



Public Health
England

Protecting and improving the nation's health

Women and HIV in the United Kingdom

Data to end of December 2017



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Contributors

We are very grateful to Laura Scott (Terrence Higgins Trust) and Jacqueline Stevenson (Sophia Forum) for their unwavering commitment to making this report a reality, providing invaluable input and guidance from inception to publication. We also acknowledge contributions at various stages of the project from Mercy Shibemba (Co-Chair, Sophia Forum), Jo Josh (Sophia Forum), Sophia Strachan (Co-Chair, Sophia Forum), Jane Shepherd (Peer Researcher, Invisible No Longer Project), and Florence Obadeyi (Peer Researcher, Invisible No Longer Project).

Foreword

There is a lot to do to ensure that women are a priority when it comes to HIV.

The story of this much anticipated report on women and HIV in the United Kingdom began in early 2017, when Sophia Forum partnered with Terrence Higgins Trust to carry out the first ever UK-based national HIV study focusing exclusively on the experiences and opinions of women living with or vulnerable to acquiring HIV. The resulting report, *Invisible No Longer*, was the first of its kind, co-produced with women living with HIV.

A key finding from *Invisible No Longer* was the striking lack of clear data on HIV prevention, treatment and support for women. This information, and the will to use it, is essential if we are to deliver HIV services that are shaped to meet women's needs.

“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.”

Florence Obadeyi and Jane Shepherd, Peer Researchers, *Invisible No Longer*

We are grateful to Public Health England for addressing two key recommendations in the *Invisible No Longer* report. Firstly, by publishing women-specific data in the annual HIV data tables, and now for producing this thorough and detailed epidemiological report.

However, there is still work to be done and we are calling on all those working in the HIV sector to consider the language used around women. For example, the term 'mother-to-child-transmission' perpetuates stigma towards mothers with HIV while the term 'vertical transmission' is accurate and less emotionally loaded. In addition, labelling women who acquired HIV via heterosexual sex as 'heterosexual women' oversimplifies female sexuality and alienates women who do not identify as heterosexual.

With this report we now have a wealth of information on how the HIV epidemic impacts women in the UK. Key findings include that women receive fewer HIV tests, and that women with HIV are still very likely to be diagnosed late, and experience a worrying level of poverty, stigma and unmet health and social needs. These findings must now be taken forward and used in work with women living with HIV to design evidence-based interventions and services to prevent inequalities in their care.

We must also act on other issues this report highlights, including the fact that young women are not currently meeting the UNAIDS 2020 targets in terms of either diagnosis

or viral suppression. It is unacceptable that anyone is left behind as we strive to meet the 2030 target of zero HIV transmissions or preventable deaths.

Every step – big or small – that is taken to ensure women are invisible no longer when it comes to HIV is important, It's vital to remember that this is very much the beginning and not the end.

Dr Jacqui Stevenson
*Sophia Forum Trustee and Invisible
No Longer project lead*

Laura Scott
Terrence Higgins Trust

Jo Josh
Sophia Forum

Summary

In the UK 1 in 3 people living with HIV are women, and women make up one quarter of all new HIV diagnoses. Today a third of women living with diagnosed infection are aged 50 years and over and some have complex health needs. However, services for people living with HIV have not necessarily been designed to meet the needs of women.

Women's voices are often missing from the discourse on living with HIV and women continue to be underrepresented in HIV research. In April 2018, the *Women and HIV: Invisible No Longer* reportⁱ produced by the Terrence Higgins Trust and the Sophia Forum concluded that equal attention to women's voices in policy, services and research was long overdue.

This report aims to go some way in addressing knowledge gaps and needs of women living with HIV in the UK. It provides an overview of HIV epidemic with respect to women, as well as providing a summary of HIV testing progress and the quality of care received by women in the UK. Data presented are for 2017ⁱⁱ, to ensure data sources were aligned with Positive Voices, a representative population-based survey of people living with HIV in the UK carried out in 2017. Brief data for 2018 is included in Appendix 1 and 2.

The good news is that the quality of HIV care and clinical outcomes among women are excellent. In the UK, the UNAIDS 90:90:90 targets have been met among women; overall 88% of all women living with HIV have achieved viral suppression and cannot pass on the virus. However, viral suppression is much lower among young women aged 15-24 compared to older women. HIV transmission is continuing in the UK and nearly half of women are diagnosed at a late stage of HIV infection. We also report findings from The Positive Voices survey showing that, while women report high satisfaction with HIV services and have a good quality of life comparable to the general population, more needs to be done to address financial hardship, stigma, loneliness and difficulties disclosing their HIV status. Furthermore, many women living with HIV report a lack of support in tackling these issues.

Health and social care services need to adapt and respond to the diverse and complex health issues of women with HIV, including sexual and reproductive health services, (contraceptive, fertility and menopause services) as well as mental health and social needs. It is only through working with and meeting the needs of women with HIV that we can succeed in reducing HIV transmission within the UK and ensure women living with HIV enjoy long, healthy lives.

Dr Alison Brown
Principal Scientist

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Principal Scientist

Dr Valerie Delpech
Head of HIV Surveillance

Definitions

Diagnosed HIV prevalence band per 1,000 residents aged 15 to 59 years:

- low: HIV prevalence less than 2
- high: HIV prevalence between 2 and 5
- extremely high: HIV prevalence of 5 or more

Eligible sexual health service (SHS) attendee: any patient attending a SHS at least once during a calendar year, excluding those patients known to be HIV positive or for whom an HIV test was not appropriate, or for whom the attendance was reported as being related for reproductive healthcare only.

Gender and gender identity: women are defined as adults aged 15 years and over who self-identify as female. When gender breakdowns are presented, transmen and transwomen were included in the gender groups with which they self-identified. Due to small numbers, those who identify as non-binary/in another way (representing 0.5% of Positive Voices respondents) are excluded from binary gender breakdowns.

Heterosexual women: women who probably acquired their HIV infection through heterosexual sex and/or people reporting their sexual orientation as heterosexual.

HIV test coverage: the percentage of eligible sexual health service (SHS) attendees who accepted a test. It represents the number of attendees tested for HIV and not the number of tests reported.

Late HIV diagnosis: an HIV diagnosis made with a CD4 cell count <350 cells/mm³ within 91 days of diagnosis.

Number needed to test: the number of people needed to test to diagnose one HIV infection.

Sexual health services (SHS) includes:

- **non-specialist sexual health services:** level 2 sexual health services, including sexual and reproductive health (SRH) services, young people's services, enhanced GPs, online sexual health services, and other sexual health services
- **specialist sexual health services:** level 3 sexual health services, including genito-urinary medicine (GUM) clinics and integrated GUM/sexual and reproductive health (SRH) services

Transwomen: the HARS and Positive Voices datasets have a question on whether gender identity is the same as gender at birth. Taken with the gender identity question, this allows classification of trans individuals.

Undetectable = Untransmittable (U=U): medicines to treat HIV can eliminate the risk of sexual and mother-to-child HIV transmission. People with HIV who maintain an undetectable viral load for at least 6 months do not transmit HIV.

Unprotected sex: HIV can be transmitted sexually if no protection is used and the sexual partner with HIV has a detectable viral load. Protective methods include consistent condom use, effective use of pre-exposure prophylaxis (PrEP) or use of antiretroviral treatment (ART) to achieve an undetectable viral load.

Glossary

AIDS: acquired immune deficiency syndrome

ART: antiretroviral therapy

BMI: body mass index

DLA: Disability Living Allowance

EQ-5D-5L: a standardized instrument for measuring generic health status and quality of life introduced by the EuroQol Group (EQ). It has 5 dimensions (5D) - mobility, self-care, usual activities, pain/discomfort, and anxiety/depression and 5 response levels - no problems, slight problems, moderate problems, severe problems and extreme problems.

ESA: Employment and Support Allowance

GP: general practitioner

GUMCAD: GUMCAD STI surveillance system

HARS: HIV and AIDS Reporting System

HIV: human immunodeficiency viruses

HPV: human papillomavirus

MPES: multi-parameter evidence synthesis

NHS: National Health Service

NNTT: number needed to test

NSU: non-specific urethritis

PrEP: pre-exposure prophylaxis

PHEC: Public Health England centre

PIP: Personal Independence Payment

PTSD: post-traumatic stress disorder

PWID: people who inject drugs

SHS: sexual health services

STI: sexual transmitted infection

U=U: undetectable=untransmittable

UNAIDS: The Joint United Nations Programme on HIV and AIDS

Key messages

HIV in women in the UK

There were an estimated 30,700 women living with HIV in the UK in 2017; 93% of whom were diagnosed, 97% of those diagnosed were treated and 96% of those treated were virally suppressed so could not pass on the virus to others (this equates to 87% of all women living with HIV). These excellent clinical outcomes exceed the UNAIDS 90:90:90 targets.

In 2017, women made up one-third (31%, 28,669/93,385) of people living with diagnosed HIV infection and a quarter (1,106/4,334) of new HIV diagnoses.

The number of new HIV diagnoses in women has more than halved in the past decade. The decline is mainly due to fewer diagnoses among women that were born in a high prevalence country.

HIV transmission is continuing in the UK. In 2017, 57% of all women newly diagnosed probably acquired HIV in the UK. Among women born abroad and diagnosed with HIV in 2017, 42% probably acquired HIV after arrival in the UK.

While the number of women diagnosed late with HIV has declined (740 in 2013 to 560 in 2017), the proportion diagnosed late remains high at 50% in 2017. Women diagnosed late have been living with an undiagnosed infection for around 3 to 5 years.

Mother-to-child transmission of HIV has almost been eliminated, thanks to the very successful antenatal HIV screening programme for pregnant women.

In 2017, one-third of the 28,669 women living with diagnosed HIV were aged 50 years or older, two-thirds were black-African and 21% were white.

In 2017, 114/28,669 women living with diagnosed HIV infection were assigned a different gender at birth.

HIV testing among women

In 2017, there were around 631,000 women were tested at antenatal services and 575,000 through sexual health services.

The HIV testing coverage rate among women attending sexual health services (57%) was lower compared to men (79%).

The number needed to test to diagnose one HIV positive woman is 137 among black African, 3,002 among white and 1,011 among black Caribbean women.

Women who are eligible for an HIV test are among those most likely to be offered or accept a test in a sexual health service; 71% of 333,110 missed HIV test opportunities occurred among women in 2017.

Experiences of women living with diagnosed HIV

The level of education among women living with diagnosed HIV infection is generally high. Two-fifths have a bachelors' degree or higher.

Whilst 58% women living with diagnosed HIV are in full or part time employment, 69% said they did not always have enough money to meet basic needs (food, rent, electricity). This compares with 39% of gay and bisexual men and 62% of heterosexual men living with diagnosed HIV.

On average, women rated HIV services very highly (9.3 out of 10); 97% of women felt supported to self-manage their HIV and 96% felt involved in decisions about their care.

Women living with diagnosed HIV report a high quality of life that was in line with that of the general population. However, women are more likely to have ever been diagnosed with depression (28%) and anxiety (19%) compared to heterosexual men (17% and 13% respectively) living with diagnosed HIV.

Women living with diagnosed HIV were more likely to be significantly overweight (41%) compared to heterosexual men (24%) or gay and bisexual men (13%) with diagnosed HIV infection.

Women living with diagnosed HIV reported a high level of unmet needs relating to social and welfare services such as housing support, claiming benefits, employment and loneliness and isolation. There was also significant unmet need for peer support, psychological support, stress management weight management and childcare support.

N. B. Addenda following the publication of HIV surveillance data tables for new HIV diagnoses and women seen for HIV care in August 2018:

www.gov.uk/government/statistics/hiv-annual-data-tables. Data in this report are for 2017 to align the latest available data sources. The 2018 data continue to follow similar trends highlighted in this report, and are summarised in Appendix 1 and 2.

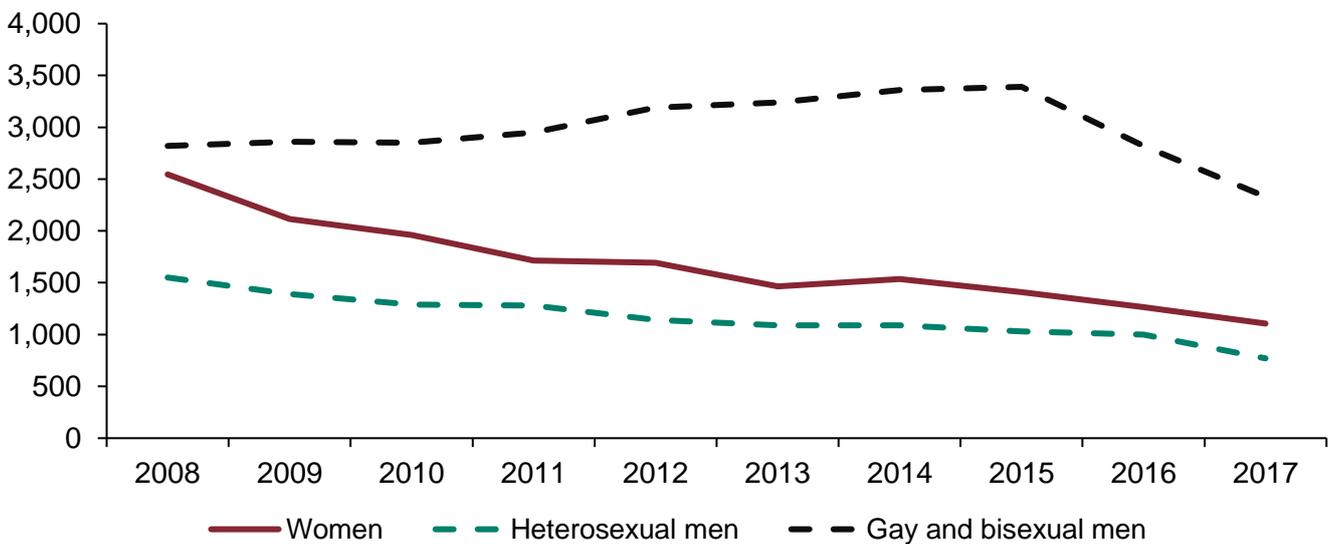
1. New HIV diagnoses in women

1.1 Recent trends in HIV diagnoses

There were 1,106 women (aged 15 years or older) newly diagnosed with HIV in the UK in 2017, around a quarter (26%) of the 4,334 new adult HIV diagnoses that year. This represented a 13% decline from the 1,265 diagnoses in 2016, continuing the overall downwards trend in new diagnoses among women over the past decade (Figure 1). In comparison, the number of new HIV diagnoses among heterosexual men decreased by 23% from 1,000 diagnoses in 2016 to 770 in 2017. Despite the decline in both populations, the number of HIV diagnoses among women has been around 15-25% higher than the number among heterosexual men over the past decade.

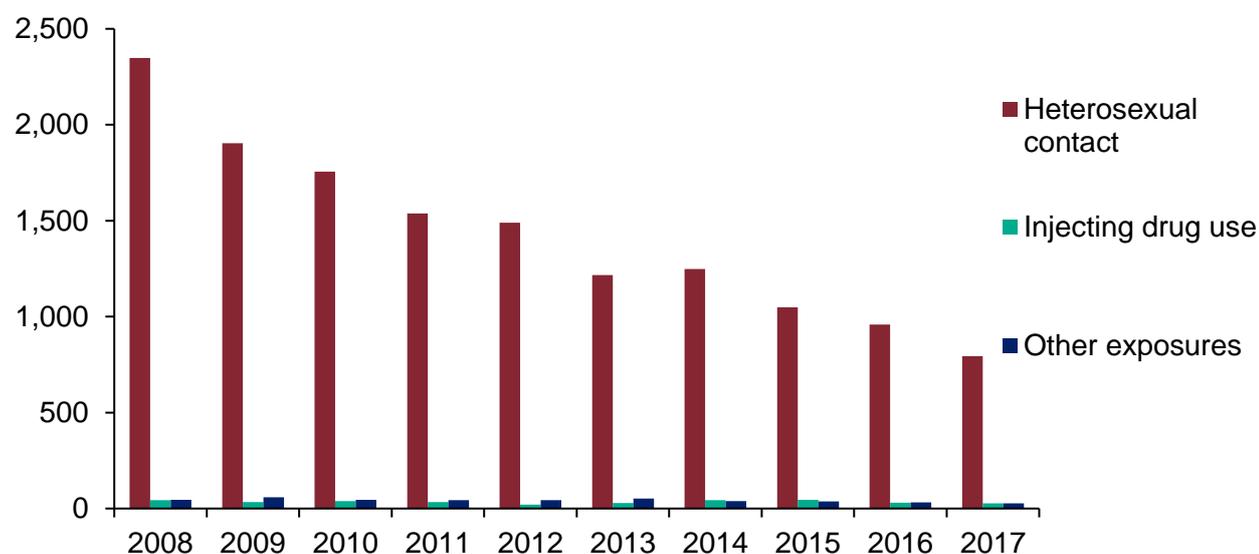
Since information on gender identity became available in 2015, 33 women with newly diagnosed HIV were recorded as trans, of whom 8 were diagnosed in 2017.

Figure 1: New HIV diagnoses among women, heterosexual men and gay and bisexual men: UK, 2008-2017



In 2017, 94% (794/848) of newly diagnosed women (with exposure data reported) probably acquired HIV through heterosexual contact, and 3% of diagnoses related to injecting drug use (27/848). These proportions have remained relatively stable since 2008, though the absolute numbers of diagnoses have decreased for both: by 66% for heterosexual contact (from 2,328 to 794) and by 37% (from 43 to 27) for women who inject drugs (Figure 2). Other reported exposures among newly diagnosed women in 2017 included mother-to-child transmission (13/848) and blood/blood products (12/848).

Figure 2: Number of women newly diagnosed, by exposure group: UK, 2008-2017



In 2017, the median age of women at HIV diagnosis was 39 years (IQR 30-48) with 69% (762/1,106) of newly diagnosed aged between 25 and 49 years. However, over the past decade, the number and proportion of women diagnosed at 50 years or over increased from 9% (229/2,545) in 2008 to 22% (241/1,106) in 2017 (Figure 3a).

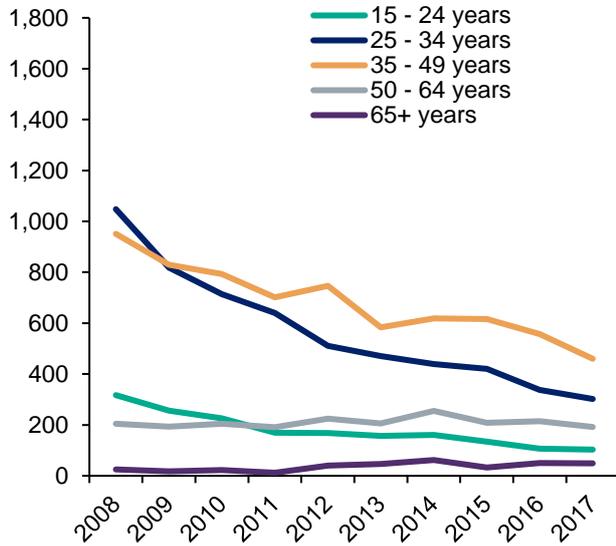
In 2017, 32% (353/1,103) of women in the UK who were newly diagnosed with HIV lived in London, although the majority lived in England outside London (61%, 670/1,103) (Figure 3b).

