

**Women's Health Strategy  
Sophia Forum and National AIDS Trust submission  
June 2021**

**1. About us**

- 1.1 Sophia Forum exists to advance the rights of all women living with and at risk of HIV and we challenge unequal access to services and opportunities based on gender. We do this through our advocacy, research and policy work.
- 1.2 National AIDS Trust (NAT) is the UK's HIV rights charity. We work to stop HIV from standing in the way of health, dignity and equality, and to end new HIV transmissions. Our expertise, research and advocacy secure lasting change to the lives of people living with and at risk of HIV.
- 1.3 This submission is informed by the results of a specific survey of women living with HIV, run by the Sophia Forum and NAT which took place in May 2021.

**2. Survey Introduction**

- 2.1 We sent out a survey across our social media networks and through contacting the wider HIV sector across the UK. We had 96 responses in total. This shows the challenges of engaging women during a pandemic, who may have other priorities, aren't necessarily engaged with services or don't have access to devices to complete the survey due to poverty. We are aware there are limitations to the findings and that further research is essential to amplify the voices of those less represented in this survey.
- 2.2 Of those who responded to our survey, 84% identified as women (both cis and trans women), 5% non-binary/gender queer, 1% intersex and 7% something else. 95% reported their gender identity was the same as assigned at birth and 4% did not identify with the same gender assigned at birth.
- 2.3 41% of respondents identified as Black African, 6% as Black Caribbean, 43% as White British, 2% as mixed heritage Black/White African, 1% mixed heritage Black/White Caribbean.
- 2.4 33% of respondents were between the ages of 45-54, 32% were aged 55-64, 17% were aged 35-44, 10% were 25-34, 4% were 18-24, 2% were 65-70 and 2% were 70-80 years of age.

2.5 40% of respondents live in London, 14% in the North West, 10% Yorkshire and Humber, 7% North East, 7% East of England, 9% South West, 5% West Midlands and 8% South East.

### **3. Women living with HIV in the UK**

3.1 Of the 98,552 people accessing HIV care in the UK in 2018, 68,088 were male and 30,388 were female, so around a third of people living with HIV in the UK are women. This is an extremely diverse group with a range of experiences and backgrounds. 4 in 5 women living with HIV are migrants, 3 in 4 are from minority ethnic communities. Of those women living with HIV, 64% are Black African, 19% White, 12% Other Black, Asian, and mixed ethnicities and 5% Black Caribbean.

3.2 The Sophia Forum and Terrence Higgins Trust's *Invisible No longer* report highlights that too little is known about the interactions between HIV and Gender and the impact of this on women's experiences in the UK. This submission will highlight emerging evidence of disparities in health outcomes due to ongoing health inequalities and racism in and outside health settings.

3.3 Of those newly diagnosed with HIV in 2019, 823 were heterosexual women, and 736 heterosexual men<sup>1</sup>. Whilst rates of diagnosis amongst gay and bisexual men have fallen significantly over the last 5 years, the levels of new diagnoses amongst women have remained steady, highlighting more work is needed to see equal improvements for women.

3.4 The majority of women living with HIV (52% in 2019) were diagnosed late. Late diagnosis leads to worse health outcomes, often women becoming very unwell before they are diagnosed and can also increase the risk of death in the first year of diagnosis.

3.5 The Positive Voices survey indicated that women are less likely to share their HIV status and more likely to need support than men living with HIV<sup>2</sup>. 1 in 6 reported they had not shared their status with anyone outside of their healthcare setting, compared to 1 in 9 for men. This can be for a range of reasons, but it is clear women often require additional support when diagnosed with HIV and fear judgment from their friends, families, colleagues, communities and healthcare staff.

#### **Our survey responses of women's experiences sharing their status with others:**

- Only 29% of respondents felt extremely comfortable sharing their status with friends. 1 in 5 women (20%) did not feel comfortable.
- More than 1 in 10 (12%) respondents had not told any of their friends.

