HIV and AIDS in the United Kingdom (UK)

KEY POINTS:

- The United Kingdom (UK) has a relatively small HIV epidemic with an estimated 89,400 people living with HIV.

- The epidemic is largely concentrated among certain key populations, including men who have sex with men and black African populations.

- The UK has made significant progress in antiretroviral treatment coverage in recent decades. 96% of those diagnosed are now accessing treatment and 94% are virally suppressed.

- However, late diagnosis remains a key challenge. In 2016 42% of diagnoses happened at a late stage of infection.

- There is also evidence that awareness and knowledge around HIV is dropping in the UK. A recent survey found that only 45% of the population could correctly identify all the ways in which HIV is and isn’t transmitted.

The United Kingdom (UK) has a relatively small HIV epidemic, with an estimated 89,400 people living with HIV in 2016. This translates into an HIV prevalence of 1.6 per 1,000 people.¹

In the same year, 5,164 people were newly diagnosed with HIV, an 18% decline from 2015. This is due to a sharp decrease in diagnoses among men who have sex with men in London, as well as a continued gradual decline in diagnoses in heterosexual men and women who were born abroad.²

Half of all new HIV diagnoses (54%) in 2016 were reported among men who have sex with men,
HIV continues to disproportionately affect men who have sex with men as well as individuals of black African ethnicity. In 2016, one in seven men who have sex with men living with HIV were black, Asian or from another minority ethnic group. Among heterosexual men and women, one in four were white.\(^3\)

Despite testing and treatment being free and universally available in the UK, around 10,400 people were unaware of their status, equivalent to 12% of the total number of people living with HIV. However the proportion of people unaware of their status has halved since 2014.\(^5\)

In 2016, 96% of people diagnosed with HIV were receiving antiretroviral treatment (ART).\(^6\) For the first time, in 2016 the death rate among people with HIV who are diagnosed promptly and on treatment was comparable to the rest of the population.\(^7\)

Despite rates of late diagnosis being on the decline, this remains one of the key challenges facing the UK. Late diagnosis means 442 people still died from AIDS-related illnesses in 2016. That said, the number of people being diagnosed with AIDS-defining symptoms and illnesses is declining, and fell by 25% in just one year, from 372 in 2015 to 278 in 2016.\(^8\)

### Groups most affected by HIV in the UK

#### Men who have sex with men

Since the 1980s, men who have sex with men (sometimes referred to as MSM) have remained the group most at risk of HIV in the UK. In 2016, an estimated 46,000 men who have sex with men were living with HIV. This means roughly 77 out of every 1,000 men (aged 15 to 59) who have sex with men are living with HIV. In London, it is an even greater number with 128 out of every 1,000 living with HIV.\(^9\)

It is estimated that in 2016 around 6,100 men who have sex with men were living with undiagnosed...
HIV, 59% of whom were aged 15 to 34. However, the number of men who have sex with men who have tested for HIV continues to rise, with 104,500 tested in sexual health services in 2016, up from 72,700 in 2012. In 2016, an HIV test was offered to 93% of eligible men who have sex with men attending sexual health services, resulting in testing coverage of 89%.

The UK government advises men who have sex with men who are having sex without condoms to test for HIV at least once a year, and every three months if they are having sex with new or casual partners. A survey of the men who tested for HIV in sexual health services in 2016 showed that 28% had tested for HIV at least once in the last year and 8% had tested two or more times. Over three-quarters of HIV diagnoses (77%) made in sexual health services in 2016 were among men who do not test regularly.

In 2016, new HIV diagnoses among men who have sex with men fell for the first time since the epidemic began over 30 years ago (21% decline, from 3,570 in 2015 to 2,810 in 2016). The decline was particularly impressive in London, where HIV diagnoses fell by 29% from 1,554 in 2015 to 1,096 in 2016. This drop has been linked to the work of five London clinics, including 56 Dean Street, London, the largest HIV clinic in Europe, where new diagnoses fell by 42%. In a comment to the Lancet, clinicians from Dean Street attributed this success to the availability of PrEP as well as to increased testing and earlier provision of treatment.

Almost three-quarters of the men who have sex with men who were newly diagnosed in 2016 were aged 25 to 49 years. This has remained the same for the past 10 years.