In 2017, 46% of new HIV diagnoses among women were black African, 23% were among white women and 7% were among black Caribbean/black other women. The number of black African women diagnosed with HIV in the UK has fallen (where information was reported) by 75% from 1,703 in 2008 to 429 in 2017 (Figure 3c). While numbers are much lower, a 70% decline was also observed among black Caribbean women from 219 in 2008 to 66 in 2017. A decline in new HIV diagnoses among white women was also observed although much lower, at 27%, from 404 in 2008 to 293 in 2017.

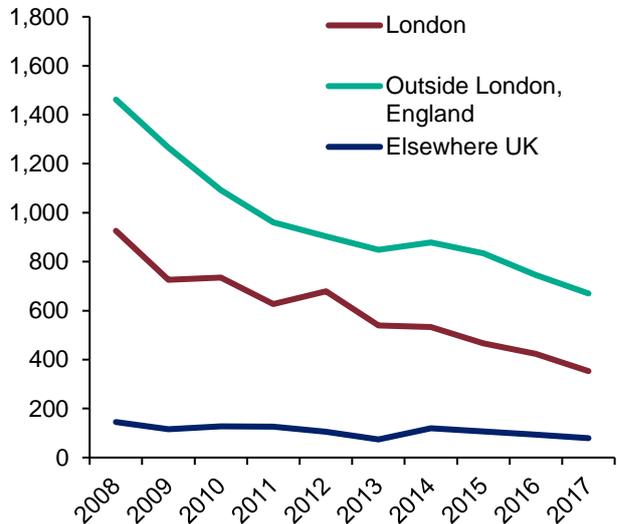
In 2017, 72% (680/941) of newly diagnosed women (with information reported) were born abroad and just over half (52%; 494/941) were born in a high prevalence country. The decline in new HIV diagnoses was steepest among women born in high prevalence countries (71%, from 1,706 to 494) when compared to women born in lower prevalence countries (27%, from 256 to 186) and women born in the UK (33%, from 389 to 261) (Figure 3d).

Figure 3: HIV diagnoses among women, by population characteristics: UK, 2008-2017

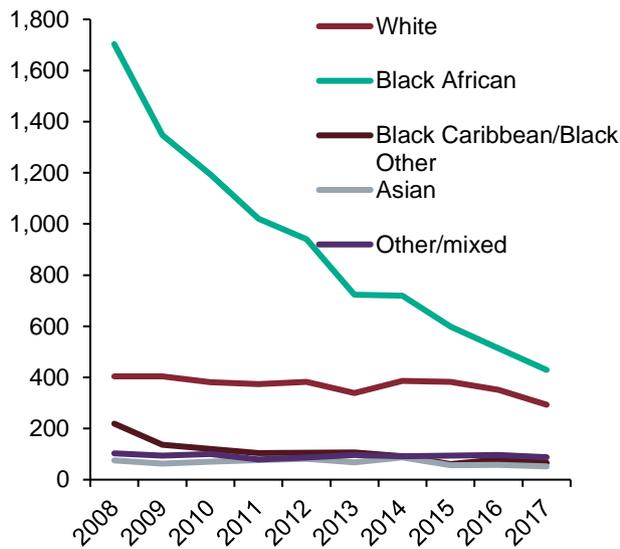
a) age group



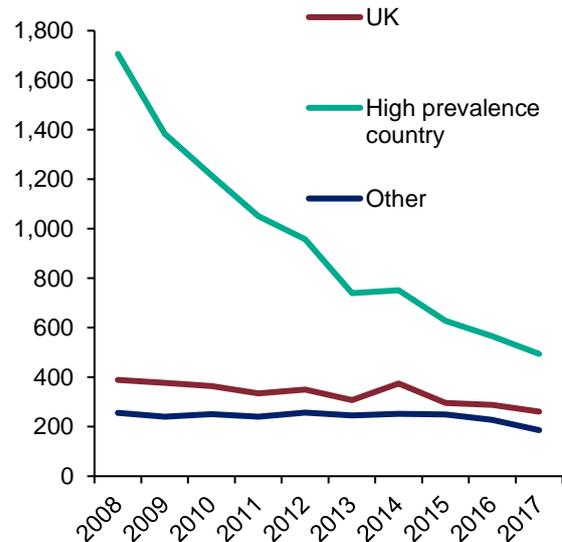
b) residence



c) ethnicity

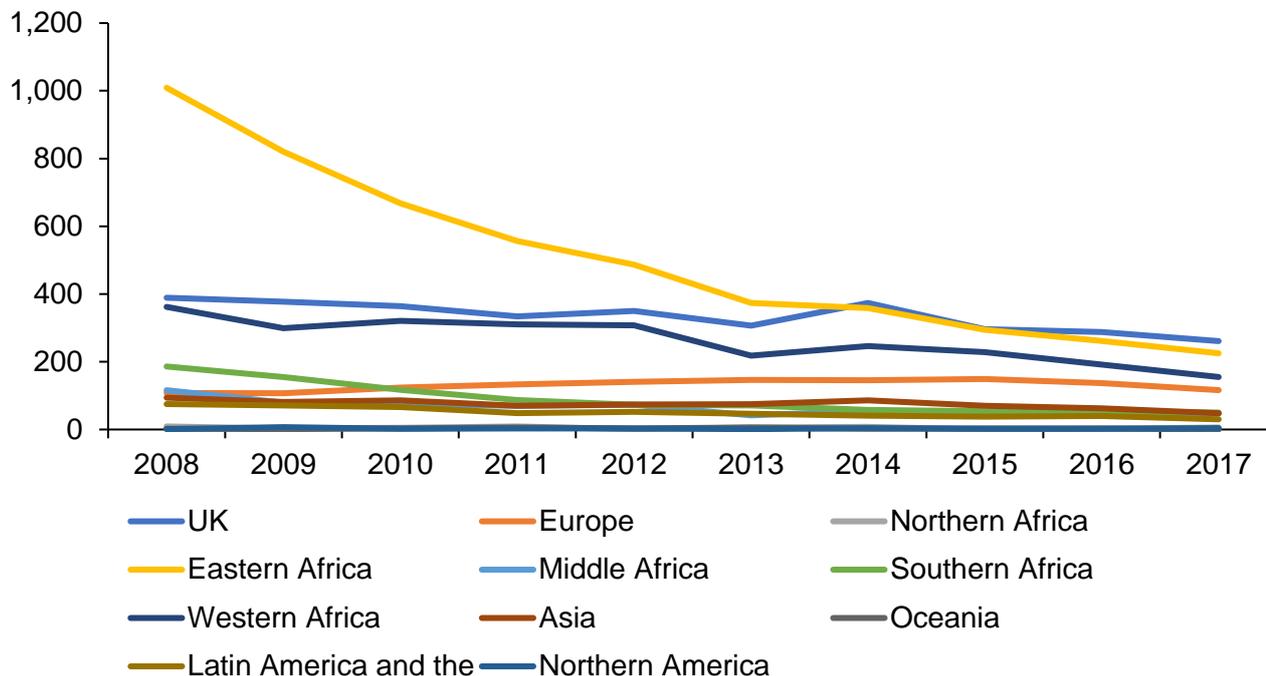


d) country of birth



Most women born abroad originated from Eastern Africa in 2017 (33%, 225/680) (Figure 4). Between 2008 and 2017, Zimbabwe in Eastern Africa was the most common country of birth among those diagnosed with HIV who were born abroad, followed by Nigeria in Western Africa.

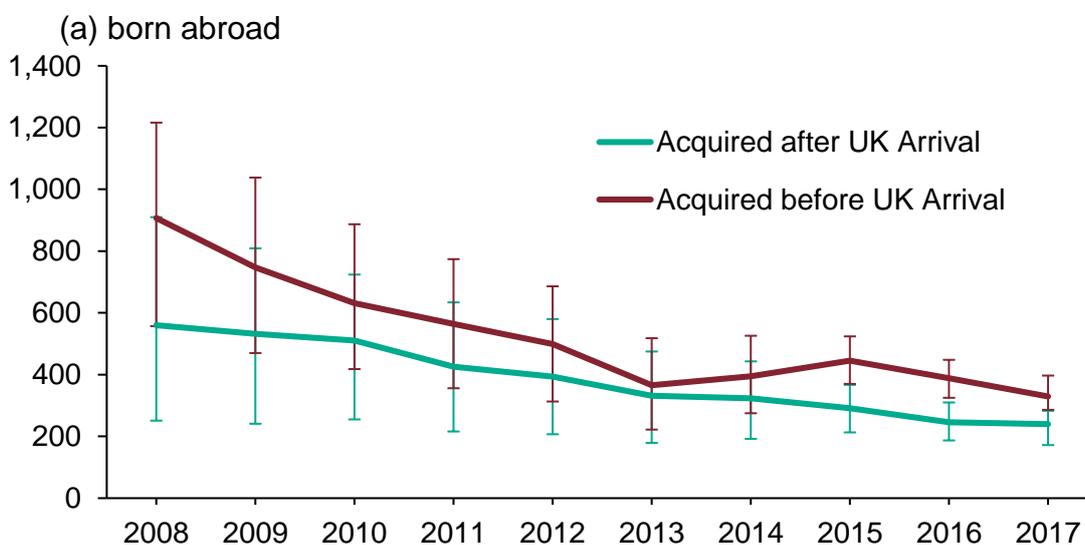
Figure 4: HIV diagnoses among women, by region of birth: UK, 2008-2017



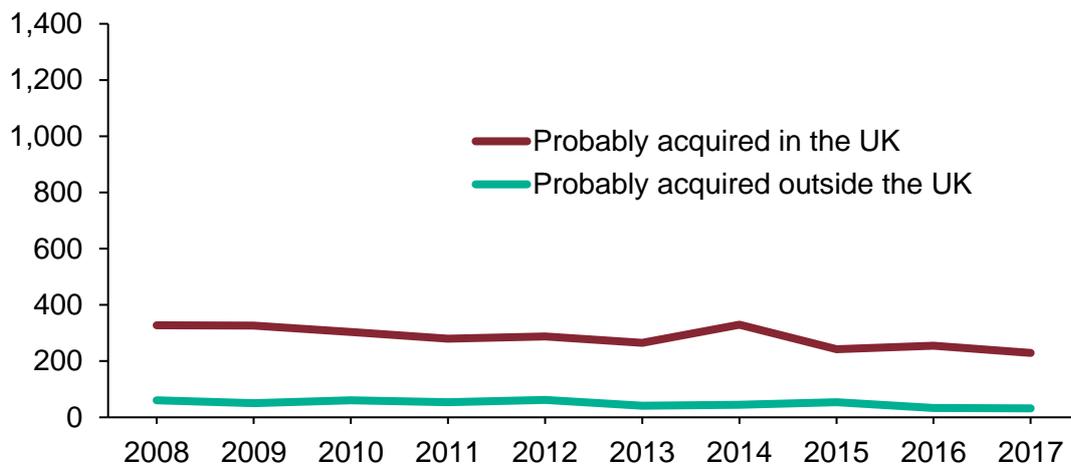
1.2 Probable country of infection

Among women born abroad and diagnosed with HIV in the UK in 2017, an estimated 42% probably acquired HIV after arrival into the UK. Among women born and diagnosed in the UK, an estimated 88% probably acquired HIV within or after arrival to the UK (Figure 5).

Figure 5: Estimated number of new diagnoses among women acquired in the UK and abroad, by country of birth: UK, 2008-2017



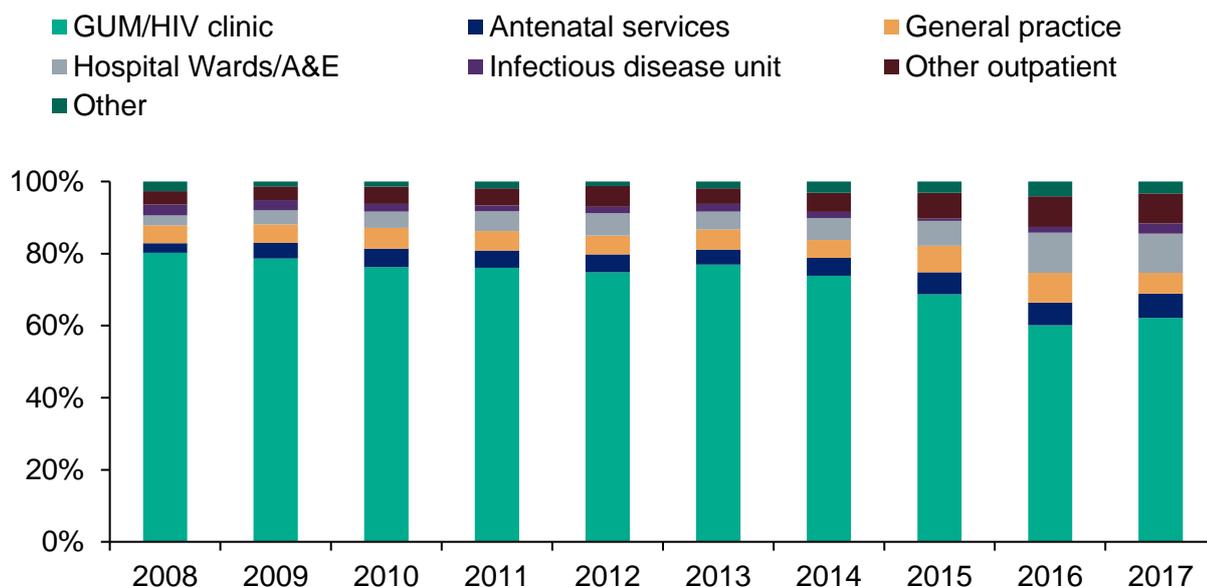
(b) UK born



1.3 Setting of HIV diagnosis

In 2017, where information was available, 62% (615/990) of HIV diagnoses among women were carried out in sexual health services (SHS), and 7% (67) in antenatal services. Over the past decade, the proportion of diagnoses occurring outside of SHS and antenatal settings has increased from 17% (415/2,418) in 2008 to 31% (308/990) in 2017, while numbers of diagnoses have declined (Figure 6).

Figure 6: Setting of first positive test among women newly diagnosed with HIV: UK, 2008-2017



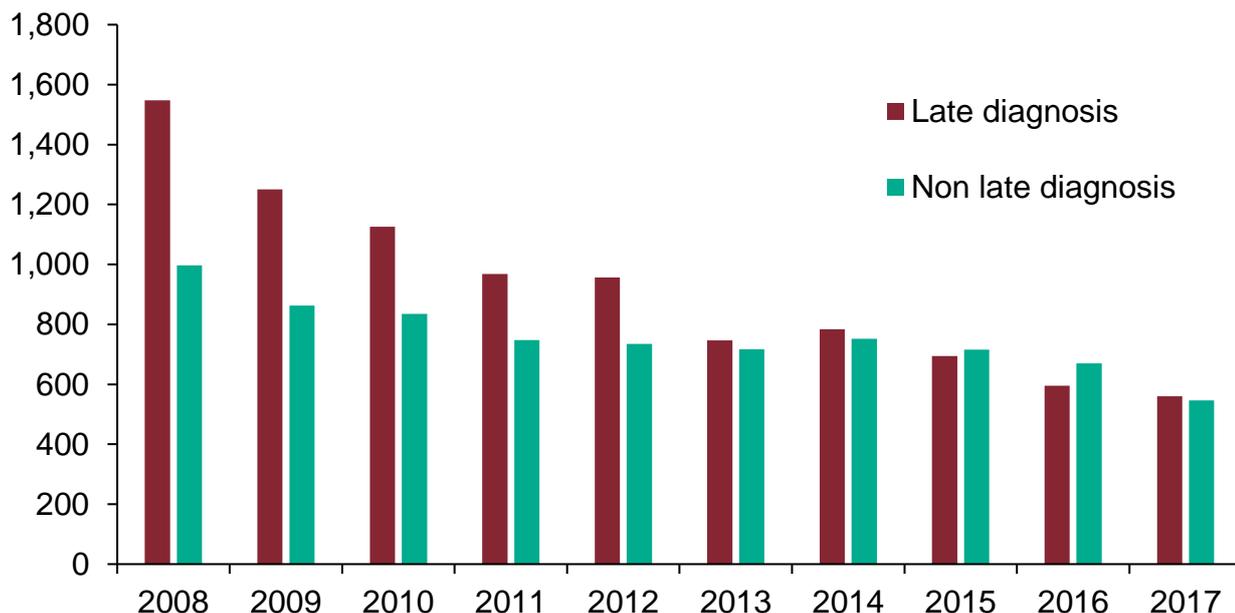
Women were more likely to have been diagnosed outside of SHS in 2017 if they were aged 50 years and above (42%, 86/203) and/or black African (42%, 168/401).

1.4 Late HIV diagnoses

A late HIV diagnosis is defined when an individual has a CD4 cell count of less than 350 cells/mm³ within 91 days of diagnosis. Women diagnosed late have a tenfold risk of death within a year compared to those diagnosed promptly³. In addition, people diagnosed late are likely to have been living with an undiagnosed infection for around 3 to 5 years⁴.

In 2017, 51% (312/624) of HIV diagnoses among heterosexual women with CD4 information (79% complete) were made at a late stage of HIV infection. The number and proportion of late diagnoses declined from 62% (1,196/1,944) in 2008 to 50% (560/1,040) in 2017, which is also thought to be due to changing patterns of migration (Figure 7). In 2017, the proportion of late diagnoses among heterosexual women was higher than among gay and bisexual men (33%) but lower than among heterosexual men (59%).

Figure 7: Adjusted number of new diagnoses among women, by late diagnosis classification: UK, 2008-2017



In 2017, 53% of black African women were diagnosed late, compared to 63% among black Caribbean women and 47% among white women. While the proportion diagnosed late fell from 65% in black African women in 2008, the proportion of black Caribbean women diagnosed late rose from 51% in the same year and among white women, the proportion remained at around 46%.

The proportion of HIV diagnoses made at a late stage of infection increased with age at diagnosis. In 2017, 33% of women aged 15 to 24 years were diagnosed with HIV late compared to 56% among those aged over 50 years.

1.5 HIV incidence

It is not currently possible to estimate HIV incidence among women since methods need to be adapted to account for the effect of migration. While it is likely that the decline in new HIV diagnoses in women is driven by changing patterns of migration, the high proportion of women, regardless of country of birth, who probably acquire HIV after arriving into this country indicates transmission is continuing in the UK.

Furthermore, the high proportion of women who were diagnosed with HIV at a late stage of infection also suggests that over half of the women newly diagnosed each year have been living with an undiagnosed infection for around 3 to 5 years. As with any group of people living with an undiagnosed infection, being unaware of their HIV would have increased the risk of passing on the infection if they were unprotected sex. In addition to preventing new infections, the most effective way to reduce undiagnosed HIV infection is by getting tested for HIV.

2. HIV testing in women

HIV test coverage is the percentage of eligible women who accept an HIV test each year. It represents the number of women tested for HIV and not the number of tests reported. The number needed to test (NNTT) reflects the number of people needed to test to diagnose one HIV infection and should be considered, together with the number of diagnoses made in each population group, to make meaningful comparisons.