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<sup>1</sup> PHE (2020) Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019

<sup>2</sup> Positive Voices (2018) Changing Perceptions: Talking about HIV and Attitudes

- Only 24% of respondents felt extremely comfortable sharing their HIV status with work colleagues, 39% were not comfortable.
- Only 29% of respondents felt extremely comfortable talking to family members about their HIV status.
- 27% said only certain family members know of their status and 4% said none of their family members knew of their HIV status.
- 60% of respondents felt comfortable talking about their HIV status to health professionals outside of their HIV clinician, 40% however did not feel comfortable.

#### **4. Experiences of accessing healthcare across the life course**

##### *4.1 Racism, stigma and the need for culturally sensitive services*

- 4.1.1 Previous survey work by Positive Voices has suggested that 21% of women avoided seeking healthcare, with many worried about being treated differently<sup>3</sup>. This can be for a range of reasons, around service suitability and accessibility, ease of access and concerns about stigma.
- 4.1.2 From our survey 30% of respondents had avoided accessing healthcare due to their HIV status. Concerns were direct experiences of stigma and discrimination. Some felt staff treated them differently once their status was known, while others feared discrimination and feelings of shame around their status. Respondents are reported not wanting to disclose their status and others felt traumatised following inappropriate questions being asked during consultations.
- 4.1.3 11% of respondents had avoided accessing health care due to their race and ethnicity. It can be important to many, that services understand and reflect their culture to better understand their experiences and needs. Experiences shared from respondents highlighted issues of direct racism, feeling they received poor care linked to their ethnicity. Respondents cited fear of being treated differently and in a negative way.
- 4.1.4 The government's policy of creating a 'hostile environment' for migrants means that some pregnant women and new mothers are being charged a fee of about £7,000 or more for accessing NHS maternity care. Many of these women are not allowed to work under the immigration rules, so they cannot afford to pay the fees and experience debt and stress<sup>4</sup>. 5% of respondents avoided accessing health care due to their immigration status, stating fear as the main driver and not feeling safe due to unstable immigration status. Even though HIV care and testing is free, awareness of this is often low and people remain confused about treatment entitlements.

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<sup>3</sup> Positive Voices (2018) Changing Perceptions: Talking about HIV and Attitudes

<sup>4</sup> 4M Network (2020) Confinement: Women HIV and pregnancy during the 2020 COVID-19 lockdown in the UK [https://4mmm.org/wp-content/uploads/2020/12/4M\\_CONFINEMENT\\_covid\\_finalNov2020.pdf](https://4mmm.org/wp-content/uploads/2020/12/4M_CONFINEMENT_covid_finalNov2020.pdf)

4.1.5 Our survey demonstrated women have variable experience of healthcare and this can depend on the setting in which they experience care. Respondents' experiences of feeling listened to by their consultants were varied. One respondent shared that overall she felt listened too but did not have joined up care. Sexual reproductive health and mental health were not part of her HIV care which results in accessing separate services and subsequently more appointments. Another respondent had approached their consultant about side effects of their anti-retroviral medication and requested to change but was refused. They felt the focus was on increasing their CD4 count over the serious side effects which has left them struggling for multiple years. One respondent felt a lot of pressure not to breastfeed but also felt unheard in their financial situation being unable to afford to buy formula milk. Management of pain by more than one respondent was felt to be poor, and that there was a lack of appropriate referral for pain management and at times the impact was under recognised. Lack of knowledge and understanding for some issues relating to ageing, such as the menopause, was shared.

