman used TasP, and three women had used condoms and TasP in the past five years.

Our findings from the Prevention survey also showed the misinformed or negative attitudes of health workers towards women who have partners living with HIV, with some women experiencing exclusion, judgement, and discrimination.

'The first clinic I went to tried to encourage me to leave my partner. I moved soon after, so was able to visit a different Trust.'

'I feel quite excluded from the HIV/sexual health service, and like I just have to deal with stuff on my own. I'm not positive, so I can't access services for positive people, and I'm not gay, trans or a migrant, so I can't access most other services. I think I'm fine though!'

Four of these women with partners living with HIV had taken their last HIV test at a sexual health clinic, two had ordered a test online, two had tested at an antenatal clinic and two at a GP surgery. However half of the women did not ask for, and were not offered, an HIV test in the last year. And half were not offered information about HIV or sexual health at their last HIV test.

'I've had a few raised eyebrows as to why a straight married female needs a test. I really shouldn't have to explain myself every time - I am sometimes made to feel like I'm wasting time/NHS money.'

'I've felt really judged and shamed by several health advisers when I've explained that I'm having sex without condoms with an HIV positive man, even though he has an undetectable viral load, including the last time I tested at XXX clinic, when the health adviser said he could offer me PEP (which would not have been in line with the UK PEP guidelines). It has put me off testing in person, but now I tend to test at home. On another occasion I asked for female condoms and they hunted around the clinic for them but couldn't find any - made me feel like it was really only a service for men.'

'I would like to feel that having an HIV test or a sexual health check was a "normal" and "responsible" thing to do. Not an opportunity to be told off and have someone roll their eyes at me.'

Recommendations

Service providers and clinicians must ensure adequate information is provided to women and their partners to fully understand TasP and U=U and enable women and their partners to enjoy a sex life free from anxiety and fear. This should occur when a woman is living with HIV, or if a woman is in a relationship with someone living with HIV.

HIV and sexual health service providers and charities should consider the needs of women who are in relationships with people living with HIV and ensure that they receive non-judgemental services.

HIV testing

'A nurse at my former GP practice was horrendous to me when I asked for hepatitis and HIV tests. I ended up upset and crying in the car park. I did get them (from a different nurse) but changed surgery immediately afterwards.'

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.

Although a large number of women in our research had taken an HIV test in their lifetime, the number of women who had been offered an HIV test in the last year was low (32%) as was the number of women who had asked for a test in the past year (27%).

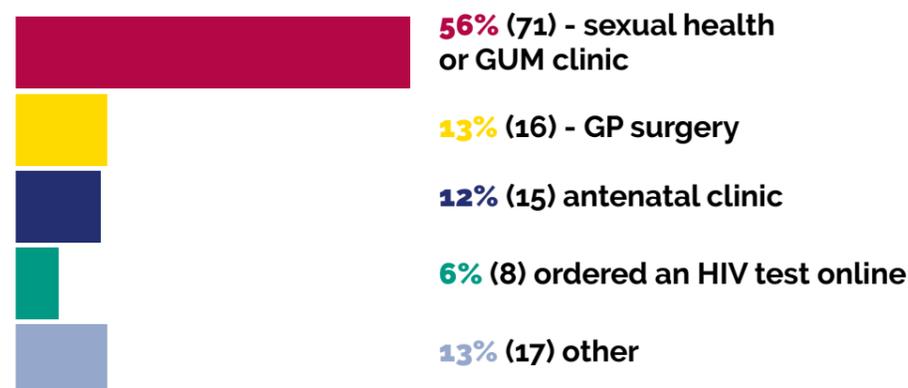
Women aged 18-24 were most likely to have been offered an HIV test in the past year (52%) but least likely to have asked for one (29%). In contrast, only 19% of women aged 50+ had been offered an HIV test in the past year.

Where are women tested?

While 62% of women felt very well informed about how and where to get tested for HIV, one in 10 women felt they were only minimally informed on this. Women had tested for HIV in a variety of settings – the most common being sexual health or GUM clinics, GP surgeries and antenatal clinics. Eight women had ordered a test online. Of the 17 women who had tested at an 'other' location, four women had tested in a community setting, one at a fertility clinic and three women said that the last time they were tested was when they donated blood.

'As a blood donor I know that my blood is screened and I would be informed.'

Where did you take your last HIV test?