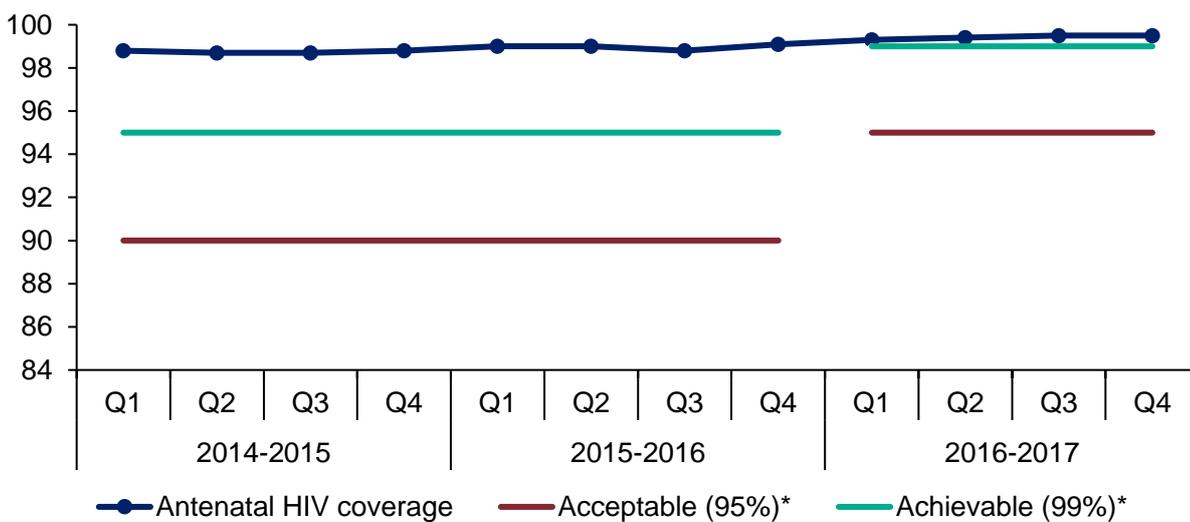
HIV testing among women occurs in 2 main settings: antenatal screening during pregnancy and in sexual health services (SHS). In 2017, around 631,000 HIV tests were carried out in antenatal services and 575,000 in SHS.

2.1 HIV testing in antenatal settings

HIV testing of pregnant women is conducted through the NHS Infectious Diseases in Pregnancy Screening (IDPS) programme. HIV screening of all pregnant women has been performed since 1999.

In the financial year of 2016/2017, HIV testing coverage exceeded 99% among 630,681 pregnant women who attended antenatal services. Positivity remains low with 0.013% of women newly diagnosed with HIV during pregnancy (Figure 8).

Figure 8: Trends in antenatal screening, England: 2014-2017⁵

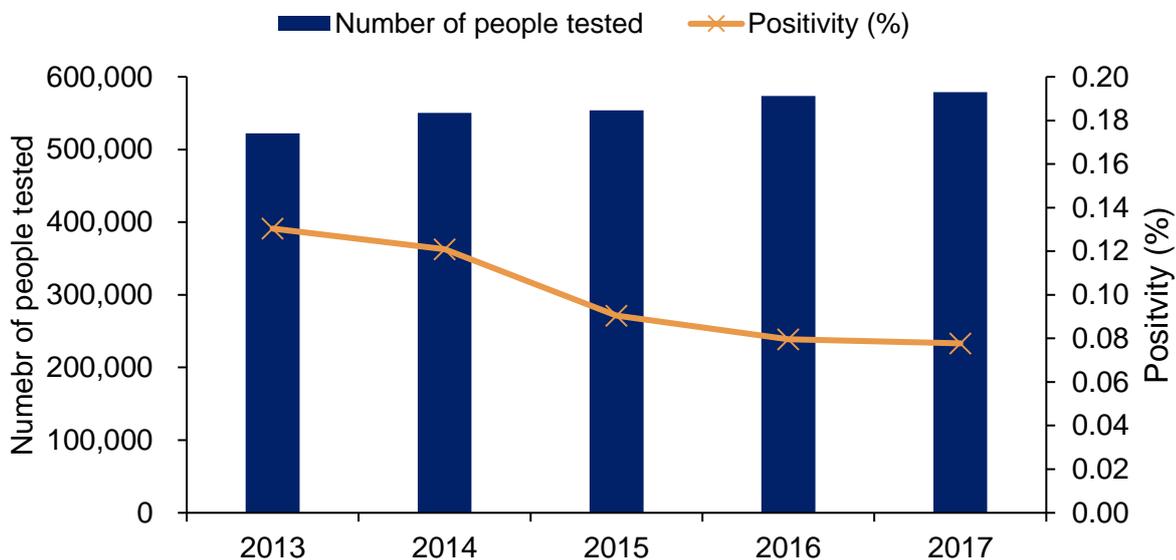


*Threshold changed between 2016 and 2017

2.2 HIV testing in sexual health services (SHS) in England

Both the number of women attending SHS and the number of HIV tests carried out has continued to rise over the past 5 years. The number of women attending SHS increased by 11% from 983,373 in 2013 to 1,091,709 in 2017. Coupled with the increase in attendees, the number of women who were tested increased by 10%, from 522,265 in 2013 to 578,881 in 2017. As the number of women getting tested increased, the HIV test positivity fell from 0.13% (681/522,265) in 2013 to 0.08% (457/573,536) in 2016 and then remained stable in 2017 (450/578,881) (Figure 9).

Figure 9: Trends in HIV testing and positivity for eligible¹ women attending SHS, England, 2013 to 2017



¹ eligible SHS attendee: any patient attending a SHS at least once during a calendar year; excluding those patients known to be HIV positive or for whom an HIV test was not appropriate, or for whom the attendance was reported as being related for reproductive health care only.

Most women who tested for HIV in a SHS (89%, 517,552/578,881) attended a specialist SHS such as a genitourinary medicine (GUM) clinic or integrated GUM/sexual and reproductive health (SRH) services^a. In these settings, the HIV test coverage among women was (57%, 517,552/911,682). This suggests that 43.52% (265,601/512,828) of women, who were eligible for testing, were not tested in 2017. In comparison, the HIV test coverage was higher in men at 79% (487,648/618,322).

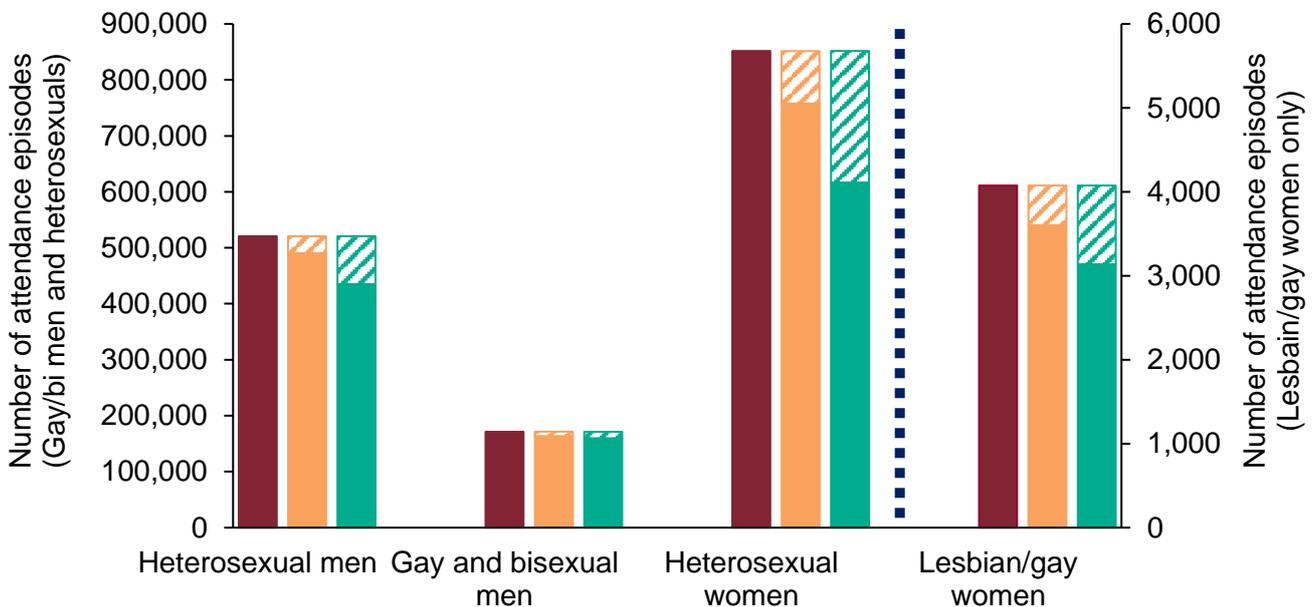
Non-specialist SHS include SRH services, young people’s services, enhanced GPs, online SHS, and other SHS². Among the 16% (180,027/1,091,709) of women who attended a non-specialist service in 2017, the test coverage was

^a Further information about the level of services provided can be found in the BASHH/MEDFASH Standards for the management of STIs

only 34% (61,329/180,027). For men, HIV test coverage was nearly double that of women at 61% (39,576/64,688).

The British Association for Sexual Health and HIV (BASHH) standards recommend that 97% of attendances with STI-need should be offered an HIV test and 85% of attendances should have an HIV test recorded. A recent analysis assessed the extent of missed opportunities for HIV testing⁶. In 2017, there were 372,559 missed opportunities to offer an HIV test and 70% of these were among women (Figure 10).

Figure 10: The percentage of STI-need attendance episodes, with an offer of an HIV test, and tested for HIV, 2017



2.3 Sexual orientation of women testing for HIV at sexual health services

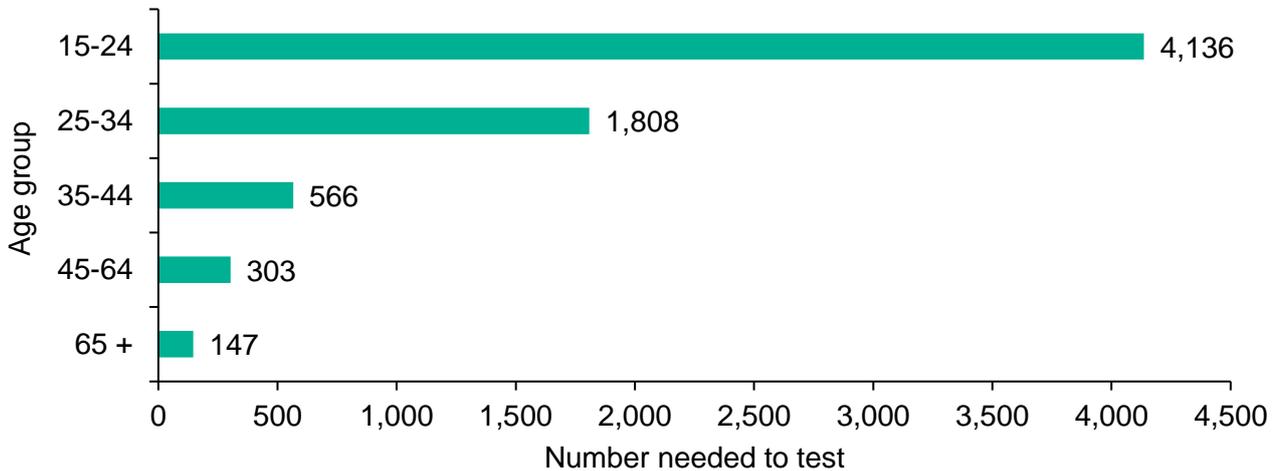
In 2017, over 95% (551,773/578,881) of women tested for HIV identified as heterosexual or bisexual and 0.5% (2,982/578,881) of women tested for HIV identified as lesbian or gay women. HIV test coverage was marginally higher in gay women at 65% (2,982/4,573) compared to heterosexual women at 55% (236,958/996,358). While, the overall HIV test positivity was the same for both groups (0.1%) in 2017, the absolute number of new diagnoses made at SHS in gay women remains very low, with 25 new diagnoses between 2013 and 2017. In 2017, 425 new diagnoses were made in heterosexual women, equating to 1,298 heterosexual women being tested to detect one HIV diagnosis.

2.4 Age of women testing for HIV at sexual health services

In 2017, the age group of women with the highest number of tests and HIV test coverage was 24-35 years at 37% (213,350/578,881) and 58% (213,350/369,766) respectively. HIV test coverage was lowest in women aged 15-24 years at 43% (53,732/181,428).

HIV test positivity among women increased with age in 2017. For example, SHS tested 303 heterosexual women aged 45-64 years to detect one HIV diagnosis compared with 4,136 women aged 15-24 years old to detect one HIV diagnosis (Figure 11).

Figure 11: Number of women needed to test to diagnose one positive by age group at all SHS, England, 2017

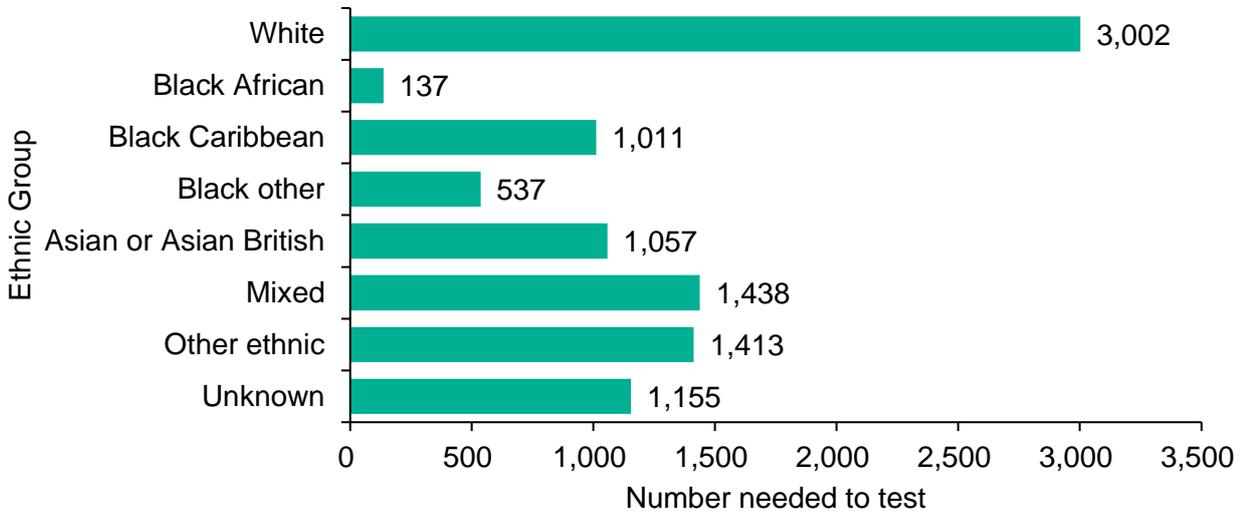


2.5 Ethnicity of women testing for HIV at sexual health services

In 2017, nearly three-quarters of women tested for HIV were white (72%; 417,237/578,881). HIV coverage varied by ethnic group and was highest in black Caribbean women (66%; 22,241/33,542) and lowest in Asian or Asian British women (22,200/48,560).

The NNTT for white women (3,002) was much higher than for any of the other gender, ethnicity, or country of birth groups. However, the large number of women being tested in this group meant that this testing activity detected 29% (131/450) of diagnoses made among women attending SHS (Figure 12). In contrast, 137 black African women needed to be tested to detect one positive.

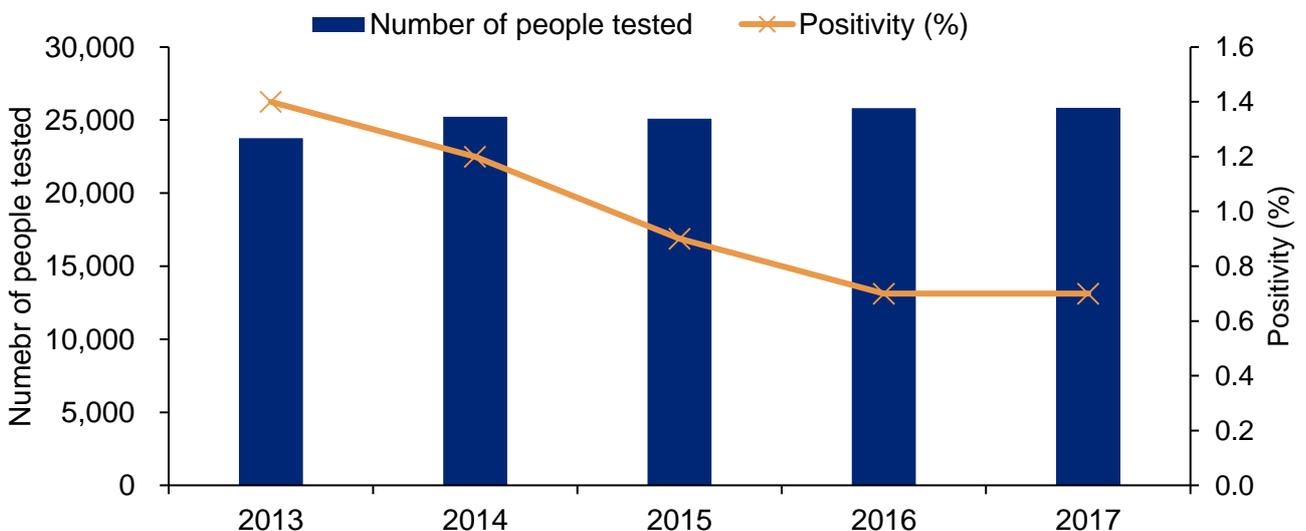
Figure 12: Number of women tested to diagnose one positive by ethnicity at all SHS, England, 2017



In 2017, 62% of 41,842 black African women attending SHS were tested for HIV. The number of black African women tested in SHS remained stable during the previous 5 years while the overall HIV test coverage in black African women increased slightly from 59% (23,772/40,458) to 62% (25,846/41,842) over the same period. The HIV test positivity in women fell from 1.4% (330 /23,772) in 2013, to 0.7% (188/25,846) in 2017 (Figure 13).

In 2017, 15,996 black African women attended an SHS but were not tested for HIV. These women comprised of 55% (8,815) who were not offered an HIV test and 45% (7,181) who were offered but declined a test.

Figure 13: Trends in HIV testing and positivity for eligible¹ SHS black African women at all SHS, England, 2013–2017

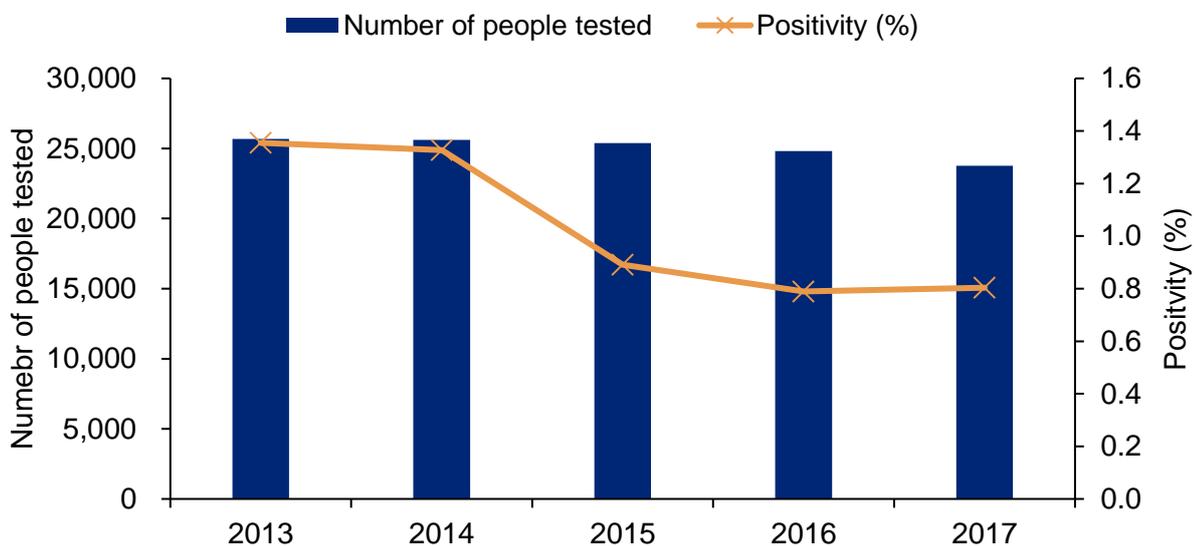


¹ eligible SHS attendee: any patient attending a SHS at least once during a calendar year; excluding those patients known to be HIV positive or for whom an HIV test was not appropriate, or for whom the attendance was reported as being related for reproductive health care only.