#### 4.2 Access and uptake of HIV testing

- 4.2.1 Access to HIV testing remains a significant issue. 27% of women felt that there were missed opportunities to test earlier for their HIV<sup>5</sup>.
- 4.2.2 Often assumptions are wrongly made about relative risk of HIV, which can mean testing is not always proactively offered to women, contributing to later diagnosis. Far too many women leave sexual health services not having been offered a test.
- 4.2.3 Findings from *The Invisible No longer* report by The Sophia Forum and THT shows that only half of women (51%) surveyed were offered information about sexual health and HIV prevention when they last took an HIV test. Significant barriers to testing for women remain<sup>6</sup> with many report feeling uncomfortable requesting test and worrying about judgmental staff attitudes.
- 4.2.4 PHE 2019 data presents this challenge in stark terms; heterosexual women were more likely than heterosexual men to decline a test (25% vs 13%) and also to not be offered a test in the first place, with 15% of Black African heterosexual women not offered a HIV test. Combined, this resulted in a third of Black African heterosexual women attending sexual health service not being tested, the largest single group of women living with HIV in the UK<sup>7</sup>. This is a significant missed opportunity. More work is needed in sexual health services to ensure staff are proactively offering tests at every opportunity, and that people feel encouraged and enable to take them.

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<sup>5</sup> Sophia Forum & Terrance Higgins Trust (2018) Women and HIV: Invisible No Longer

<sup>6</sup> Ibid.

<sup>7</sup> PHE (2020) Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019

4.2.5 Increasing access to HIV testing in services women often access is a key opportunity to diagnose more women living with HIV earlier, and find those remaining women living with undiagnosed HIV. Maternity services have been a real success story in recent years. With opt-out HIV testing introduced, coverage is now over 99% of mothers being tested (679,542 tested in 2018/19), resulting in 13.9 per 100,000 people tested positive during pregnancy. This has helped all but end vertical HIV transmission from mother to baby in the UK.

4.2.6 Exploring options for increasing access to HIV testing in termination clinics and cervical screening should be a priority for the current HIV action plan and NHS. Despite cervical cancer (CIN2+) being a recognised indicator condition of HIV, we know that HIV testing is often not offered to women presenting with this condition, and that the national guidance from the cervical screening programme and specific clinical guidance from national clinical bodies does not promote HIV testing as recommended by national HIV and NICE guidance.

#### *4.3 The need for services focused towards women*

4.3.1 Only 7% of respondents to our survey attended a clinic specifically designed for women. One trans female respondent attends 56T, a service for trans and non-binary patients and one at a North London Trust. 73% of respondents wanted more women designed services within the broader sexual health provision.

4.3.2 Those living in more rural areas stated there were no support groups for women in their small town. 15% of respondents asked for more training and better literacy around issues relating to trans and non-binary people. A women's hub was suggested to prevent travel to different hospitals or departments as it is frequently said health care feels increasingly fragmented.

4.3.3 Services should ensure they engage with women and involve them in decision making, both on an individual level about their own care, but also about planning services more broadly. It is also important to engage with voluntary / third sector organisations led by women, who work with women, especially migrant women.

#### *4.4 Trans women and the need for Trans-specific support services*

4.4.1 Trans women often experience specific challenges in accessing health care and need additional support and specific tailored services. Stigma and other structural barriers mean that trans people do not have adequate access to the services that can support HIV prevention or provide care for those who are living with HIV. There is a need for gender identity training for staff.

4.4.2 Where they are not adequately supported, gender affirming behaviours can increase the risk of acquiring HIV. For example, delayed access to gender identity services

may result in unregulated use of hormones which can be detrimental to a person's health and wellbeing and, specifically, it can increase HIV risk if people resort to sharing needles.