It is important to understand where women would prefer to take an HIV test and work with women to ensure that getting an HIV test is as easy a process as it can be.

When asked where they would like to take an HIV test⁵⁷ over half (57%) of women said they would like to take a test at a sexual health clinic and just under half (46%) of women would like to test themselves at home. A third (31%) of women would like to take a test at their GP surgery and a third (29%) of women also said they would like to take a test in a community setting (eg, through an HIV charity or community group).

There seems to be a discrepancy between where women test for HIV versus where they would like to test. Respondents expressed clear preferences for more HIV testing than is currently occurring to be done at home, in community settings and at the GP. Service pilots are needed to explore the use of self/postal testing for women, as well as how women can access HIV tests in primary care and community settings.

Why do women take an HIV test?

Why did you take your last HIV test?	number of respondents
Routine sexual health check-up	38
Change in relationship status	16
Due to unprotected sex	12
As part of antenatal screening	11
Due to a potential exposure (unprotected sex not mentioned)	10
Partner has HIV	10
Had possible symptoms/felt unwell	5
Due to anxiety	3
Had been diagnosed with an STI	3
Undergoing fertility treatment	3
Had been raped	3
Compulsory testing (reasons for compulsory nature not given)	2
Was giving blood	1

⁵⁷ Note – multiple answers could be given to this question.

More women (31%) were tested as part of routine sexual health check-ups than for any other reason.

'I was getting a check on my implant and it was offered, I'm sexually active and it wouldn't hurt to take one.'

In total 20% of women took a test because they had had unprotected sex or felt that they had potentially been exposed to HIV.

'Someone forced me to have anal sex with them and I felt I was at risk.'

'Previously I had an HIV test after being raped although this was some time after the event because I was unsure about where to go and didn't feel safe at my then GP. Later I had told her I was raped so didn't feel comfortable having a smear test. She didn't follow this up with STI testing info or counselling info or even asking if I was okay! The police also didn't mention STI testing (I didn't report it straight away so no evidence was gathered eg, for DNA tests)'

Antenatal screening is still an important route for testing for HIV. PHE, in their recent report on HIV testing⁵⁶, found that the uptake of HIV testing by pregnant women through antenatal screening continues to increase with 98% of eligible women tested in 2015. This demonstrates that women are willing to take HIV tests, but it is important to place antenatal screening in context. A diagnosis during pregnancy is particularly challenging and earlier testing opportunities to diagnose HIV as early as possible pre-pregnancy should be the ultimate goal.

Reasons women in the Prevention survey gave for testing were of course varied but most were proactive – testing as routine or at the start of a new relationship. More exploration is needed into the cohort of women who are testing after a potential exposure incident, as this could better inform prevention efforts and provide an insight into women's conceptualisation of risk.

Overcoming barriers to HIV testing

Over half of women (58%) said nothing would prevent them getting an HIV test. However, 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.

⁵⁶ Public Health England, HIV testing in England, 2017 report https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/666478/HIV_testing_in_England_2017_report.pdf

Would anything prevent you taking an HIV test?	% of respondents (n=139)
Nothing would prevent me	58%
I do not see myself as being at risk	29%
Services are not easy to access	18%
I feel awkward asking for an HIV test	11%
I am worried about judgemental service staff	9%
I cannot take the time off work	8%
I am concerned about the stigma of living with HIV	7%
I am not sure where a test is offered	4%
I have household or childcare responsibilities	4%
I would rather not know if I have HIV	3%

While the majority of women in the Prevention survey had positive experiences of accessing sexual health services, a number of women said that the way that they were treated by staff made them reluctant to return for an HIV test.

'Asked in my history of why I was having the test, they judged my partner. That in itself has nothing to do with them. I was there to get tested, not listen to them trying to give me sympathy. The relationship side was for me and my recently confirmed bi husband. Q: what is a normal relationship these days?'

'Negative phrasing of questions puts you off. "You haven't had sex with anyone else in that time, HAVE YOU?" Well yes I have but now I'm not going to tell you.'

Barriers to accessing an HIV test also included household or childcare responsibilities and not being able to take time off from work. In these cases, it would be useful to explore whether HIV self testing (at home) could help to overcome these barriers. Women were also worried about the impact if the test came back as positive with 7% of women saying that they were concerned about the stigma of living with HIV and 3% of women would rather not know if they had HIV.

Women with disabilities described feeling even more excluded from HIV testing in sexual health services, particularly due to accessibility issues.