2.6 Women born in high HIV prevalence countries HIV testing at sexual health services

Two-thirds (63%; 23,767/37,848) of women born in countries of high HIV prevalence (>1%) who attended SHS were tested for HIV. Since 2013, the number of women tested declined by 7% from 25,686 in 2013 to 23,767 in 2017. This was coupled with a slight reduction in HIV test coverage from 65% in 2013 to 63% in 2017 (Figure 14). In 2017, 191 HIV diagnoses were made in this group, which represented 42% of all new HIV diagnoses made in women at SHS. The HIV test positivity among women born in high prevalence countries has decreased from 1.4% in 2013, to 0.8% in 2017.

Figure 14: Trends in HIV testing and positivity for eligible¹ SHS women born in a country with a high HIV prevalence² at all SHS, England, 2013–2017



¹ eligible SHS attendee: any patient attending a SHS at least once during a calendar year; excluding those patients known to be HIV positive or for whom an HIV test was not appropriate, or for whom the attendance was reported as being related for reproductive health care only.

² Countries where known HIV prevalence is >1% in people aged 15-49

2.7 Trans women testing for HIV at sexual health services

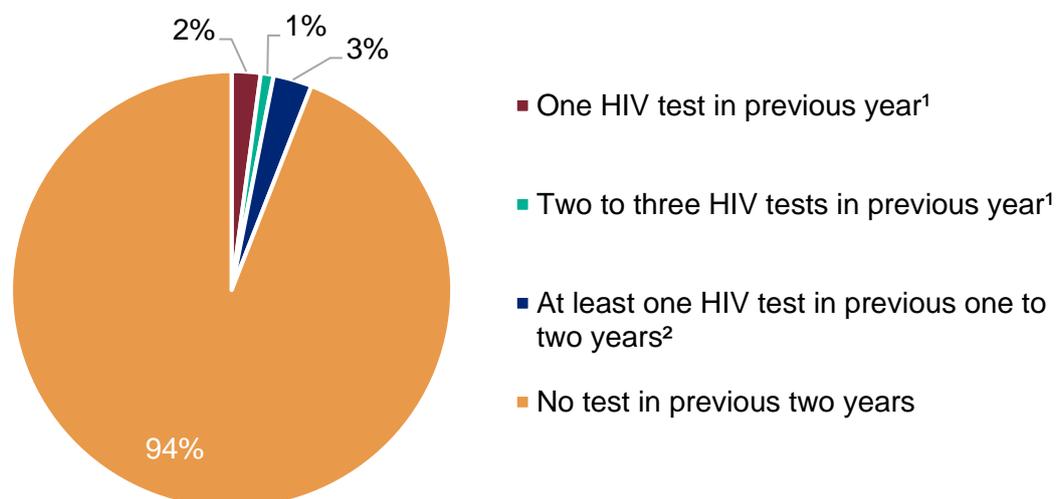
In 2017, 8 transwomen were reported as having attended SHS and were eligible for HIV testing. All were offered an HIV test, and one declined the offer. This low number reflected the introduction of a new code used to identify trans attendees in the dataset, and the numbers is therefore likely to be an underestimate.

2.8 Previous HIV testing

In 2017, 94% of new diagnoses among women who attended specialist SHS had not been tested at that clinic during the previous 2 years. Of the remaining

women, 3% had at least one HIV test in the previous one to 2 years, 2% had one HIV test in the previous year and 1% had 2 to 3 tests (Figure 15).

Figure 15: Women diagnosed with HIV at specialist SHS: previous HIV tests, England, 2017



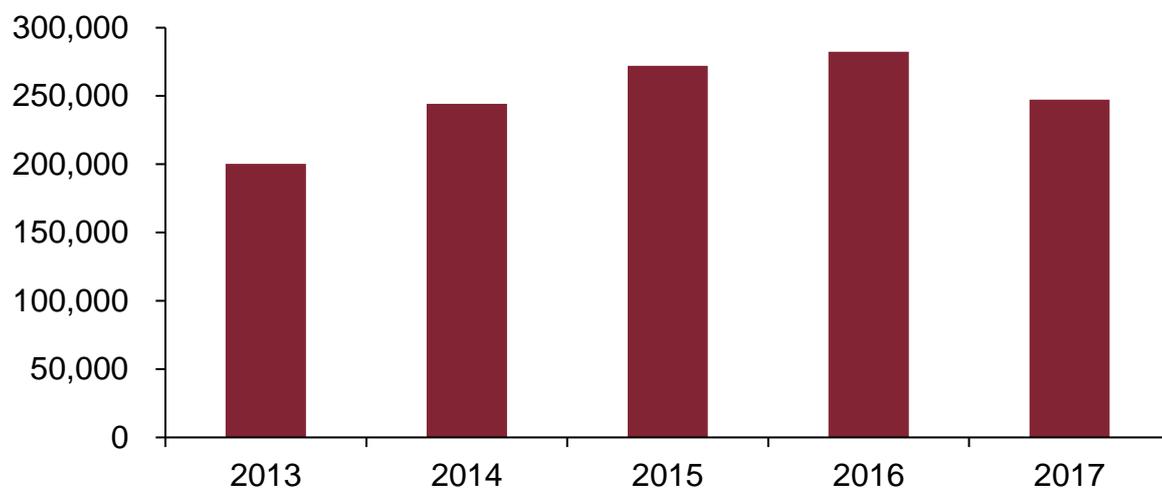
¹ previous year - 43-365 days before the last test in a calendar year or date of new diagnosis

² one to 2 years - at least one test in the 366-730 days and no tests in the 43-365 days before the last test in a calendar year or date of new diagnosis

2.9 Declining an offer of HIV testing

Between 2013 and 2016, the number of women who declined the offer of an HIV test increased by 41% from 200,344 in 2013 to 282,464 in 2016 (Figure 16). However, from 2016 to 2017, the number of women who declined a test fell by 12%, from 282,464 in 2016 to 247,277 in 2017. This reduction in the number of women declining testing was accompanied with a slight decrease in the number of women offered tests (3%, 856,000 to 826,108), but the number of women eligible for testing stayed the same (1,090,540 in 2016 and 1,091,709 in 2017).

Figure 16: Number of women who declined HIV testing, all SHS, 2013-2017



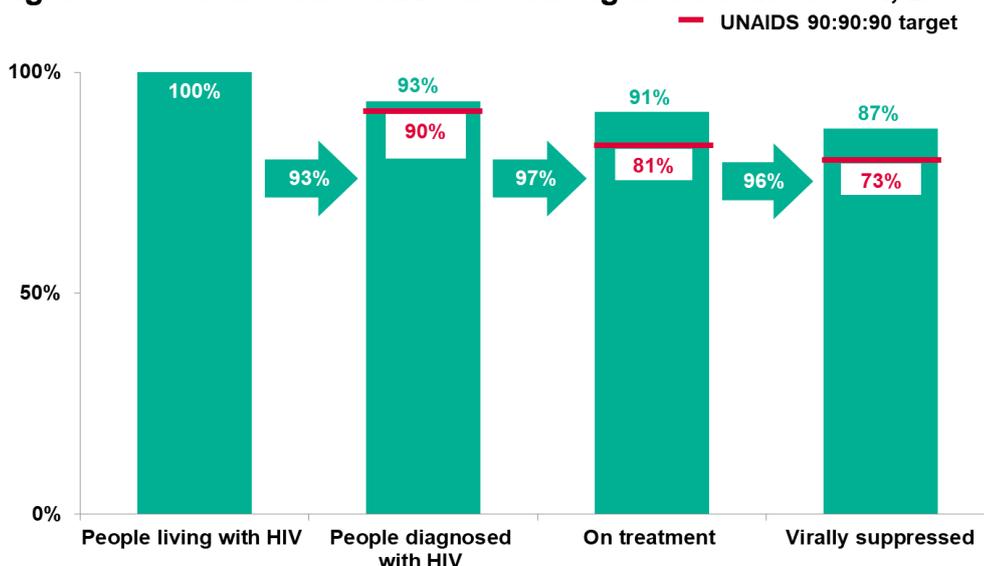
3. The continuum of care in women living with HIV

The continuum of HIV care shows the proportion of individuals living with HIV who were engaged at each stage along the patient pathway from initial HIV diagnosis to viral suppression. Viral suppression, whereby the level of virus is undetectable, means that it would not be possible to pass HIV on to others, even when no condoms are used during sex (Undetectable =Untransmissible or U=U).

The continuum of HIV care provides an opportunity to assess progress towards the Joint United Nations Programme on HIV/AIDS (UNAIDS) 90:90:90 targets of 90% of people living with HIV to be diagnosed, 90% of people diagnosed to be receiving antiretroviral therapy (ART) and 90% of people on treatment to be virally suppressed⁷. In 2017, the UK met the UNAIDS targets for all people living with HIV.

Additionally, the 90:90:90 targets for women living with HIV in 2017 were met and exceeded: 93% (CrI 91 to 95%) of the estimated 30,700 women living with HIV in the UK were diagnosed, 97% of those diagnosed were receiving treatment, and 96% of those receiving treatment were virally suppressed (Figure 17). Overall, 87% of women living with HIV in the UK were estimated to have an undetectable viral load and therefore unable to pass on the infection. The data used for each part of the continuum of HIV care for women have been described in further detail in the sections below.

Figure 17: Continuum of HIV care among women in the UK, 2017

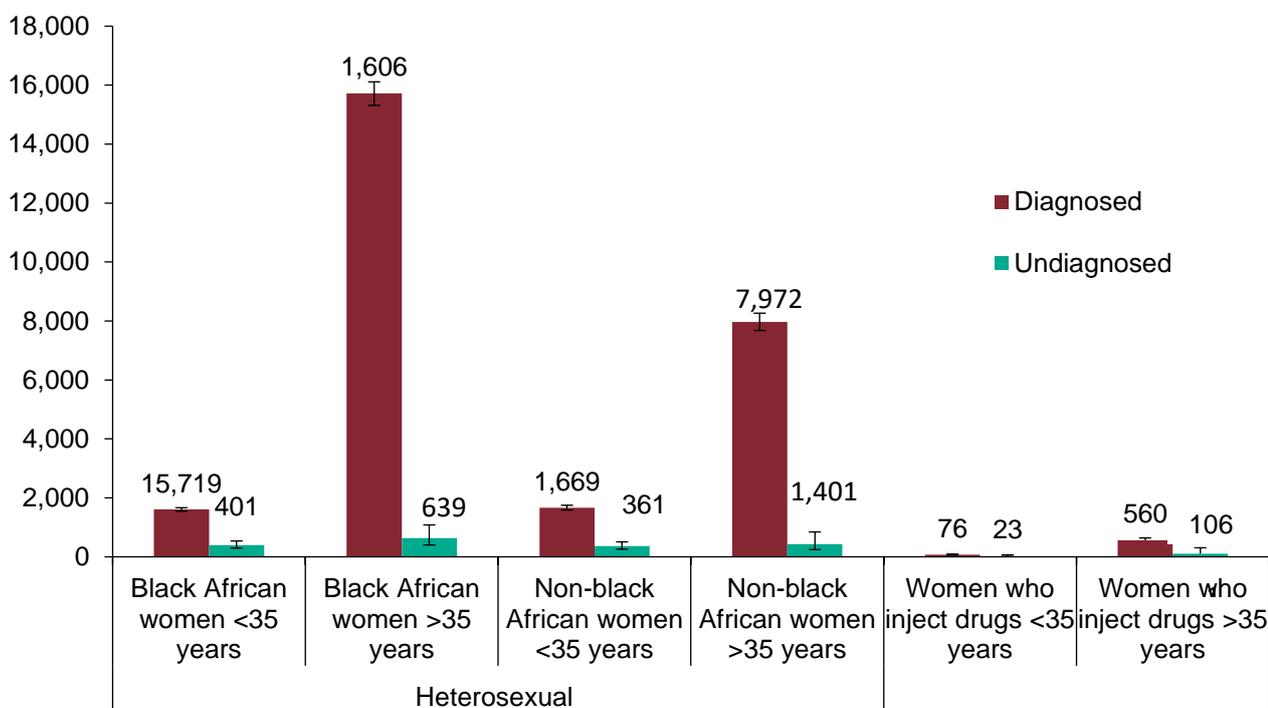


3.1 Total number of women living with HIV in the UK

In 2017, an estimated 30,678 (CrI 30,117 to 31,432) women aged 15 to 74 years were living with HIV infection in the UK (Figure 18). The overall prevalence of HIV among women in England in 2017 was 1.3 per 1,000 (CrI 1.3 to 1.4). HIV prevalence was 3 times higher in London compared to elsewhere in England (3.2 per 1000, CrI 3.1-3.3 and 1.0 per 1000, CrI 1.0-1.0, respectively).

Black African women had a much higher HIV prevalence (46.6 per 1,000, CrI 45.8 to 47.4) than women of other ethnicities (0.5 per 1,000, CrI 0.5 to 0.5), and women who inject drugs (19.2 per 1,000, CrI 14.1 to 26.8).

Figure 18: Estimated number of women aged 15-74 years living with HIV (diagnosed and undiagnosed), UK: 2017



3.2 Undiagnosed HIV

There were an estimated 2,018 (CrI 1,589 to 2,699) women aged 15-74 years living with an undiagnosed HIV infection in 2017; this was 7% (CrI 5 to 9%) of all women living with HIV. This corresponds to 93% (CrI 91 to 95%) of women living with HIV diagnosed, which exceeds the UNAIDS target of 90%.

The undiagnosed proportion was significantly higher in women aged below 35 years (16%, CrI 13-19) compared to women aged over 35 years (5%; CrI 3-9%). A slightly lower proportion of women living with HIV were undiagnosed in London (5%, CrI 4%-6%) compared to elsewhere in England (7%, CrI 6% - 10%).

3.3 Women living with diagnosed HIV

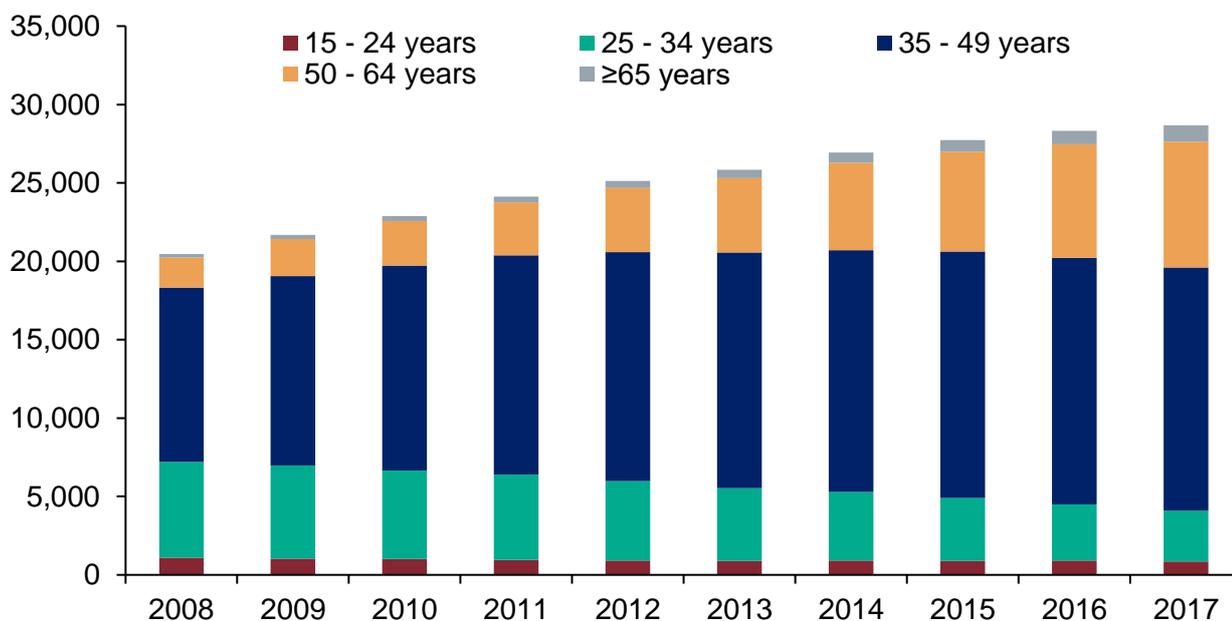
In 2017, there were 28,669 women (aged 15 years or over) living with diagnosed HIV infection and receiving HIV care in the UK. This was a 40% increase on the number a decade ago (20,462 in 2008). In 2017, 114 women receiving HIV care in the UK were reported as transgender (0.4%). Heterosexual contact was the probable route of infection for 94% (26,477/28,078) of women in HIV care, and injecting drug use for 2% (549).

Most women in HIV care (54%; 15,505/28,669) fell within the 35-49 year age bracket in 2017. However, the median age had increased over the previous decade from 38 years (IQR 32-44) in 2008 to 45 years (IQR 38-51) in 2017, and the number and proportion of women age 50 years and above more than tripled from 10% (2,132/20,462) to 32% (9,068/28,669) in 2017 (Figure 19a).

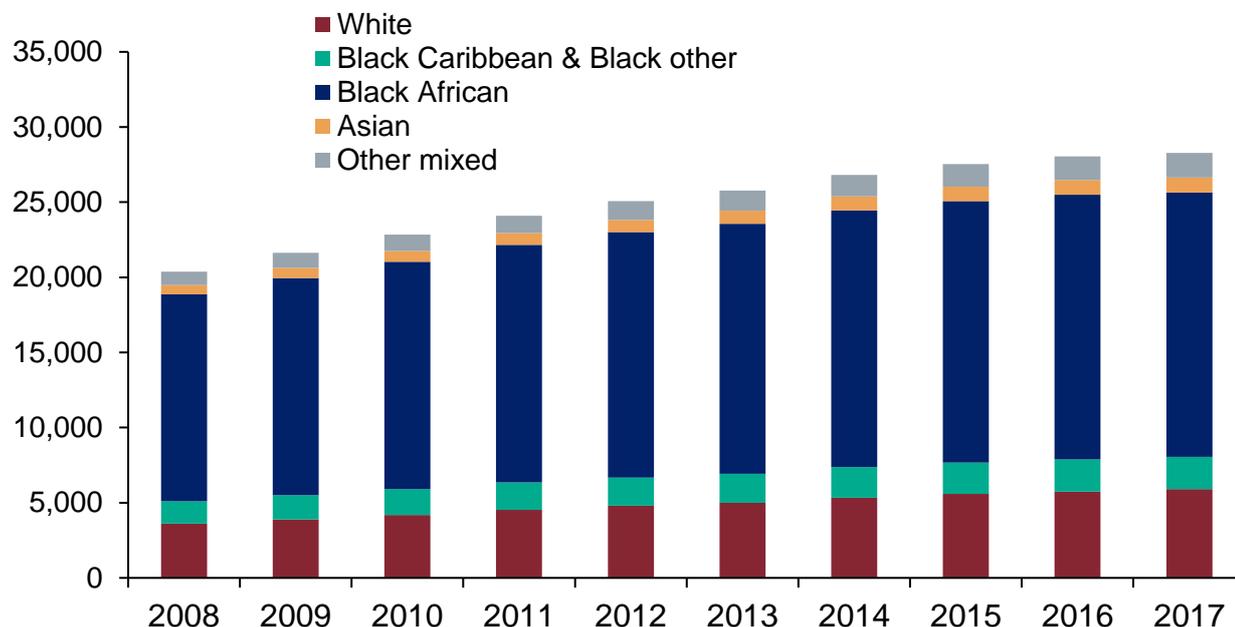
Black African women accounted for almost two-thirds of those receiving care in 2017 (62%, 17,599/28,273; 62%) (Figure 19b). White women accounted for one-fifth of those in HIV care (5,902/28,273; 21%), an increase of 64% since 2008 (3,608/20,385; 18%).