- 4.4.3 The experience of stigma and transphobia is destructive and is especially detrimental to those without access to good support services. In previous research, one respondent explained that where transphobia undermines gender identity, sex can be a powerful element of gender affirmation, especially among younger people. Where sex takes place within an unequal power relationship – and this is evidenced by high levels of violence, including intimate partner violence, against trans people – vulnerability can lead to difficulties in negotiating safe sex practices. One survey respondent shared that trans people experience trauma in a multitude of ways and it is suggested more questions beyond relating to partner violence may enable a trans women to disclose where else they are being traumatised covertly.
- 4.4.4 Accessible health and wellbeing services are vital for supporting HIV prevention and treatment. However, trans people routinely report difficulties accessing treatment including overt stigma, misgendering and poor trans awareness, and lack of appropriate medical knowledge among healthcare professionals. More than one respondent said gender identity is changing rapidly and those who do not fit the binary male/female avoid accessing health care.
- 4.4.5 A positive solution to inadequate service provision is to facilitate access to trans-led health and wellbeing facilities, namely Trans specific services such as those at Dean Street and provided by CliniQ, based at King's College Hospital. However, funding for these services are woefully inadequate. Adequate healthcare is a basic right, and this is an area that must be addressed if the Government is serious about equality for trans people.

#### *4.5 Responding to the needs of women as they age with HIV*

- 4.5.1 Care for women ageing with HIV was a strong theme in our survey as the largest number of respondents were aged between 45-64. Older women with HIV face specific challenges, including high levels of menopausal symptoms and difficulties accessing appropriate care, increased risk of comorbidities such as osteoporosis and cardiovascular disease and high levels of stigma. Data from the PRIME study reported almost 50% of women were underprepared for the menopause<sup>8</sup>. When asked if their HIV consultant or nurse had had a conversation with them about the menopause prior to presenting with any possible symptoms, 78% of respondents answered no and just 13% said yes. Whilst 70% of respondents knew what hormone

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<sup>8</sup> Shema Tariq and PRIME Study Group (2018) Menopause in women living with HIV in England: findings from the PRIME study [https://thebms.org.uk/wp-content/uploads/2018/05/PRIME-report-2018\\_web\\_EMBARGOED.pdf](https://thebms.org.uk/wp-content/uploads/2018/05/PRIME-report-2018_web_EMBARGOED.pdf)

replacement therapy was, 30% said no, and only 13% had been directed to resources of information around the menopause.

- 4.5.2 When asked if a discussion around possible symptoms and hormone replacement therapy options available to them, 78% of respondents had not had that conversation. 19% of respondents had said a conversation had taken place. 40% of respondents did not know where they could access hormone replacement therapy, 16% not sure and of those who did know, 39% cited information via The Sophia Forum, a specialist HIV clinician and social media adverts.
- 4.5.3 Women living with HIV described particular challenges during the menopause as a result of living with HIV. These included difficulties distinguishing menopausal symptoms from HIV-related symptoms, difficulties accessing appropriate menopause care, and the impact of menopausal symptoms on HIV management e.g. adherence to antiretroviral therapy.
- 4.5.4 Further research on experiences of women ageing with HIV in London by Dr Jacqui Stevenson - *I was not meant to be here and I'm still here*, highlighted again the impact of side effects of medication, pain and menopause were significant for the women<sup>9</sup>. It also highlighted the differing needs of women as we age with HIV especially those who were diagnosed before effective antiretroviral medication was available and the psychological and emotional challenges this brings. It explored both positive and negative experiences and what enables women to live well, peer support being cited in both pieces of research. The Sophia Forums advocacy asks from their We Are Still Here campaign include accurate, accessible and comprehensive menopause information and support in clinics, along with treatment advocacy and peer support tailored to women including menopause mentors to support women through the menopause transition.
- 4.5.5 Only 12% of respondents said their HIV clinic also had a menopause service. 47% were unaware if that service was available. More information is needed for women around the services available within their HIV clinics. 52% of respondents said their current HIV clinic has no service with a focus on ageing with HIV.

#### 4.6 *The need for whole-person care*

- 4.6.1 Respondents reported concerns about the fragmentation of care and needing to have multiple conversations with different care providers. There is often poor to no communication between healthcare providers. Those living with HIV can face fears of opening-up to new providers of care who may be ignorant about HIV, and face increasing anxiety around new hospital admissions due to experiences of discrimination or a lack of health care professional knowledge.