'I cannot access testing as a disabled person, it's too far from a bus stop in my city, I can't spend two hours waiting at a drop-in clinic and appointments are difficult to make as they don't do them. Taking a carer to a clinic also feels like an incredibly personal step for me to make, and as I'm single I don't have a partner who could take me and help me either. It means I have never been tested even when sexually active with multiple partners.'

Women were asked what would encourage them to take an HIV test⁵⁷. Many responses centred on convenience of accessing a service that fitted in with women's lives – shorter waiting times, more convenient opening times, quick test results, and the ability to book appointments ranked highly.

What would encourage you to take an HIV test?

73% - non-judgemental service staff

72% - if I could get test results back quickly

68% - shorter waiting times when accessing an HIV test

69% - more convenient opening times

52% - the option to be able to test at home

Other things that would encourage women to take an HIV test include:

'Make HIV testing a part of a health screen ...urine test, blood pressure, HIV, weight. Normalise screenings.'

'Not having to put it on my medical records. Used to have HIV tests for foreign work but was warned that it can affect mortgage applications etc. This may have changed now but I've never asked.'

In the past two years PHE has placed greater focus on exploring national data around HIV testing, including by gender. In 2017 its report⁵⁸ on HIV testing in England found that of all women eligible⁵⁹ for HIV tests at sexual health services, 84% were offered an HIV test and only 61% were tested. This is the lowest coverage of all populations⁶⁰. With regards to testing in non-specialist settings⁶¹, 67% of eligible women were offered an HIV test, and only 22% were tested⁶². For black African women, Public Health England found that the number of women declining HIV testing in sexual health services has increased by 52% between 2012 and 2016. Why is it that women are not being offered tests? Why is it that women are not taking up tests when offered?

Testing continues to be one of the top priorities for commissioners and service providers but it is clear from our own research as well as PHE data that the approach to testing is not currently working for all women. More needs to be done to research in more depth what women want and pilot new and improved approaches to HIV testing in women.

⁵⁷ Note – multiple answers could be given to this question.

⁵⁸ www.gov.uk/government/news/phe-publishes-elimination-of-hiv-and-hiv-testing-reports-2017

⁵⁹ Women not eligible included attendances by known HIV positive patients, where an HIV test was not appropriate or where the attendance was reported as being related to sexual and reproductive health (SRH) care only.

⁶⁰ Coverage of HIV testing in heterosexual men was 78% and 88% in gay and bisexual men.

⁶¹ PHE definition: refers to SRH services, young people's services, online sexual health services, pharmacies, outreach and other community-based settings.

⁶² This compares to 60.1% of heterosexual men and 77.1% of gay and bisexual men who took tests when offered in these settings.

Recommendations

As a matter of urgency, Public Health England and researchers should examine why rates of HIV testing are declining in sexual health services, and make recommendations on how HIV testing for women can be increased in these and other preferred testing settings.

Service providers should work with women to pilot testing schemes, including exploring the use of HIV self-testing and testing in community settings.

Women's sexuality and sexual fluidity

'I have experienced confusion from professionals who didn't understand that sexual behaviour can be fluid, beyond your declared identity.'

There is a particular lack of understanding of women's sexuality and sexual fluidity in relation to HIV prevention.

'LGBT organisations and healthcare professionals are not giving women information about HIV.'

As already noted in Section 1, women who do not identify as heterosexual are often even more invisible in the response to HIV. Our Prevention survey and workshop indicate that the sexual health needs of women who are not heterosexual are not well understood by health services and so not included in HIV prevention work. In some instances there were reports of discriminatory behaviour within health services.

Seven women responding to the Prevention survey had avoided or delayed attending sexual health services in the past five years due to concerns about how they would be treated because of their sexual orientation. Seven women had experienced negative treatment at an HIV or sexual health service due to their sexual orientation.

'I am often aware of the expectation placed on me to "come out" to health professionals and counteract their assumption that I am at risk of pregnancy.'

'[There is] stigma around bisexuals and people not taking you seriously.'

Non-heterosexual women who took part in this research said they want up-to-date information and education on HIV so that they can make informed decisions about their own sexual health.

'Where to go for HIV education, HIV testing services for women. Lack of information on protection during sex.'

Non-heterosexual women also want healthcare professionals, sexual health clinics and service providers to be more knowledgeable and supportive of sexual fluidity and sexual health for all women.