Figure 19: Women diagnosed with HIV receiving HIV specialist care, UK: 2008-2017

a) by age group



b) by ethnic group



Overall, 55 of the 325 local authorities in England had a high diagnosed prevalence rate that was greater than 2 per 1,000 women aged 15-59 years in 2017 (Figure 20). Of those, 7 local authorities, all of which were in London, had an extremely high diagnosed prevalence rate of greater than 5 per 1,000 women aged 15-59 years. Outside of London, the local authorities with the highest diagnosed prevalence rate among women were Luton (4.6 per 1,000) and Leicester (4.3 per 1,000). See Appendix 3 for a full listing of the local authorities with high diagnosed HIV prevalence.

3.4 Treatment coverage

In 2017, 97% (27,925/28,669) of women who attended for HIV care in the UK received antiretroviral therapy (ART), which exceeded the UNAIDS target of 90%. The treatment coverage had increased from 80% (16,222/20,383) in 2008. (Figure 21).

Treatment coverage was high across subgroups in 2017 and had increased from 94% (806/856) in 15-24 year olds to 99% (1,017/1,031) in those aged 65 years and above.

Figure 20: Diagnosed HIV prevalence (per 1,000 population women aged 15-59 years): England, 2017

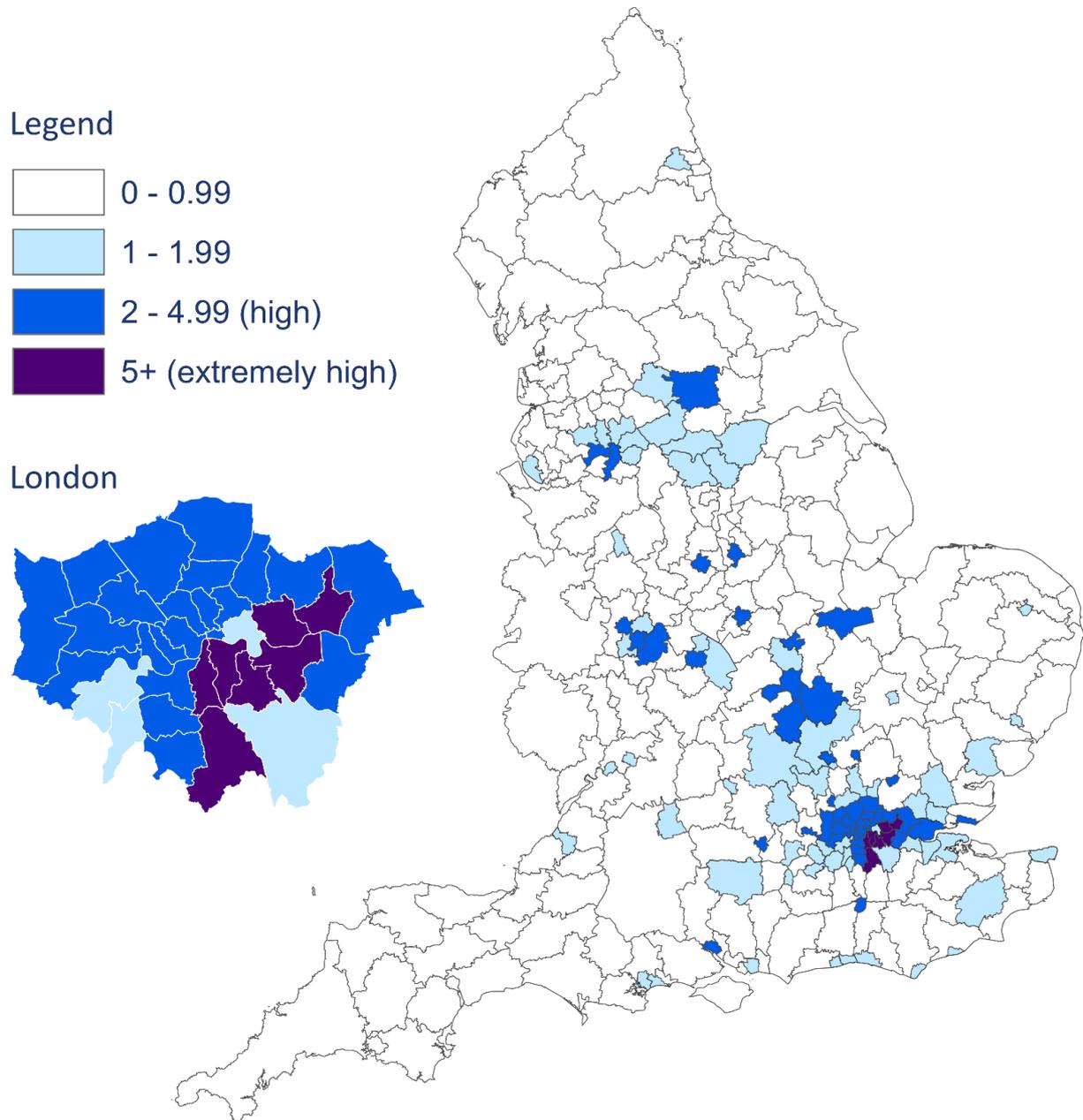
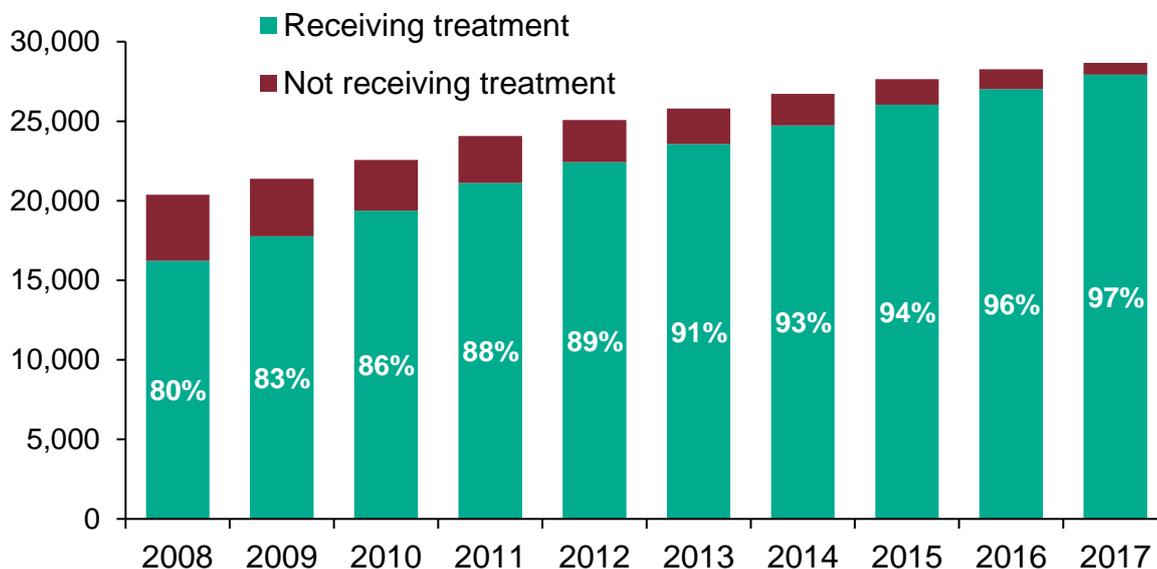


Figure 21: ART coverage among women accessing HIV specialist care in the UK, 2008-2017



3.5 Virological suppression

In the UK in 2017, 86% of women who received treatment had their viral load measurement reported. Of those, 96% (23,047/24,022) had had an undetectable viral load, exceeding the UNAIDS target of 90%.

Rates of virological suppression increased with age, with 86% (621/725) virally suppressed among women aged 15-24 years compared to 98% (7,372/7,545) among women aged 50 years or older. Rates were lower among women who were probably exposed to HIV through injecting drug use (90%, 444/492) or mother-to-child transmission (85%, 734/855) compared to heterosexual women (97%, 22,579/23,347). Virological suppression was high across regions and ethnicities in 2017.

4. Experiences of women living with diagnosed HIV

4.1 Background

Positive Voices is a survey of the lives and experiences of people living with HIV in England and Wales. Between January and September 2017, people were randomly sampled from 73 HIV clinics and invited by Public Health England to take part in the survey. Questionnaires were completed by 4,422 participants (51% response rate), representing approximately one in 20 people living with HIV in England and Wales.

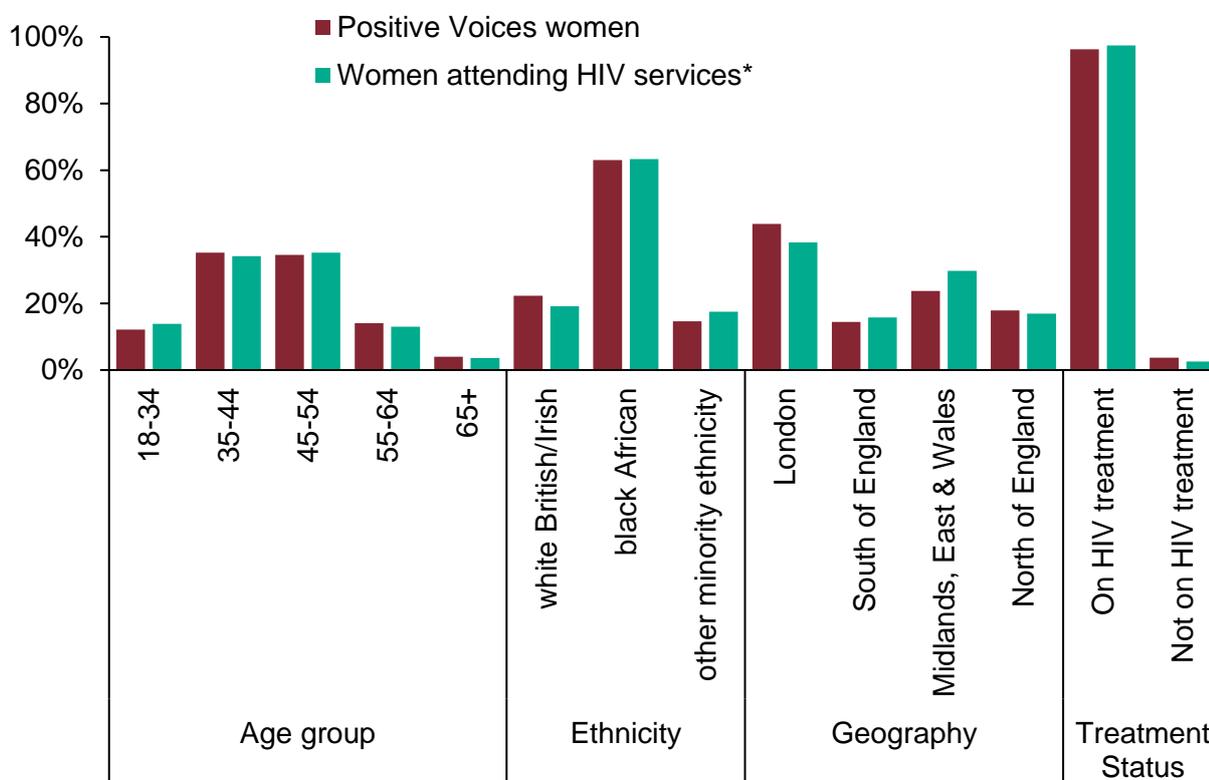
The survey asked about: health and wellbeing, non-HIV health conditions and medications, experiences with healthcare, met and unmet needs, sex and relationships, lifestyle issues, and financial security. Further details of the survey methodology can be found in the Positive Voices 2017 survey report⁸ and full data tables.

4.2 Characteristics of *Positive Voices* survey women participants

Of the 4,424 participants, 1,208 (28%) were women, including 14 transwomen. Women included in Positive Voices were broadly representative of all women attending HIV services in 2017 (Figure 22). Most women (95.9%) had probably acquired HIV through sexual contact, with 1.7% through vertical transmission, 1.5% through injecting drug use and 0.9% through blood or blood products. Two-thirds (63.3%) of women from the survey were black African and 19% were white British or Irish.

The survey data presented in the rest of this report have been weighted to adjust for small differences in the demographic profile and ensure the estimates in this report are representative of women accessing HIV care in England and Wales. Consequently, findings are presented in terms of sample percentages rather than frequencies. Estimated population sizes (Ns) are given when the data represents a subset of the total sample.

Figure 22: Representativeness of Positive Voices women participants compared to women accessing HIV outpatient services in England and Wales in 2017



Source: HIV and AIDS Reporting system: adult women (aged 18+) attending HIV services and resident in England and Wales

4.3 Socio-demographics

Among women, 42% of women (N=10,400) had completed secondary school (school up to 18 years), 29% (N= 7,290) had completed a bachelor’s degree or equivalent and 12% (N=3,020) had completed a postgraduate degree (Figure 23). Nine percent (8.9%, N= 2,220) of the women had undertaken technical/vocational education or training. Completion of primary and secondary education up to 16 years was reported by 8.4% (N= 2,090).

Overall, 22% (N=5,570) of women owned or were in the process of purchasing their home. An additional 44% (N=11,080) of women reported renting from the council or a housing association and 23% (N=5,720) rented from a landlord of a privately-owned (Figure 24). The remaining 7.1% (N=1,790) were living rent-free in accommodation provided by friends or family, 0.5% (N=130) lived in sheltered accommodation, 1.8% (N=450) lived in temporary accommodation and 0.9% (N=230) were homeless.

Figure 23: Highest level of education completed by women living with HIV

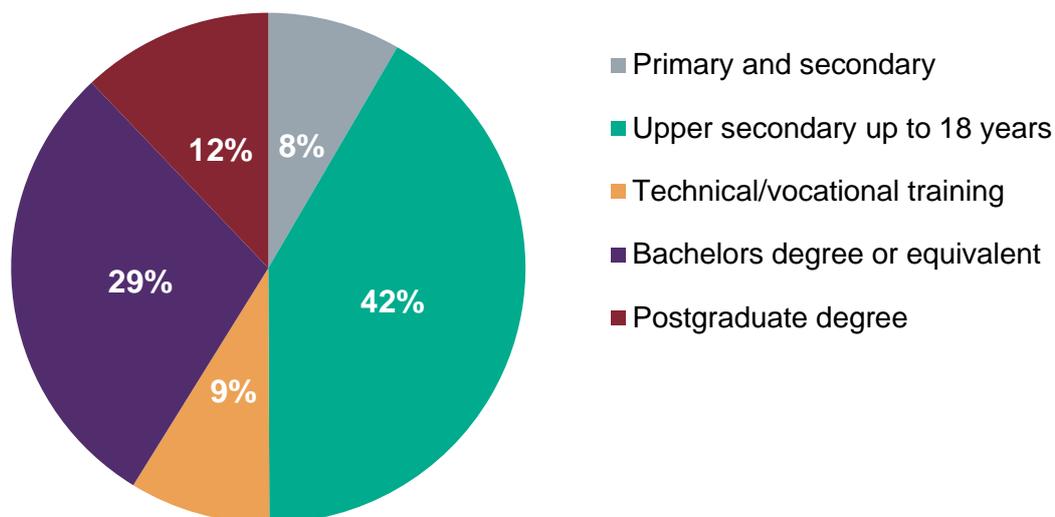
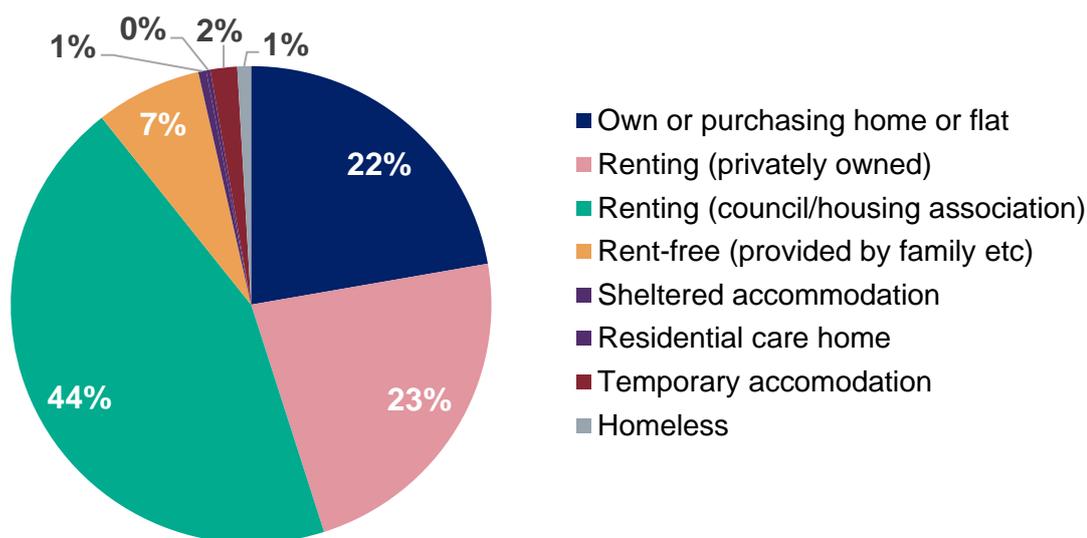
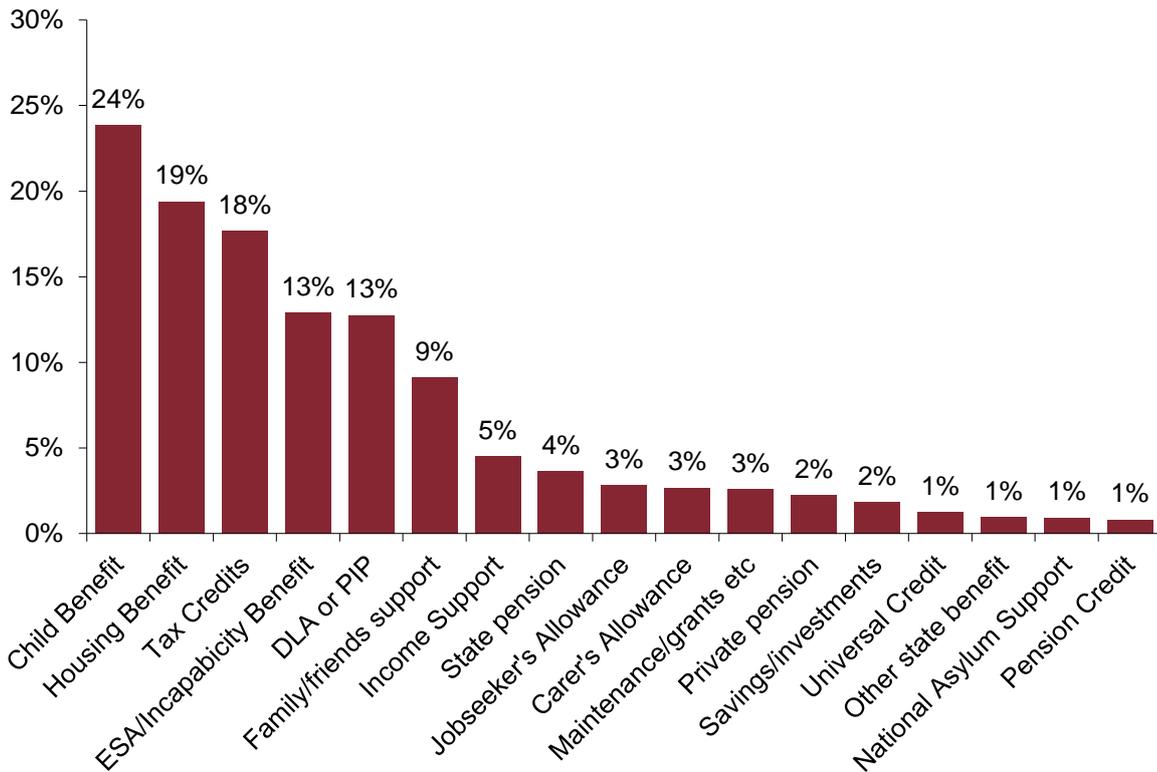