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<sup>9</sup> Dr Jacqui Stevenson (2019) We are still here <https://sophiaforum.net/wp-content/uploads/2020/09/Im-Still-Here-research-summary-Dr-Jacqui-Stevenson.pdf>

- 4.6.2 There is a need for services to understand women's complete health needs. When asked in our survey about other health conditions, 39% were also living with a mental health condition, along with 39% going through some stage of the menopause. 34% are managing high cholesterol. Other common conditions women are also living with are osteoporosis, fibroids, hypertension, neuropathy, chronic or intermittent pain, diabetes, arthritis and kidney disease.
- 4.6.3 13% of respondents said the side effects of the medication affect their day to day living a great deal. For one respondent, a change of medication due to high cholesterol resulted in weight gain on the new regime, which subsequently impacted their mental health, leading to another change of treatment. Other respondents mentioned nausea, fatigue, memory and concentration loss. Just 1 in 3 respondents (32%) experienced no side effects.
- 4.6.4 Sexual reproductive health and mental health were not part of their HIV care which results in accessing separate services and subsequently more appointments. One respondent had approached their consultant about side effects of their anti-retroviral medication and requested to change but was refused. They felt the focus was on increasing their CD4 over the serious side effects which left them struggling for multiple years as they are now irreversible. Management of pain was felt to be poor by more than one respondent, and lack of knowledge of appropriate referral for pain management and at times impact under recognised.

#### *4.7 Meeting the needs of mothers with HIV*

- 4.7.1 There are often challenges reported by mothers living with HIV accessing formula milk<sup>10</sup>. Mothers are advised to use formula-feed to prevent vertical HIV transmission to their newborns, however this can be expensive to purchase, and with high levels of financial insecurity and many migrant mothers having no recourse to public funds, they often have to go without food themselves to feed their babies or rely on foodbanks and patchy support accessing formula milk via healthcare settings.
- 4.7.2 As well as services not being funded and available, where there is provision, such as via foodbanks, formula milk is often not given out directly in attempts to promote breastfeeding. When provision is not made for those living with HIV this can lead to unnecessary stigmatising situations and barriers in accessing formula. There needs to be provision available, free, to all mothers living with HIV.

#### *4.8 Women with HIV face significant issues around poor mental health*

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<sup>10</sup> NAT, (2017) Policy Briefing: Access to formula milk for mothers living with HIV in the UK



- 4.8.1 There are significant levels of additional support needs reported by women living with HIV. From high levels of mental health support as well as financial pressures being experienced. The Sophia Forum and THT report in 2018 outlined that 43% of women had a mental health diagnosis since being diagnosed with HIV, and almost half would like support with their mental health needs<sup>11</sup>. Many find it hard accessing mental health support, and there can often be long waits for these services.
- 4.8.2 When asked in our survey if women had been given a mental health diagnosis since being diagnosed with HIV, 68% of this survey respondents have been diagnosed with depression, 65% with anxiety, 23% with post-traumatic stress disorder and 12% with complex post-traumatic stress disorder. One respondent felt they had a mental health issue but had not received a formal diagnosis.
- 4.8.3 Of those who have been diagnosed, 41% had not been able to access specialist support for their mental health, and when asked why they hadn't been able to access support, 38% had stated there was no psychology service within their HIV clinic and they were not comfortable accessing mainstream services. A further 21% didn't know how to access services elsewhere. 33% of respondents have been referred for support but remain on a waiting list. When addressing barriers to engaging in mental health support 29% felt they were not culturally sensitive to their needs.
- 4.8.4 A recent secondary cross-sectional analysis of the PRIME study data explored association between psychological symptoms and ethnicity<sup>12</sup>. 72% of the women were Black African. Findings revealed 40% of the women were socially isolated, 23% were experiencing psychological distress and 30% were currently on antidepressants. Black Caribbean and Black African women were found to be twice as likely to be experiencing social isolation than White British women. Psychological distress was five times more likely amongst Black Caribbean and three times more likely among Black African women compared to White British women. Despite this, Black African and Black Caribbean women were the least likely to have been diagnosed with depression. Continued reporting of ethnic disparities in mental health outcomes present examples of health inequalities in the UK.
- 4.8.5 Peer support was accessed by 54% of respondents specific to their mental health, and 15% of respondents stated they would prefer to access specialist support. Positive Voices found that HIV support services were particularly important to women, with 44% of women using services at some point since their diagnosis, and 88% saying this had been important for their health and wellbeing. Of those needing peer support, almost half had not received this, and many find accessing support services challenging. These services are often poorly funded and a postcode lottery in terms of access across the country. Those women living in rural areas have