Recommendation

HIV and sexual health service providers should work with women who do not identify as heterosexual to understand their needs, ensure that quality resources are available on HIV and that current HIV and sexual health services are reflecting the needs of this population of women.

HIV prevention: next steps

It is clear that there is a lot more to learn about how, when and why women access HIV prevention interventions, what the barriers are to accessing prevention, how these barriers can be overcome, and how innovative HIV prevention methods, including PrEP and the use of HIV self testing, can help to overcome some of these barriers. Our findings have only scratched the surface of what HIV prevention women want. It will take the whole system to help overcome these gaps in knowledge.

As the UK moves past the 90-90-90 HIV targets and aims to get to zero new HIV infections, it is clear that this will not be achievable until it is better understood which HIV prevention interventions work for women. It is an exciting time – PrEP, TasP and HIV self testing are opening the possibilities to people who want to take preventative action but the benefit of these interventions for women has not yet been explored. Why is that?

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 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, gay 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.

Appendix 1

Project Advisory Group members

- Claudia Carvell, Programme Co-ordinator, LGBT Foundation
- Valerie Delpech, Head of National HIV Surveillance and Monitoring, Public Health England
- Chenai Mufanawejingo, Project Lead - Shropshire and Telford Champions of Change, Terrence Higgins Trust
- Luisa Orza, Lead: HIV Technical (Gender), International HIV/AIDS Alliance
- Irene Parker, Aneurin Bevan University Health Board - Sexual and Reproductive Health
- Juno Roche, Trustee of the Sophia Forum
- Kelsey Smith, Policy and Campaigning Officer, HIV Scotland
- Shema Tariq, NIHR Postdoctoral Clinical Research Fellow and Honorary Consultant HIV/Sexual Health Research, University College London; also on the board of Supporting Women With HIV Information Network (SWIFT)

Appendix 2

Stakeholder interviews

- Hosanna Bankhead, Founder of Hwupenya Health, Scotland
- Del Campbell, Policy, Police and Training Lead of National Ugly Mugs
- Claudia Carvell, Programme Co-ordinator, LGBT Foundation
- Zoe Cousens, Programme Lead for Sexual Health, Public Health Wales
- Valerie Delpech, Head of National HIV Surveillance and Monitoring, Public Health England
- Caroline Foster, Clinical Lead for Transitional Care in HIV and Consultant in Adolescent HIV and Infectious Diseases, Imperial College Healthcare NHS Trust
- Yvonne Gileece, Consultant in HIV and Sexual Health, Lead for HIV in Pregnancy and Conception, Lead for HIV and Liver Disease, Chair of Sussex HIV Network, Chair of SWIFT
- Andria Mordaunt, member of ACT UP Women UK
- Mercy Ngulube, ex Chair of Children's HIV Association (CHIVA) Youth Committee
- Eamonn O'Moore, Director for Health and Justice, Public Health England
- Silvia Petretti, Deputy Director, Positively UK
- Juno Roche, Trustee of the Sophia Forum
- Michelle Ross, Co-Founder cliniQ, Co-lead on Service Development
- Liat Sarnier, Sexual Health Clinical Lead for Barts Health NHS Trust
- Lynda Shentall, Trustee of the Sophia Forum
- Jacqui Stevenson, Trustee of the Sophia Forum
- Shema Tariq, NIHR Postdoctoral Clinical Research Fellow and Honorary Consultant HIV/Sexual Health Research, University College London; also on the board of SWIFT
- George Valiotis, Chief Executive, HIV Scotland

Appendix 3

HIV service mapping respondents

We had responses from the following nine organisations:

- BHA for Equality
- Bloomsbury Clinic - Mortimer Market Centre
- Herts Aid
- LGBT Foundation
- NAM
- Positively UK
- Staffordshire Buddies
- Yorkshire MESMAC
- Waverley Care



April 2018

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

Sophia Forum c/o 345 City Road, London EC1V 1LR
Email: info@sophiaforum.net Website: www.sophiaforum.net Twitter: [@SophiaForum](https://twitter.com/SophiaForum)

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The HIV and sexual health charity for life

Terrence Higgins Trust 314-320 Gray's Inn Road London WC1X 8DP
Tel: 020 7812 1600 Email: info@ttht.org.uk Website: www.ttht.org.uk THT Direct: 0808 802 1221

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