Figure 24: Housing accommodation of women living with HIV



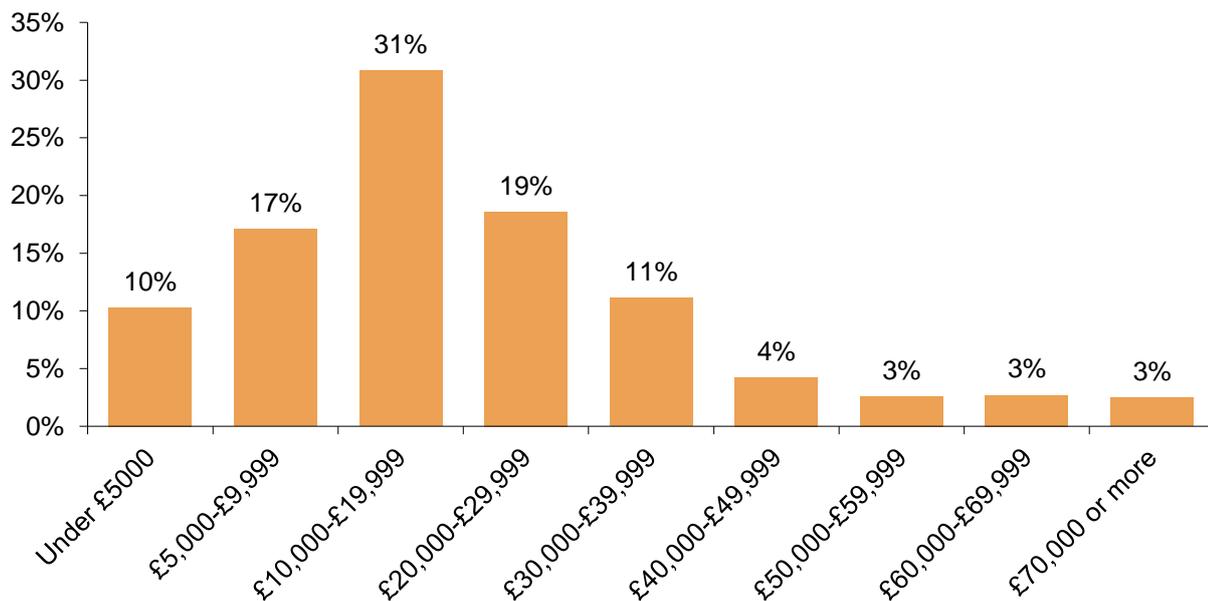
Overall, 63% (N=16,300) of women living with HIV were full-time or part-time employed. Fifteen percent (N=3,850) were unemployed and 8.4% (N=2,220) were on long-term sick/disabled for at least 3 months. In comparison, the proportion of gay and bisexual men with HIV who were unemployed was 6.0%, and the overall unemployment rate for British women over the same period was 4.3%⁹. Apart from earnings from salary or wages, 24% (N=5,960) were in receipt of Child Benefit, 18% (N=4,420) received either Working Tax credit or Child Tax Credit, 13% (N=3,220) received Employment and Support Allowance (ESA) or Incapacity Benefit, and 13% (N=3,190) received Disability Living Allowance (DLA) or Personal Independence Payment (PIP) for their disability or for their child's disability (Figure 25).

Figure 25: Non-employment based sources of income of women living with HIV



Women living with HIV were asked about their total household income before tax in the previous year. The median annual household income for women was between £10,000 and £19,999. One in 4 (27%) had a household income less than £10,000 per year and 10% had an income less than £5,000 (Figure 26).

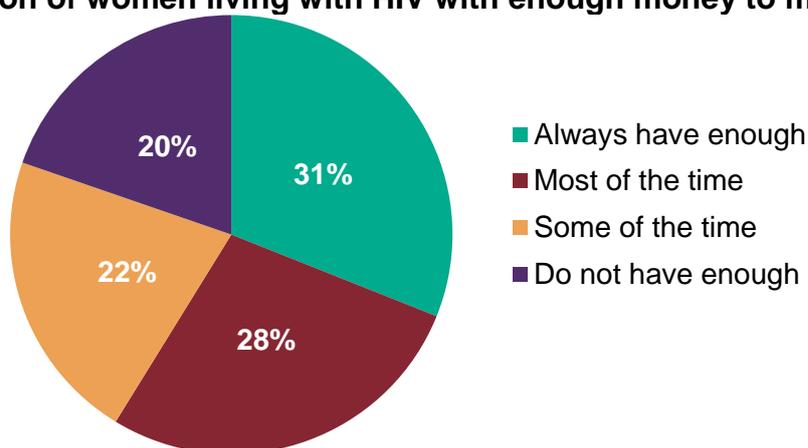
Figure 26: Gross annual household income (before tax) of women living with HIV



When asked about how their household had managed keeping up to date with bills and credit commitments during the previous year, 53% of women (N=13,340) stated that they were up to date with all their bills, 35% (N=8,750) were behind in some of their bills, 5.5% (N=1,380) were behind with all of their bills and 6.0% (N=1,490) preferred not to say.

When asked whether they had enough money to meet basic needs (food, rent gas, electricity, water, etc.) 31% (N=7,760) of women said that they always had enough money to meet their basic needs. However, 69% did not always have money to meet their basic needs: 28% (N=6,920) had money for basic needs most of the time, 22% (N=5,390) some of the time, and 20% (N=4,920) never had enough money for basic needs (Figure 27). In comparison, 61% of gay and bisexual men and 38% of heterosexual men reported that they always had enough money to meet their basic needs.

Figure 27: Proportion of women living with HIV with enough money to meet basic needs



“I was very lucky that my housing association provided a care support worker who helped me for a year sort out my [claims]. Before it was awarded, I couldn’t pay bills, [and relied on] food banks.” (Agnes, aged 61) *Names are fictional and for descriptive purposes only. Quotes are from Positive Voices survey participants.*

4.4 HIV clinic service satisfaction and patient-reported experience measures (PREMs)

Participants were asked to rate their HIV clinic on a scale of 0 to 10. On average, women rated their HIV clinic 9.3 out of 10. Just over half (55% (N=13,760) said their satisfaction level had stayed the same over the previous 2 years, 41% (N=10,160) said that their satisfaction had increased and 5% (N=1,160) said their satisfaction had decreased.

Participants were asked to agree or disagree (5-item Likert scale) with the following statements about their experience with HIV clinical services: (Agreement was defined as a “Strongly Agree” or “Agree” response).

“I have enough information about my HIV”

“I feel supported to self-manage my HIV”

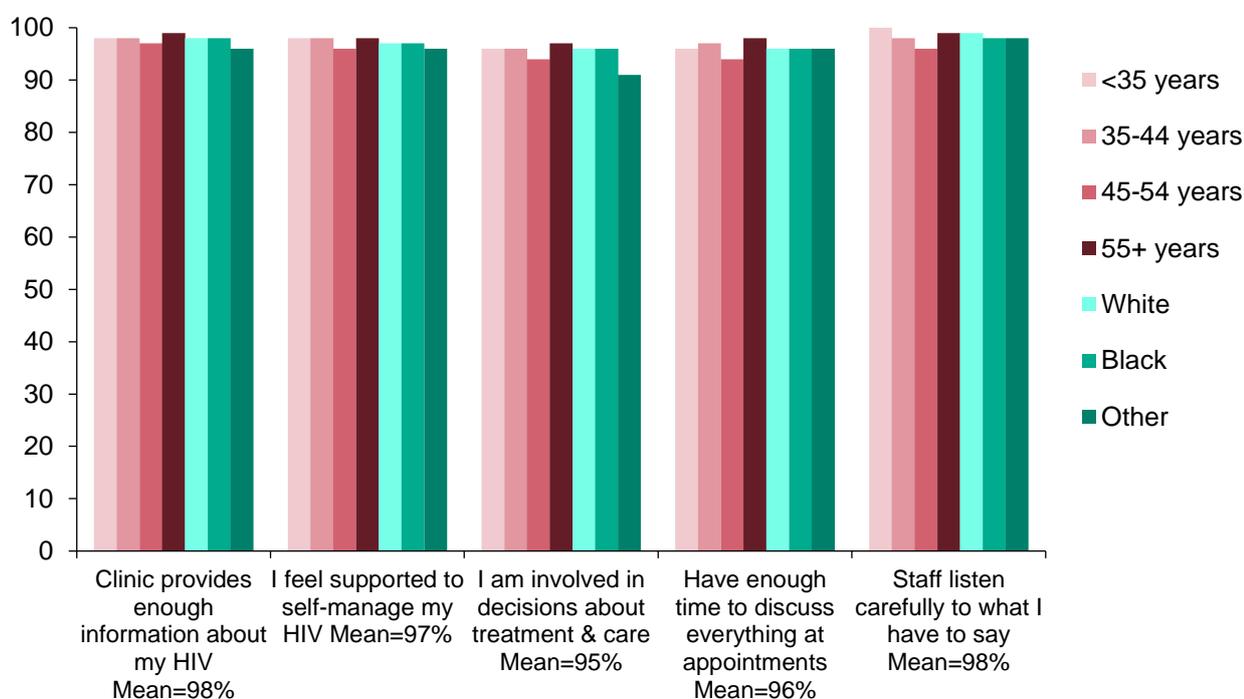
“I am involved in decisions about my HIV care”

“At appointments, I have enough time to cover everything I want to discuss”

“The staff listen carefully to what I have to say”

Agreement by women to all statements was >95%. No significant differences were observed between age and ethnic groups indicating high levels of satisfaction with HIV services (Figure 28). Overall, 97% of women felt supported to self-manage their HIV and 96% felt involved in decisions about their care.

Figure 28: Agreement with patient-reported experience measures (PREMs) about HIV clinical service (%) among women living with HIV, by age and ethnicity



“The first day/weeks/months after I was first diagnosed the nurses on the clinic were incredible, along with my doctor....helping me understand my new medical condition”
(Sarah, aged 44)

4.5 GP service satisfaction and patient reported experience measures (PREMs)

Overall, 98% (N=24,690) of women living with HIV were registered with a GP practice; of these 96%, (N=23,960) had shared their status with their GP. Participants registered with a GP were asked to rate their GP service on a scale of 0 to 10. On average, women rated their GP service 7.0 out of 10, closely in line with men (6.9/10), (Figure 29).

Participants were asked to agree or disagree (5-item Likert scale) with the following statements about their experience with GP services as relates to their HIV: (Agreement was defined as a “Strongly Agree” or “Agree” response).

“My GP knows enough about my HIV condition and treatment”

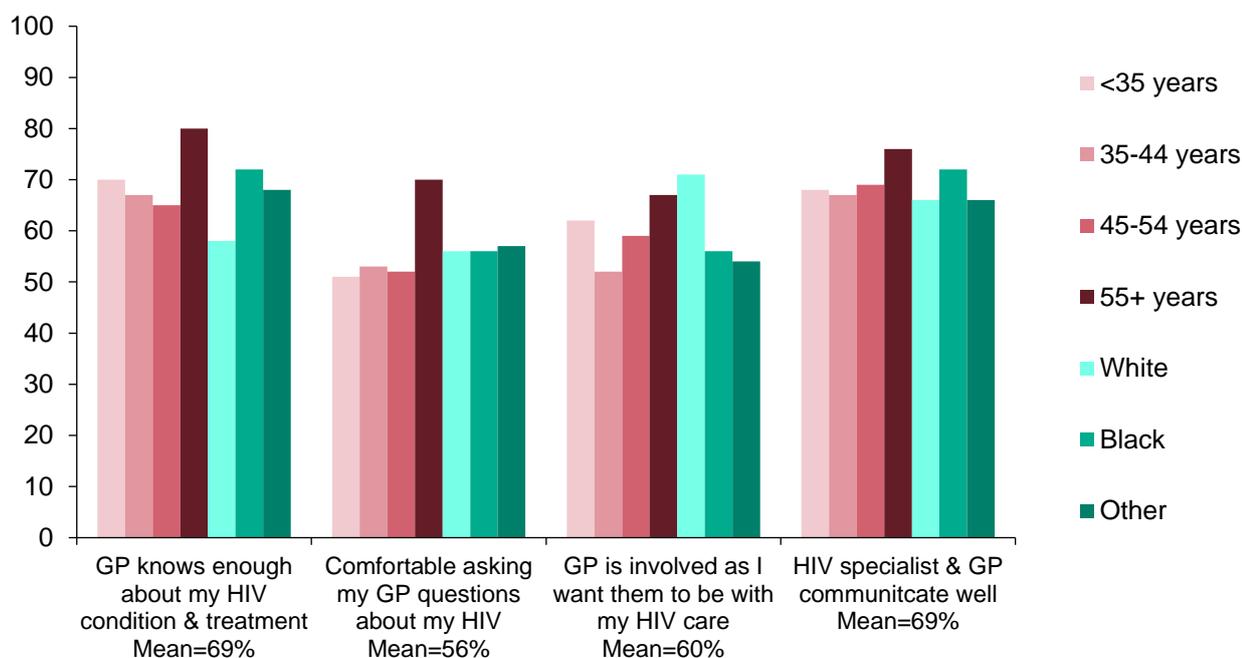
“I am comfortable asking my GP questions about my HIV”

“My GP is as involved as I want them to be with my HIV care”

“I feel that my HIV specialist and my GP communicate well regarding my health”

Average agreement was lower for GP services compared to HIV services, as 69% (N=17,180) of women felt that their GP knew enough about HIV and 56% (N=13,970) of women were comfortable asking their GP questions about HIV

Figure 29: Agreement with statements about experience with GP services (%) among women living with HIV, by age and ethnicity



“My GP does not know my HIV tablet’s side-effects and my clinic does not want to know about my other health problems. There is a lack of communication between GP and clinic.” (Patricia, aged 60)

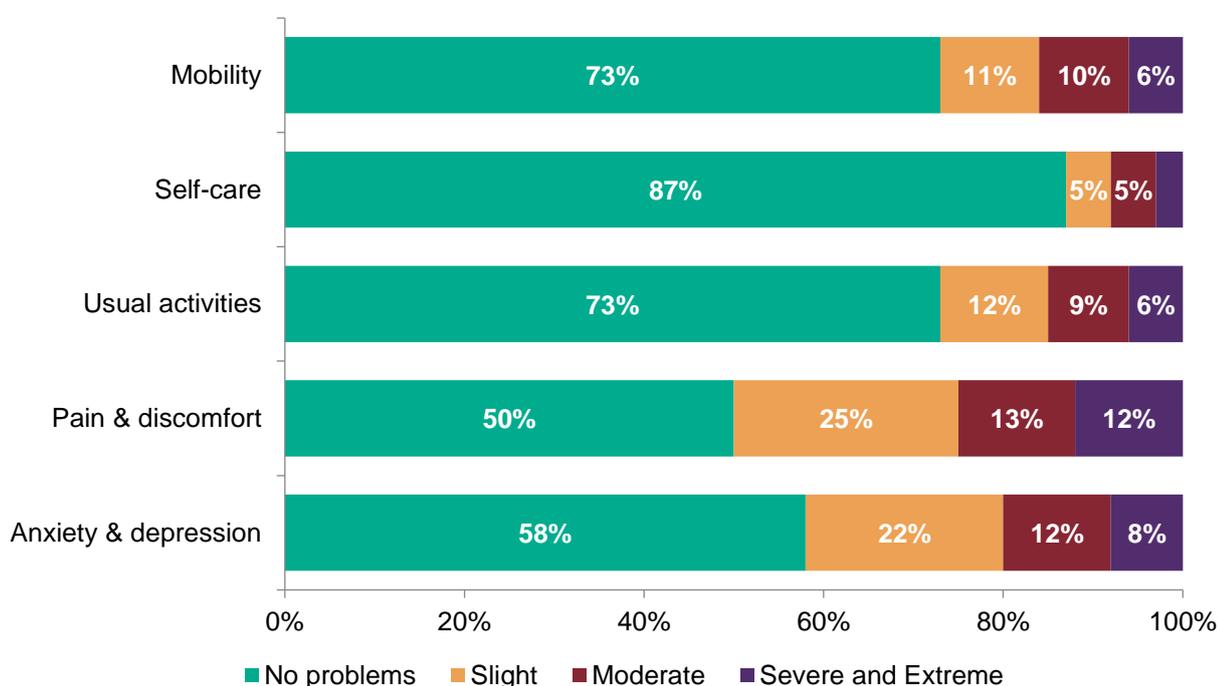
4.6 Quality of life

Participants were asked to rate their health on the day of the survey. Overall, 75% (N=18,870) of women rated their current health as good or very good. This was similar for gay and bisexual men (70%) and heterosexual men (77%). Participants reported life satisfaction on a scale of 0 to 10 where zero is “not satisfied at all” and 10 is

“completely satisfied.” The average life satisfaction score for women was 7.7 and 7.2 for men.

The survey included a standardised health-related quality of life instrument, Euroqol (EQ-5D-5L), which examines 5 domains of physical and mental health: mobility, self-care (washing and dressing), ability to do usual activities (eg work, study, housework, family or leisure activities), pain and discomfort, and anxiety and depression (Figure 30)¹⁰. Pain and discomfort was the most challenging areas affecting women, with 50% (N=12,430) reporting some problems. Feelings of anxiety and depression were also prevalent, with 42% (N=10,400) of women reporting some symptoms.