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<sup>11</sup> Sophia Forum & Terrance Higgins Trust (2018) Women and HIV: Invisible No Longer

<sup>12</sup> Danielle Solomon et al, (2021) Ethnic inequalities in mental health and socioeconomic status among older women living with HIV: results from the PRIME Study

consistently reported poor access to peer support services, this has been driven by funding cuts, change of service provision, travel to these spaces are at times too far or low income is a barrier to women being able to travel to spaces of support. Peer support is an essential component in a holistic model, improving the lives and wellbeing of people living with HIV with models of delivery developed and integrated into healthcare settings over the years. 49% of respondents to this survey wanted to access peer support through their HIV clinics.

4.8.6 Disruption to services due to the COVID-19 pandemic has resulted in a shift to online peer support implemented across the UK. Positively UK has seen a doubling of numbers in people accessing their services, as many of their members needed more support during these unprecedented times.

#### 4.9 *Tackling gender-based violence*

4.9.1 HIV has long been recognised globally as a cause and consequence of violence and COVID-19 has seen an increase of violence toward women and girls globally. Domestic abuse killings have doubled in the UK amid COVID-19. Over half of women (58%) reported experiencing some form of violence or abuse due to their HIV status<sup>13</sup>. It is clear there needs to be additional support focused on women via healthcare and voluntary settings to deal with domestic violence and all healthcare services need to be screening for domestic violence as part of regular healthcare.

4.9.2 83% of the respondents in our survey had never been asked if they'd experienced domestic violence by their HIV consultant or nurse. 7% answered yes they had been asked, when asked how long ago this was, the time ranged from between one and eighteen years ago. 87% of survey respondents had not been asked by their HIV consultant or nurse whether they had experienced any form of domestic violence in the last year. From women who had experienced domestic abuse in the last year, 16% of those from the survey were unable to access any support.

#### **Our survey responses about how access to HIV services could be improved to meet their needs:**

- 55% of respondents wanted to access psychology support through their HIV clinic.
- 51% of respondents would like to see an HIV consultant or nurse based in their GP practice.
- 49% of respondents wanted to access peer support in their HIV clinic.
- 43% of respondents would like HIV appointments outside NHS settings.
- 31% of respondents said they felt cultural competency training would improve their access and experience in services.

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<sup>13</sup> Sophia Forum & Terrance Higgins Trust (2018) Women and HIV: Invisible No Longer