**Heterosexual black African men and women**

In the UK those of black African ethnicity carry a disproportionate burden of HIV. This includes those born in the UK who identify as being of black African descent, as well as those born in Africa.

In 2016, an estimated 18,000 heterosexual men and 20,900 heterosexual women were living with HIV in the UK. Of these, 8,900 were black African men and 13,200 were black African women.

Overall, 39% of new diagnoses were among black African men and women, this is despite them making up only 1.8% of the population of the UK, according to the last census in 2011. However, this is a proportional decrease from previous years, in 2007 this population made up 68% of new diagnoses.

While diagnoses among black African heterosexuals has been decreasing in recent years, those among white heterosexuals have remained relatively stable but low at around 750 per year over the past decade. Overall the rate of new diagnoses among heterosexuals has halved over the past 10 years, from 4,060 in 2007 to 2,110 in 2016.

Many of the HIV infections among heterosexuals are thought to have occurred outside of the UK. In 2016 it was estimated that only half (55%) of all new diagnoses among heterosexual men and women were acquired in the UK.

It was estimated that around 3,900 (10% of) heterosexual men and women were living with undiagnosed HIV in 2016. Overall, it is estimated that 74% of heterosexual men who are unaware they have HIV are aged over 35. Among heterosexual women with undiagnosed HIV, 55% are over 35, while 41% of men who have sex with men who are undiagnosed fall in this age bracket.
People who inject drugs

In 2016, it was estimated that 1 person in every 100 who injects drugs was living with HIV. Most of these people have been diagnosed and are accessing HIV care. However, people who inject drugs (sometimes referred to as PWID) are often diagnosed late, with 51% diagnosed at late stage of infection in 2016.24

Although needle and syringe sharing among people who inject drugs has fallen across the UK, it is still a problem. In a 2016 survey, 1 in 6 reported having shared needles and syringes in the past month.25

There were 145 new HIV diagnoses associated with injecting drug use in the UK during 2016. This is slightly lower than the annual average of 168 new HIV diagnoses between 2006 and 2015.26

In 2016, only 77% of people who inject drugs reported ever having tested for HIV. However, 82% of those who had never tested for HIV, had attended a clinical service that year, meaning opportunities are being missed to get more members of this group testing for HIV.27 There are concerns about the increase in injection of methamphetamine and mephedrone in recent years. Certain populations of men who have sex with men are thought to be using these drugs during sex (known as ‘chemsex’). This is a particular concern as high levels of sharing of equipment and low condom use are reported.28

Other key affected populations

Between 2016 and 2017, just over 37,400 HIV tests were carried out in English prisons. This covers only 17.5% of the new prison intakes and transfers of these two years. A total of 942 people were found to be living with HIV, representing 2.5% prevalence. However, it is not known whether these were new diagnoses or ones that have already been registered.29

In 2016, 84% of around 5,000 sex workers were tested for HIV at specialist sexual health services. 11 of the people tested were found to be living with HIV, equivalent to 0.3% prevalence.30

In 2016, 41 children were newly diagnosed with HIV – down from 131 in 2005. Of these, 36 were born abroad and arrived in the UK at an older age.31

HIV testing and counselling (HTC) in the UK

In 2016, more than a million people were tested for HIV. Most (87%) of these people were tested in specialist sexual health services.32 However, HIV testing rates in general services have increased by 17% between 2014 and 2016 in high prevalence areas.33

Men who have sex with men were most likely to have an HIV test (89%) compared with 77% of heterosexual men and 56% of heterosexual women.34

While testing coverage among men who have sex with men and heterosexual men has increased since 2009, it has fallen among heterosexual women. This is thought to be due to lower attendance of integrated sexual and reproductive health clinics in which this population is routinely tested for HIV.35

A total of 179 out of 223 health clinics achieved the recommended testing coverage of 80% among men who have sex with men, consistent with British Association for Sexual Health and HIV (BASHH) recommendations for this group.36

However, one survey detected an annual HIV testing rate of just 36.8% among black African
populations in the UK. Another study indicated that only one quarter of black African or black British individuals (a more general term which includes people of black Caribbean descent as well as others) attended the same sexual health clinic at least once in the previous five years. By contrast, there was a 97% uptake of HIV testing among women attending antenatal clinics.