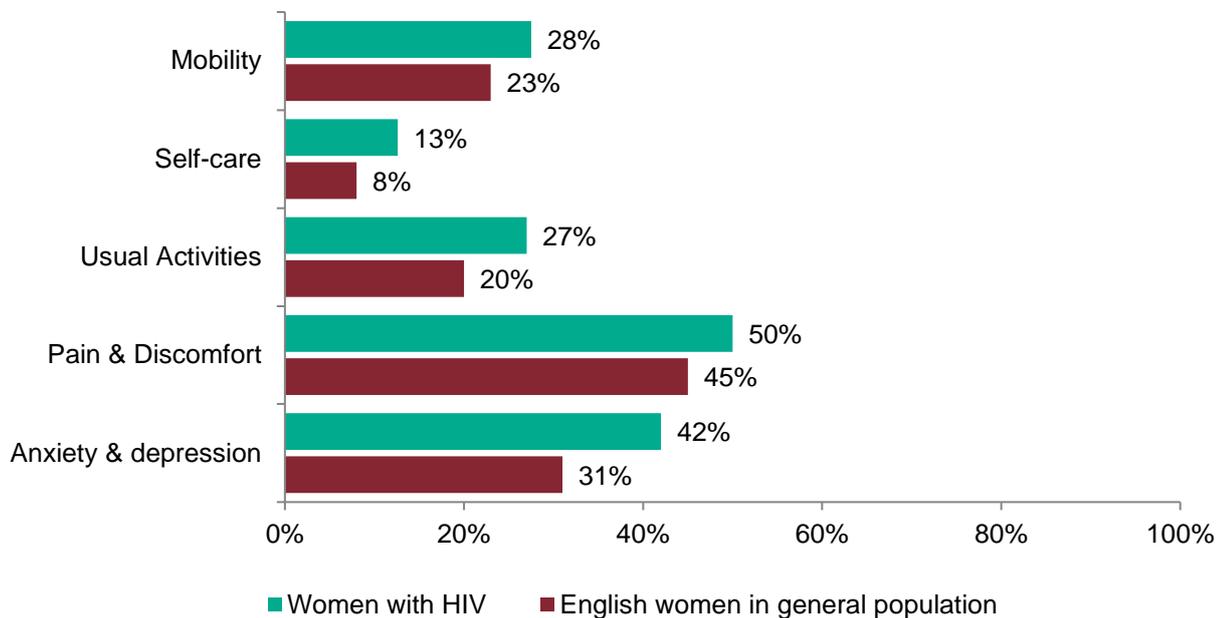
Figure 30: Current health-related quality of life by domain of women living with HIV



These data were compared to Health Survey for England (HSE) 2017 data on women in the general English population. Across all domains, women with HIV reported more problems and symptoms, particularly anxiety and depression (42% vs 31%) (Figure 31).

The 5 dimensions were then scored to create a utility value which ranged from 0 to 1, where 0 represents the worst possible health and 1 represented the best possible health. The overall score for quality of life of women living with HIV nationally was 0.83, compared to 0.87 for women in the general English population¹¹.

Figure 31: Proportion reporting any problems or symptoms: women with HIV compared to women in the English general population

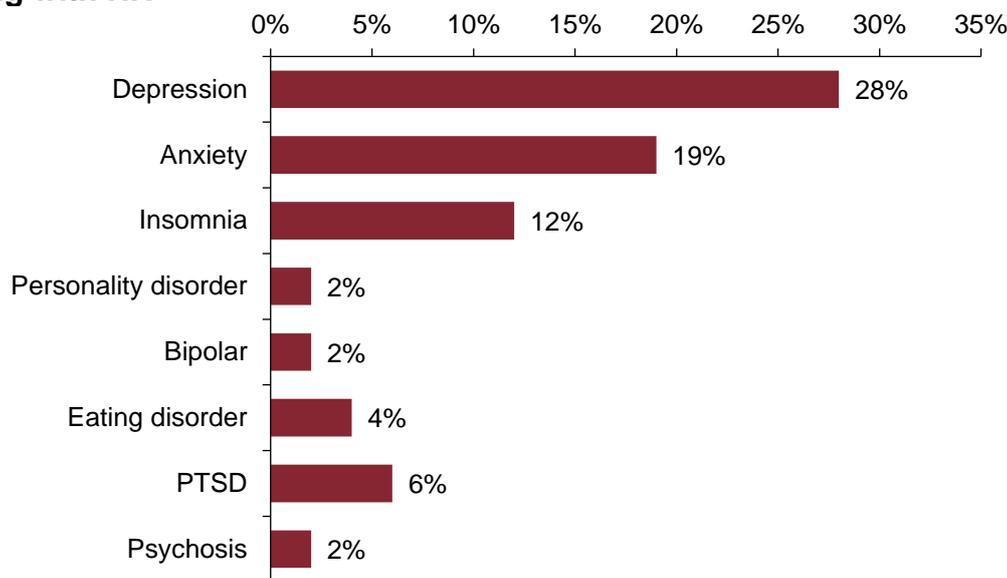


4.7 Mental health conditions

Mental health diagnoses were commonly reported by women with HIV, with 35% (n=8,780) women having ever been clinically diagnosed with a mental health condition. In comparison, 24% of heterosexual men with HIV had ever been diagnosed with a mental health condition, while the equivalent figure for gay and bisexual men was 50%.

The most commonly diagnosed mental health conditions were depression (28%) and anxiety (19%). There were also significant experiences of rarer conditions such as sleep disorders (12%, N=3,090), post-traumatic stress disorder (6.0%, N=1,490), eating disorders (4.1%, N=1,020), psychosis/schizophrenia (2.3%, N=560) and bipolar disorder (1.7%, N=410) (Figure 32).

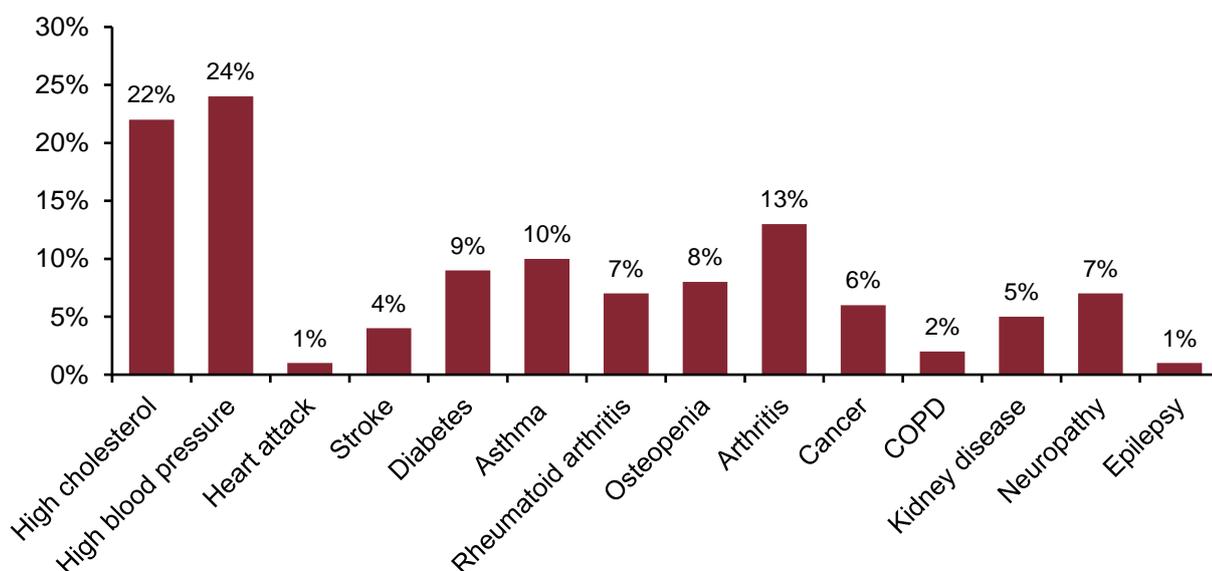
Figure 32: Prevalence of ever clinically diagnosed mental health conditions among women living with HIV



4.8 Long-term physical health conditions

The most common long-term physical health conditions (LTCs) reported were high cholesterol, hypertension and arthritis, with 22% (N=5,520), 24% (N=5,900) and 13% (N=3,190) of women having ever been clinically diagnosed, respectively (Figure 33).

Figure 33: Prevalence of ever diagnosed long-term health conditions among women living with HIV



Other diagnosed chronic conditions reported by women with HIV included asthma (10%, N=2,580), diabetes (8.9%, N=2,230) osteopenia (7.9%, N=1,970), peripheral neuropathy (6.8%, N=1,690), rheumatoid arthritis (6.9%, N=1,720), cancer (6.0%, N=1,500) and kidney disease (4.8%, N=1,200).

4.9 Smoking, alcohol and drug use

Just less than half 47% (N=11,570) of women were non-drinkers, while (53%; N=13,340) reported drinking alcohol. This was lower compared to men, of whom 82% drank alcohol. Among those who drank alcohol, one in 8 (12%, N=2,810) were binge drinking (having 6 or more drinks in a single occasion) on a weekly or daily basis. 8.4% of women were current smokers, compared to 24% of men.

Recreational drug use in the previous 3 months was reported by only 4.9% (N=1,220) of women living with HIV, compared to 31% of men with HIV. The most commonly used drugs were cannabis (3.9%, N=970) and cocaine (1.3%, N=310).

4.10 Weight management

Body mass index (BMI) is a measure that uses height and weight to determine whether people are a healthy weight. One in 4 (27%, N=6,810) of women were a healthy weight (BMI 18.5 and 24.9) and 2.5% (N=630) were underweight (BMI below 18.5).

Overweight women represented 29% (N=7,070) of all women with HIV (BMI 25 and 29.9) and 41% (N=10,340) were obese (BMI over 30). The proportion of those who were obese was high in comparison to 24% in heterosexual men and 13% of gay and bisexual men.

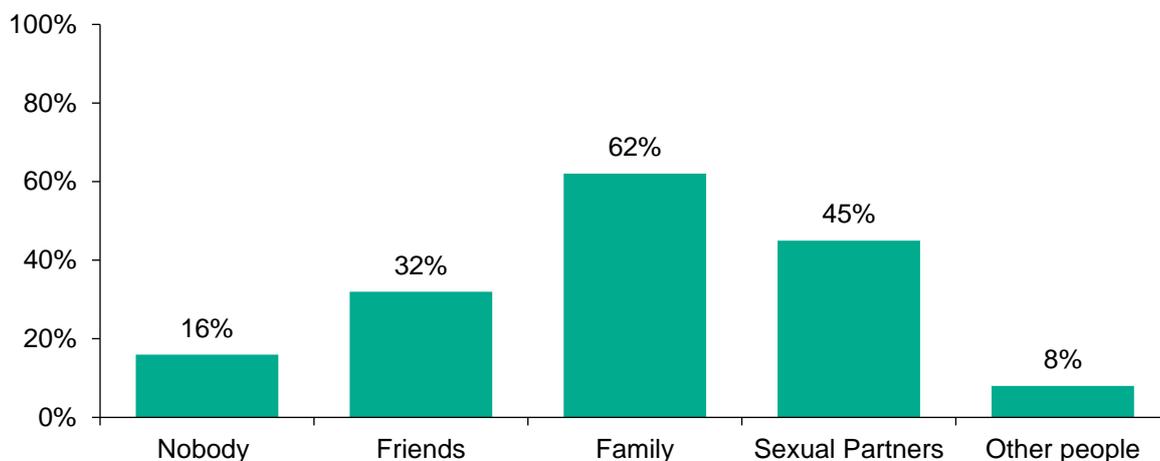
4.11 Stigma, discrimination and disclosure

“I can never reveal my HIV status to anyone other than my doctors and family as there is still a terrible stigma attached to having HIV. In fact, most people don't seem to know the difference between HIV and AIDS” (Grace, aged 53)

One in 6 (16%, N=4,030) women had not shared their HIV status with anyone outside of their healthcare setting, compared to 11% (N=6,370) of men (Figure 34). Among women, non-disclosure was reported more commonly by older women (20% aged over 50) and women of other white ethnicity (23%). Women who shared their HIV status most commonly told family members (62%, N=15,470), followed by sexual partners (45%, N=11,340) and friends (32%, N=8,100). Only 8.2% (N=2,050) of women shared their status outside of their immediate social network, such as with neighbours or co-workers.

Experienced and perceived discrimination in healthcare settings in the previous year was reported. One in 5 (21%, N=5,260) women reported that they had been worried about being treated differently to other patients due to their HIV status. Furthermore, 13% (N=3,170) said they had avoided seeking healthcare when they had needed it because of their HIV. During the past year, 7.3% (N=1,820) felt that they had been refused healthcare, or their medical procedure had been delayed, due to their HIV status.

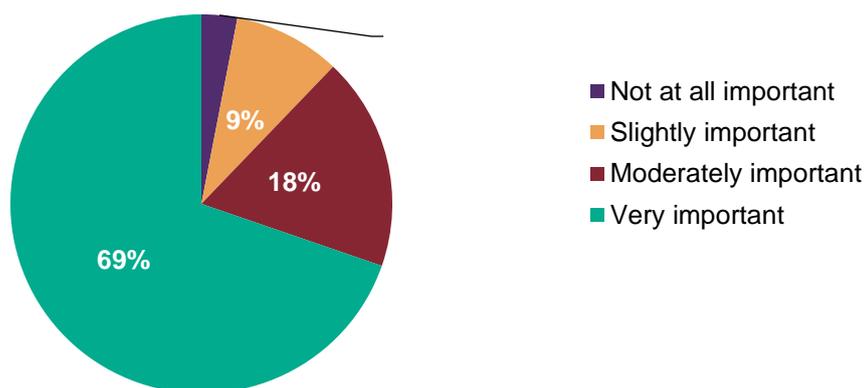
Figure 34: Proportion of women with HIV that told others about their HIV status and who they have told



4.12 Support services

Use of and experience with HIV support services provided by charities and voluntary organisations was reported. Women with HIV were more likely than men to have ever had contact with HIV support services (44% vs. 35%, N=10,870). Of those women who used these services, 87% (N=20,030) said that support services have been important for their health and well-being (Figure 35). One in 3 (31%, N=6,830) women said that HIV support services had become more difficult to access in the previous 2 years.

Figure 35: Importance of HIV support services to women living with HIV



4.13 Relationships

Participants were asked how they identified their sexual orientation. The majority (94%, N=23,640) of women identified as heterosexual, 0.5% (N=120) gay or lesbian, 1.9% (N=480) bisexual, 0.8% (N=210) as asexual or other (Figure 36).

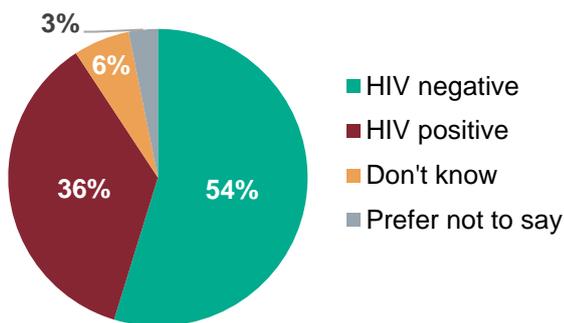
Half (55%, N=13,810) of women living with HIV were in a committed relationship, 98% (N=12,440) of whom with a male partner. Of those with a partner, 54% (N=6,940) had a

HIV negative partner, 36% (N=4,590) had an HIV positive partner, and 6.0% (N=810) of women did not know their partner’s HIV status (Figure 36).

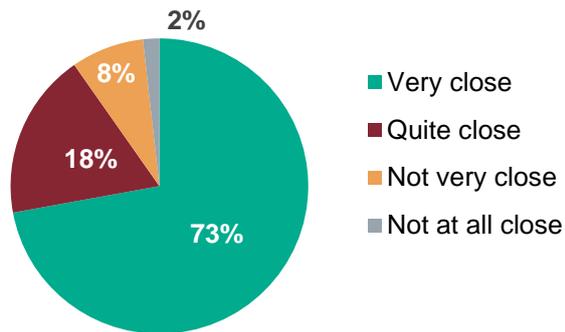
Of those women with a main partner, 73% (N=9,310) reported being very close to them, 18% (N=2,310) were quite close, 8.0% (N=970) were not very close and 1.8% (N=190) were not at all close (Figure 36).

Figure 36: HIV status of main partner and closeness to main partner

(a) HIV status of main partner



(b) Closeness to main partner

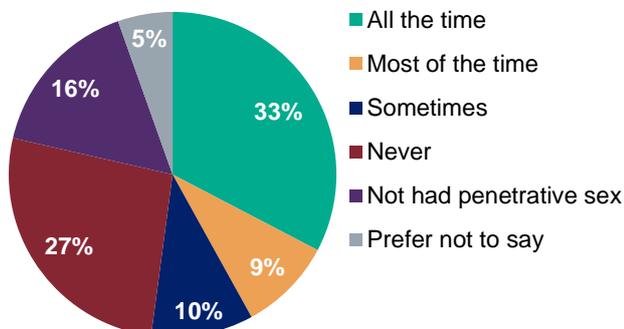


Compared to women with close main partners (defined as “Very close” or “Quite close”), women who were not close to their main partner (defined as “Not very close” or “Not at all close”) were more likely to be of black African ethnicity (88% vs 62%), not to have had sex in the preceding 3 months (14% vs 6.6%), and to have needed domestic violence support in the past year (21% vs 4.1%).

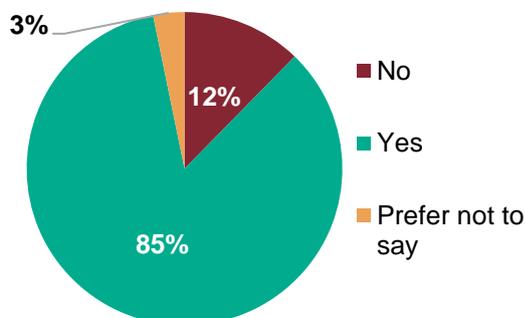
One in 3 (33%) women with a main partner always used condoms while having vaginal or anal sex in the previous 3 months, 19% used condoms intermittently, 27% never used condoms (Figure 37). One in 4 (25%, N=6,200) women reported a casual sexual partner in the previous 3 months: most of whom (23%) reported one partner. Twelve percent (N=2,080) of women living with HIV had had condomless sex with a casual partner in the previous 3 months despite most women living with HIV being unable to pass on HIV due to attaining viral suppression.

Figure 37: Condom use with main and casual partners of women living with HIV in the previous 3 months

(a) With main partner

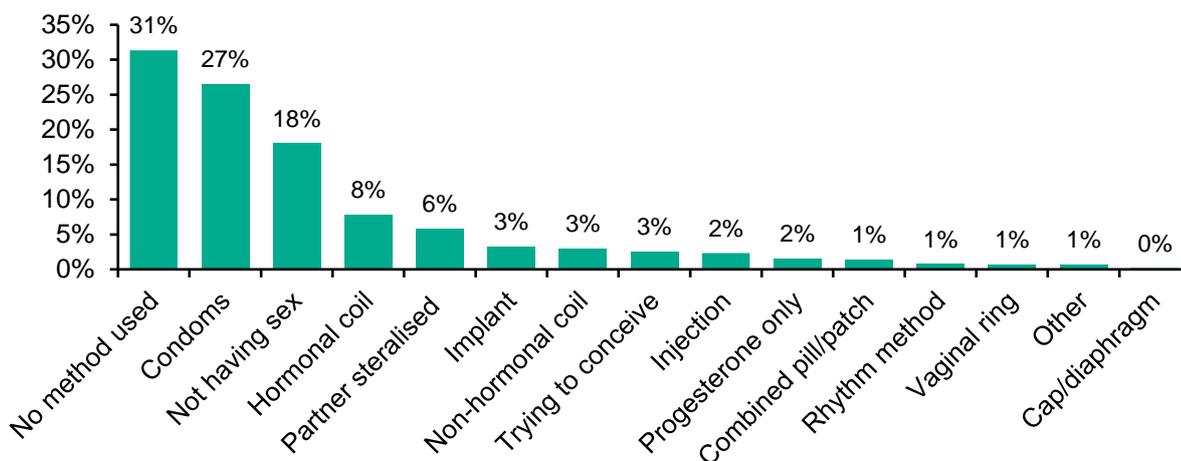


(b) With casual partner(s)



Women were asked about their contraceptive use in the previous 4 weeks. Thirty-one percent (N=8,350) of women in the survey were not using any form of contraception, 2.5% (N=580) were trying to conceive and 18% (N=4,610) were not on contraception because they were not having sex (Figure 38).