## 5. Targeted information and education on HIV for women

- 5.1 There is a consensus that the visibility of women living with HIV has been too low, and information targeted to them has not been sufficient. Our survey found women wanted more information about a range of topics, targeted at issues that affect them and are written directly for women.
- 5.2 The absence of women-focused messaging is also evident in health promotion efforts and campaigns. There has been extremely low uptake of the HIV prevention drug PrEP amongst women, with early information suggesting those participating in the trial and routinely commissioned PrEP are almost completely men. This is largely due to low awareness of PrEP, the lack of targeted messaging to women about who may be eligible and the benefits of PrEP. If this is not reversed, we are likely to see significantly fewer women being aware of and accessing PrEP and the benefits this can have in reducing future transmissions.
- 5.3 The Sophia Forum and NAT have been campaigning for equity in access to PrEP since 2016. The work of the IMPACT Trial 'Women and other group' led to a strategy being developed by a group of community activists from the underrepresented groups where low uptake had occurred in the trial. A series of videos were made, and future investment is needed to continue this work. A website [www.womenandprep.org.uk](http://www.womenandprep.org.uk) was also developed as a resource to support women. Current work is also taking place to explore other alternative settings where PrEP could be provided, such as community pharmacy and GPs to widen access.
- 5.4 When asked how women would like to receive information about HIV, 82% of respondents wanted it from their HIV consultant, 51% would like to access it via their GP, whilst 44% would like information via online peer support and 42% via face-to-face peer support. Other preferred methods were 40% via their sexual health clinic, 50% by social media platforms and 23% would like to access via schools and universities.

### **Our survey responses outlined the information women would like to see available:**

- 59% of respondents asked for information around ageing with HIV.
- 47% of respondents want information around the menopause and HIV and bone health.
- 43% of respondents wanted information on future treatment options including injectable options.
- 33% of respondents want to see diverse representation and messaging that speaks to the community they are from, alongside more culturally sensitive information to meet their needs.
- Further information is wanted on managing pain, diet and exercise, how to access peer support and charities that support my community living with HIV.
- 29% of respondents want to see more sex positive messages including U=U.

## **6. Research, evidence and data about women and HIV**

- 6.1 There is a need for better data collection and analysis around women living, and at risk of HIV. Current data is broad-brush, with data often presented only about heterosexual women or Black African women in reporting. The lack of granularity makes it more challenging to target prevention programmes and interventions. This lack of granular data available does not reflect the diversity of experience of women. A report by Sophia Forum and THT in 2018 outlined that there are common assumptions that women living with HIV are heterosexual, and there is a lack of interventions and support for lesbian and bisexual women<sup>14</sup>.
- 6.2 As well as data collection, women also must feature more prominently in clinical trials and research. The lack of representation of women in clinical research is an ongoing challenge and means that the effectiveness of new treatments and interventions are not suitably assessed for women, which can also delay access to the latest treatments and preventative interventions.
- 6.3 Recent findings from the UK CHIC analysis highlights HIV clinical outcomes amongst heterosexual people by ethnicity and ethnic disparities in CD4 count, time engaged in care and viral rebound<sup>15</sup>. The conclusions reported heterosexual people from Black, Asian and minority ethnic groups presented with lower CD4 cell counts, spent less time engaged in care and were more likely to experience viral rebound than white people. Further work to understand and address these differences is needed.

## **7. Impact of COVID-19 on women's health**

- 7.1 74% of respondents to our survey said the biggest impact of COVID-19 was increased isolation from friends and family. 57% said there had been an impact on their mental health. One respondent shared about increased anxiety as her and her family had COVID-19 which created difficulty to look after her family. Not being able to access children's services or activities for their baby, left the baby isolated and reintegrating back into 'normality' is creating anxiety for both the child and mother. 35% of respondents had not been able to connect with their community.
- 7.2 28% of respondents had experienced additional bereavements during COVID-19 along with increased family responsibility and care needs. 18% of respondents had experienced an increase in poverty during this pandemic. 11% of respondents said the risk of job loss and being furloughed are their greatest concern.

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<sup>14</sup> Sophia Forum & Terrance Higgins Trust (2018) Women and HIV: Invisible No Longer

<sup>15</sup> Dr Rageshri Dhariyawan et al, (2021) Differences in HIV clinical outcomes amongst heterosexuals in the United Kingdom by ethnicity <https://pubmed.ncbi.nlm.nih.gov/33973878/>

7.3 Others cited the impact of COVID-19 on cancelled or postponed appointments and limited ability to get to speak to their consultant.

7.4 Menopause also featured for women's experiences and challenges during COVID-19, with respondents citing increases in symptoms, the inability to get a review and shortages of Hormone replacement therapy during lockdown. Four respondents identified themselves from a minority community and felt reluctant to access health services. This reflects women's experiences one year ago during the first lockdown<sup>16</sup>.

## 8. Recommendations

- The meaningful involvement of women living with HIV is encouraged at all stages of research, policy, service design and evaluation, with the inclusion of people from racially minoritized backgrounds so a diversity of views are represented.
- Improved collaboration, coordination and communication between GPs, consultants, other healthcare professionals and HIV clinics, including accurate, accessible and comprehensive menopause information and support in HIV clinics.
- Long-term funding investment is needed to develop sustainable projects that can help address the racial and health inequalities women experience during the life course as they age.
- A proactive and holistic approach to HIV care should include adherence support from a specialist pharmacist, access to interpreters, mental health services, peer support and referral pathways to organisations that can support the wider socio-economic experiences of women living with HIV.
- Holistic HIV care requires awareness of the psychosocial needs of older women living with HIV, which may be more pronounced in racially minoritized communities, which require prompt referral for support including psychology and peer support and advice about benefits.
- The Secretary of State for Health and Social Care, Matt Hancock, announced a goal to end HIV transmissions in England by 2030 and set out a clear commitment to develop an Action Plan for achieving this<sup>17</sup>. The specific needs of women living with and at risk of HIV, as outlined in this submission must be central to this Action Plan.
- Local Authorities and the NHS nationally need to focus on providing a range of access to HIV testing outside of sexual health clinics, this includes introducing HIV testing more widely in cervical screening programme, GPs, and universal online access.
- Local authorities and sexual health service providers need to focus work to improve the offering and uptake of HIV tests to women in HIV sexual health services.
- Women living with HIV want and need targeted information that meets their needs, and about specific areas of support such as the menopause and childbirth.

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<sup>16</sup> Sophia Forum (2020) Experiences of women living with HIV during COVID-19 Pandemic <https://sophiaforum.net/index.php/experiences-of-women-living-with-hiv-during-covid-19-pandemic/>

<sup>17</sup> Department of Health and Social Care website: <https://www.gov.uk/government/news/health-secretary-announces-goal-to-end-hiv-transmissions-by-2030>

- We need to recognise the higher levels of mental health needs, financial insecurity and issues of gender-based violence that health care services and the government's strategy should factor in these key areas of focus.
- All healthcare settings, including HIV and sexual health services must ensure domestic violence screening is routinely asked at each appointment and appropriate trauma-informed support is provided to women experiencing gender-based violence and abuse.
- Women with HIV face significant stigma and this acts as a barrier in engaging with healthcare, and other community services. There needs to be nationally funded anti-stigma campaigns and long-term investment in community-based projects to raise awareness of HIV and women and HIV specifically.
- Women value and need specific peer support and support services but find these challenging to access. Local Integrated Care Systems (ICSs) and commissioners need to provide long term funding to these services, especially services focused towards the needs of women.
- Trans-specific services need to be funded and accessible across the country.
- Additional funding should be made available to promote PrEP to women specifically, and PrEP should be made available in wider healthcare settings such as via GPs, pharmacy and termination clinics/the cervical screening programme to widen access.
- PHE/UKHSA should work to provide more granular data on women living with and at risk of HIV to guide support and prevention initiatives.
- All mothers living with HIV in the UK should have access to free infant formula milk and feeding equipment as a key prevention right. NHS England should consider funding free formula milk for mothers living with HIV nationally through specialised commissioning as part of the prevention of vertical transmission. Whilst commissioning at a national level is being considered, local authorities and CCGs (or equivalent) should fill the gap in provision in the meantime.
- Those responsible for implementing the Baby Friendly Initiative in the UK should give due consideration to UK clinical guidelines that mothers living with HIV exclusively formula feed their babies to prevent transmission. Explicit exemptions should be made so as not to restrict the commissioning and provision of free formula milk to mothers living with HIV.