Figure 38: Method of contraception in women living with HIV



4.14 Viral suppression

Ninety-six percent (N=23,780) of the women had a viral load of less than 50 copies/mL and were therefore considered as having an undetectable viral load (Figure 39). When viral suppression rates were examined by demographic and sexual behaviour, viral suppression rates were high, and no significant variation was observed.

Viral suppression was high across all women and did not vary between women according to reported condom use. Overall, viral suppression was 97% among women who always used a condom with their main partner compared to 96% among women who never used condoms.

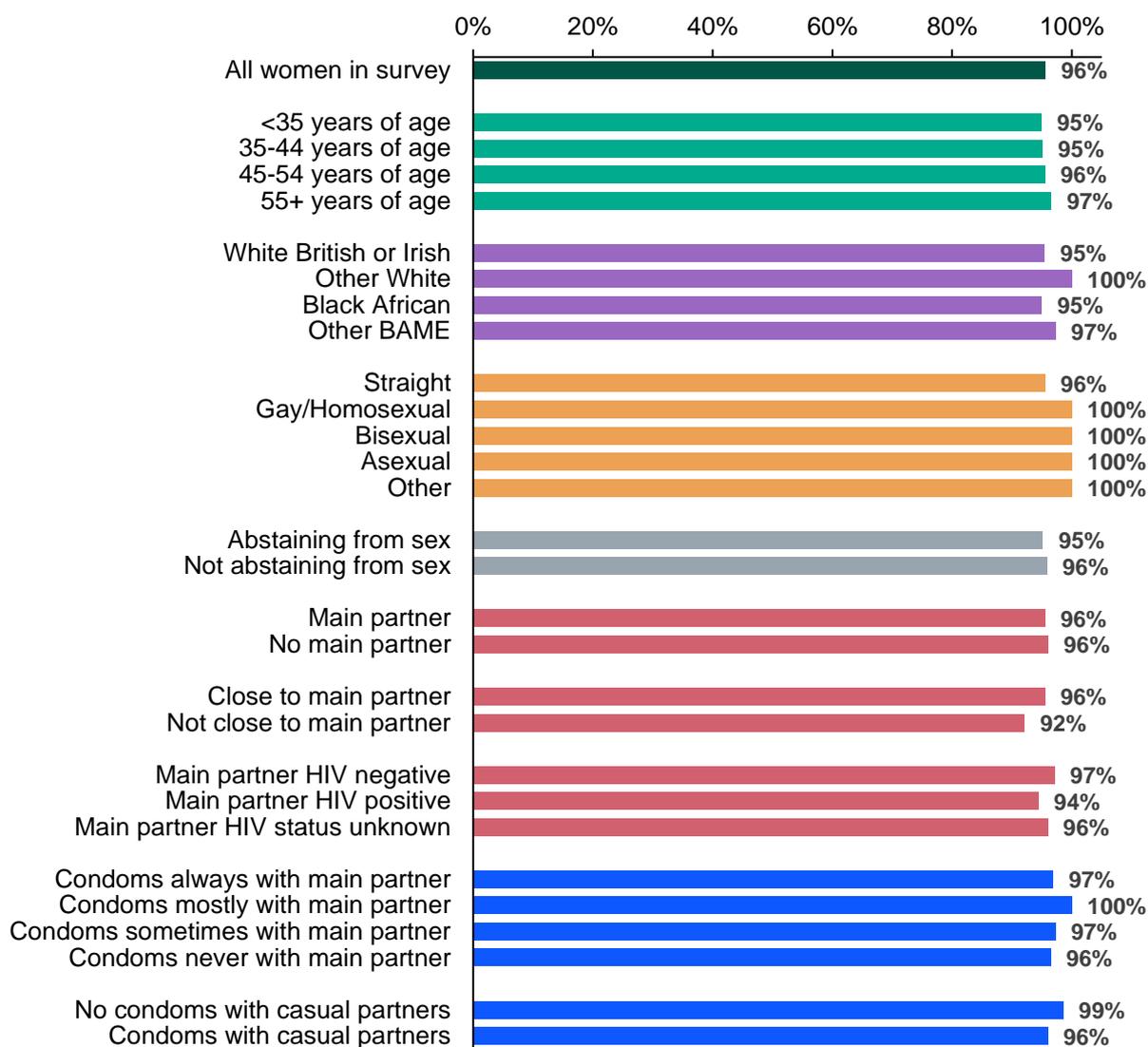
4.15 Menopause

Two-thirds (63%, N=16,310) of women with HIV were in the reproductive or premenopausal stage, 4.2% (N=1,070) were in the menopause transition stage and 33% (N=8,543) were post-menopausal.

4.16 Sexually transmitted infections

The women participating in the survey self-reported any sexually transmitted infections (STIs) diagnosed within the previous 3 months. The most commonly reported bacterial STI was chlamydia (2.6%, N=630), followed by syphilis (1.5%, N=380). The most common viral infections were genital herpes (13%, N=3,380), followed by human papilloma virus (HPV) (12%, N=2,980).

Figure 39: Proportion of women living with HIV who had an undetectable viral load by demographic and behavioural factors



4.17 Met and unmet needs

“Support services especially peer support, enabled me to understand my conditions and develop confidence and skills to manage HIV if I am not happy with services – support network helped with self-acceptance” (Maria, aged 50)

The survey included a comprehensive needs assessment of 29 specific services in the past year, and whether women had received the services required. The services were divided into 3 categories: HIV-related (6 services), health-related (11 services), and social and welfare (12 services) (Figure 40).

Need was defined as the percentage of women who stated a need for specific services. Unmet need was defined as the percentage of women with a specific need for which they did not receive help, either because it was not available, or they did not seek it.

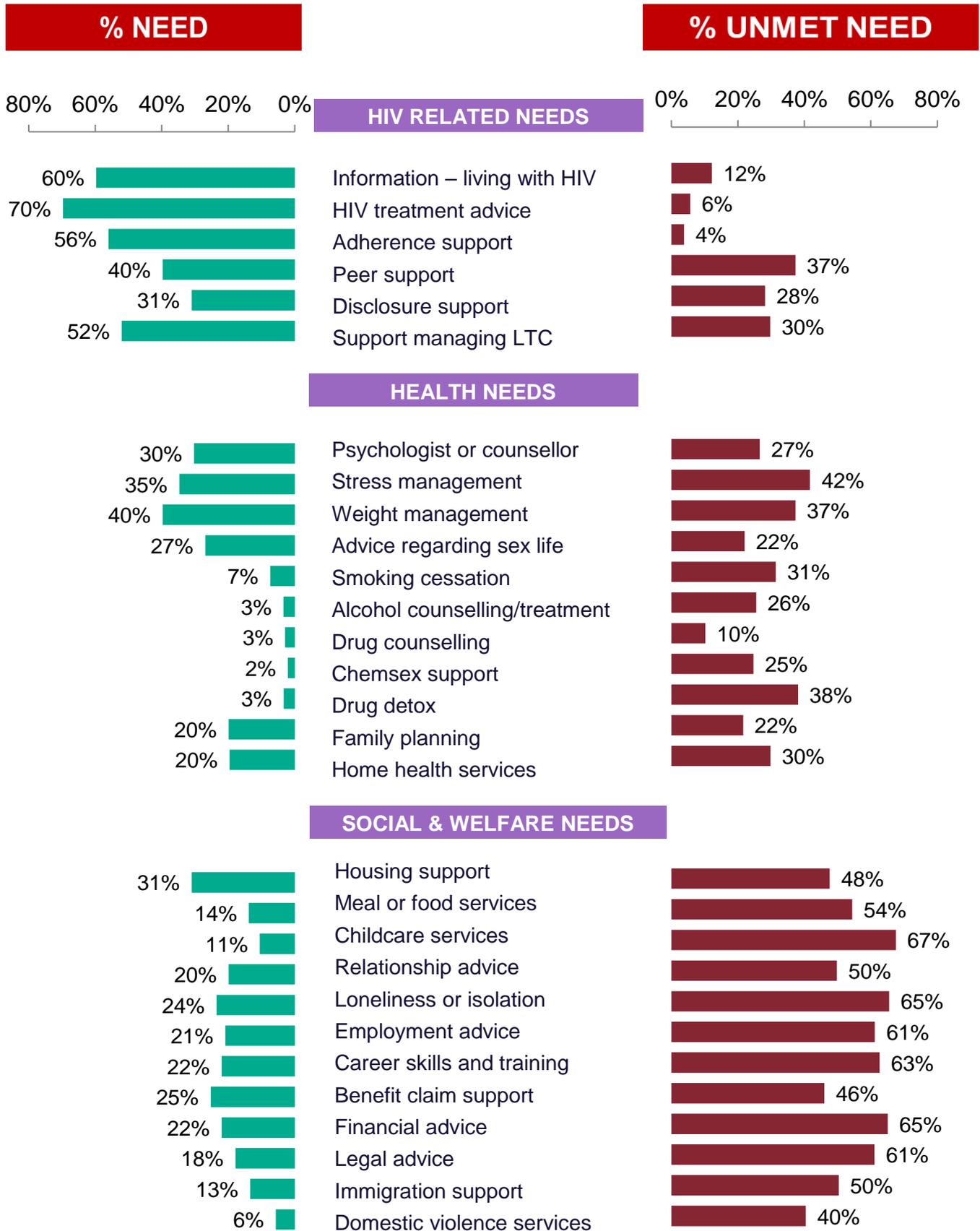
Overall, 81% (N=20,460) of women needed an HIV-related support in the past year, such as HIV treatment (70%, N=17,370) and adherence (56%, N=13,950) and living with HIV (60%, N=14,870). Overall, 96% and 94% of those who needed HIV treatment and adherence support, respectively, received it and 88% of those who needed information about living with HIV received it.

Of the 38% (N=9,450) of women who needed peer support or social contact with other people with HIV in the past year; over a third (38%) said this need was unmet. Half of women (51%, N=12,920) said they needed advice on how to manage long-term health conditions, and 29% said that this need was unmet.

In total, 71% (N=17,820) of women reported having at least one health need (not related to HIV) in the past year. The most common health-related needs were for weight management (40%, N=9,900), stress management (35%, N=8,640), psychologist or counsellor (30%, N=7,540), and family planning (20%, N=4,960). Unmet need was observed for 41% of those requiring help with stress management, 36% requiring help with weight management, 31% requiring help to stop smoking, and 27% of those who needed a psychologist or counsellor.

Finally, 59% (N=14,900) of women living with HIV had a need for at least one social and welfare services in the last year. These included services like housing support (31%, N=7,750), benefit claim support (25%, help dealing with isolation and loneliness (24%; N=5,840) and financial advice (22%; N=5,480). Among women, the area of greatest unmet need was for social and welfare services, with over half of women who needed this help saying that they did not receive it: childcare services (67%), help dealing with loneliness and isolation (65%), financial advice (65%), career skills and training (63%), legal advice (61%) and employment advice (61%).

Figure 40: Met and unmet HIV, health, social and welfare needs of women living with HIV



5. Appendices

Appendix 1: New HIV diagnoses among women by demographic group: UK, 2018

Among women in 2018:

- 1,185 new HIV diagnoses, 57 AIDS at diagnosis and 131 deaths

Among women newly diagnosed in 2018:

- 2% (21) were aged <15, 10% (115) were aged 15-24, 27% (322) were aged 25-34, 39% (466) were aged 35 to 49, 18% (215) were aged 50-64 and 4% (46) were aged 65 and over
- 93% (826) acquired HIV through heterosexual contact, 2% (19) through injecting drug use, 4% (32) through vertical transmission and 1% (13) through other transmission routes
- 31% (297) were white, 48% (466) were black African, 4% (37) were black Caribbean, 4% (36) were black other, 4% (43) were Asian and 9% (92) were other/mixed
- 25% (242) were born in the UK, 14% (137) were born elsewhere in Europe, 51% (492) were born in Africa, 5% (44) were born in Asia, and 4% (42) were born elsewhere
- 29% (347) lived in London, 63% (745) lived elsewhere in England, 2% (23) lived in Wales, 2% (21) lived in Northern Ireland and 4% (43) lived in Scotland
- 47% (398/846) were diagnosed at a late stage of HIV infection

Appendix 2: Women seen for HIV care by demographic group: UK, 2018

In 2018:

- there were 29,712 women seen for HIV care in the UK
- 1% (187) girls were aged <15, 3% (914) were aged 15-24, 11% (3,272) were aged 25-34, 52% (15,576) were aged 35-49, 29% (8,643) were aged 50-64 and 4% (1,120) were aged 65 and over
- 94% (27,185) acquired HIV through heterosexual contact, 2% (545) through injecting drug use, 4% (1,027) through vertical transmission and 1% (291) through other exposure routes
- 21% (6,128) were white, 62% (18,067) were black African, 4% (1,116) were black Caribbean, 4% (1,225) were black other, 4% (1,037) were Asian and 6% (1,676) were other/mixed ethnicity
- 36% (10,649) lived in London, 157% (7,013) lived elsewhere in England, 2% (509) lived in Wales, 1% (236) lived in Northern Ireland and 4% (1,304) lived in Scotland.
- 97% (28,747/29,712) received HIV treatment

Appendix 3: Local authorities with women’s diagnosed HIV prevalence rates above 2 per 1,000 population – England, 2017²

PHE Centre	Local Authority	Female residents accessing HIV care (aged 15-59)	Estimated female population in 1,000s (aged 15-59)	Diagnosed women’s HIV prevalence per 1,000 (aged 15-59)
London	Barking and Dagenham	429	65.28	6.57
London	Lewisham	628	102.18	6.15
London	Southwark	674	110.34	6.11
London	Newham	596	108.12	5.51
London	Greenwich	473	89.92	5.26
London	Lambeth	602	114.79	5.24
London	Croydon	625	120.23	5.20
East of England	Luton	288	63.31	4.55
London	Hackney	430	96.16	4.47
East Midlands	Leicester	477	110.80	4.31
London	Haringey	349	88.66	3.94
London	Enfield	387	103.73	3.73
West Midlands	Wolverhampton	280	75.54	3.71
West Midlands	Coventry	405	110.82	3.65
East Midlands	Northampton	245	67.08	3.65
East of England	Milton Keynes	285	79.88	3.57
South East	Reading	177	51.03	3.47
South East	Slough	154	44.96	3.43
East of England	Southend-on-Sea	176	52.34	3.36
North West	Manchester	595	180.67	3.29
London	Hammersmith and Fulham	201	62.32	3.23
London	Brent	321	100.47	3.19
London	Merton	209	65.89	3.17
East Midlands	Nottingham	326	107.01	3.05
London	Kensington and Chelsea	140	48.88	2.86
London	Bexley	210	74.99	2.80
East Midlands	Corby	57	20.83	2.74
London	Waltham Forest	238	87.06	2.73
London	Camden	229	83.82	2.73

² Population data from Office for National Statistics mid-2017 population estimate.

London	Westminster	205	76.64	2.67
East of England	Stevenage	71	26.68	2.66
East of England	Watford	79	29.69	2.66
East Midlands	Derby	199	75.58	2.63
London	Hounslow	216	82.05	2.63
London	Redbridge	228	91.51	2.49
East of England	Thurrock	126	51.52	2.45
East of England	Bedford	120	49.22	2.44
London	Islington	205	84.15	2.44
East of England	Peterborough	140	57.76	2.42
London	Barnet	284	118.48	2.40
West Midlands	Sandwell	228	95.55	2.39
South East	Crawley	77	33.68	2.29
Yorkshire and Humber	Leeds	557	243.86	2.28
London	Sutton	141	62.20	2.27
London	Ealing	237	104.73	2.26
London	Harrow	164	73.08	2.24
London	Wandsworth	262	117.56	2.23
East Midlands	Wellingborough	48	22.34	2.15
East of England	Harlow	55	25.64	2.15
London	Hillingdon	196	92.10	2.13
South East	Southampton	167	78.93	2.12
London	Havering	161	76.30	2.11
North West	Salford	156	76.09	2.05
London	City of London	4	1.98	2.02
West Midlands	Birmingham	705	350.62	2.01

6. References

- ⁱ Sophia Forum and Terrence Higgins Trust. Women and HIV: Invisible No Longer. April 2018. www.tht.org.uk/sites/default/files/2018-08/women-and-HIV_report_final_amended.pdf
- ⁱⁱ Nash S, et al (2019). Progress towards ending the HIV epidemic in the United Kingdom: 2018 report: www.gov.uk/government/publications/hiv-in-the-united-kingdom.
- ³ Chadborn, T.R., et al, The late diagnosis and consequent short-term mortality of HIV-infected heterosexuals (England and Wales, 2000-2004). *Aids*, 2006. 20(18): p. 2371-9.
- ⁴ Lodi, S., et al, Time from human immunodeficiency virus seroconversion to reaching CD4+ cell count thresholds <200, <350, and <500 Cells/mm(3): assessment of need following changes in treatment guidelines. *Clin Infect Dis*, 2011. 53(8): p. 817-25
- ⁵ Public Health England. NHS Infectious Diseases in Pregnancy Screening Programme: Screening standards data report 1 April 2016 to 31 March 2017. May 2019. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/800511/IDPS_data_report_2016-17.pdf
- ⁶ Nash, S.G., et al, *How many attendees with STI related needs are offered and tested for HIV in sexual health services in England?* in British Association for Sexual Health and HIV. 2019. Birmingham, England. www.bashh.org/media/4668/abstractbook.pdf
- ⁷ Joint United Nations Programme on HIV/AIDS (UNAIDS). 90-90-90: An ambitious target to help end the AIDS epidemic. Geneva: UNAIDS; 2014. Available from: www.unaids.org/sites/default/files/media_asset/90-90-90_en.pdf
- ⁸ Kall, M. et al. Positive Voices: The National Survey of People Living with HIV - Findings from the 2017 survey. November 2019.
- ⁹ Office for National Statistics. Labour market statistics time series(LMS): Female unemployment rate (aged 16 and over, seasonally adjusted) www.ons.gov.uk/employmentandlabourmarket/peoplenotinwork/unemployment/timeseries/mgsz/lms
- ¹⁰ Devlin N. J., et al. (2017). Valuing health-related quality of life: an EQ-5D-5L value set for England. *Health Economics*. 2018; 27: 7–22. <https://doi.org/10.1002/hec.3564>
- ¹¹ Szende A., et al. (2014) *Self-reported population health: an international perspective based on EQ-5D*. Dordrecht: Springer.