Around 60% of people not at high risk of HIV who attended specialist sexual health services were tested for HIV. This group accounted for 29% of all HIV diagnoses made in these services in 2016. The number of people from this group who decline an HIV test is increasing and stood at 27% in 2016.

In the UK, 42% of people diagnosed with HIV in 2016 were diagnosed at a late stage of HIV infection - this is defined as having a CD4 count under 350 within three months of diagnosis. However, progress is being made in this area, with the number of late HIV diagnoses falling by 45%, from 3,930 in 2007 to 2,170 in 2016.

Rates of late diagnosis are highest in heterosexual men (60%) and heterosexual women (47%). This is a particular issue in black African communities, amongst whom 65% of men and 49% of women were diagnosed at a late stage of infection in 2016. The lowest proportion was among men who have sex with men, where 32% were diagnosed late. Overall, 51% of people who inject drugs were diagnosed late.

Although late diagnosis of HIV has declined in the last decade, from 56% in 2005 to 42% in 2016, this figure remains unacceptably high and further work to expand HIV risk awareness, testing and diagnosis is needed.

Many groups continue to push for a move from ‘opt-in testing’ to ‘opt-out testing’ (where patients are given an HIV test alongside routine checks unless they decline it). The National Institute for Health and Clinical Excellence (NICE) has advocated for expanding testing outside clinical settings by engaging community organisations, developing local strategies to increase testing, and by providing rapid HIV tests.


As of 2016, all parts of the country now provide access to alternative HIV testing options such as HIV self-sampling services or community-based HIV testing.

**HIV prevention programmes in the UK**

HIV prevention programming in the UK is largely run by HIV Prevention England (HPE) which is coordinated by the Terrence Higgins Trust and focuses primarily on the needs of men who have sex with men and black Africans.

**Pre-exposure prophylaxis (PrEP)**

Pre-exposure prophylaxis (PrEP) is a daily course of antiretroviral drugs (ARVs) that can protect HIV-negative people from HIV.

Since October 2017, a 3-year trial of PrEP is being rolled-out across 200 sexual health clinics in England. The trial will provide 10,000 people who are at high risk of acquiring HIV with PrEP. Previously, the NHS in England had argued that it did not have the funds to pay for PrEP, however this decision not to fund PrEP was overturned in court.
As part of the trial, data will be collected on PrEP need, uptake and duration of use.48

**Harm reduction**

*Needle and syringe programmes (NSPs)*

The last measure of *needle and syringe programme* (NSPs) coverage in the UK was in 2006. At the time, 80% of NSPs were pharmacy-based while the remainder were specialist centres. In 2014, the NICE released new guidance on the provision of NSPs calling for a better mix of services.49

The UK has reached the recommended World Health Organization target of 200 syringes distributed for every person who injects drugs per year. However, a survey carried out for Public Health England (PHE) in 2016 found less than half (46%) of people in England, Wales and Northern Ireland who had injected drugs in the past 28 days had adequate needles and syringes. This figure rose to 72% among people who had injected drugs in the past six months in Scotland.50

*Opioid substitution therapy (OST)*

In England and Wales, progress in the provision of opioid substitution therapy (OST) is being threatened by a drive towards abstinence-based treatment. In 2017, the British government released an updated drugs strategy which stated its overall aims as being a reduction in all illicit and other harmful drug use, and an increase in the rate of individuals fully recovering from their dependence.51

An abstinence-based treatment approach has been disputed by many groups who say this is only a realistic target for a minority of drug users and that many would finish treatment too early, leading to a relapse.52

**HIV education and awareness**

*School education*

In the UK, state schools have to provide sex and relationship education (SRE) but private schools do not. Parents also have the right to withdraw their children from SRE, though few do so.53

In a review of the National Curriculum in 2013, the UK government said that all state schools "should make provision for personal, social, health and economic education (PSHE), drawing on good practice"54 and that SRE is an "important and necessary part of all pupils’ PSHE education."55

However, in the same year, a report by Ofsted - the official body that regulates schools in England - reported that curriculum provision for this subject area was only ‘good’ or ‘better’ in two-thirds of schools.56

In 2017, the UK government went further by making it a statutory requirement for primary schools (ages 5-10) to provide relationships education, for secondary schools (ages 11-16) to provide relationships and sex education and for both to provide personal, social, health and economic education. This was put into law in March, 2017, and will be effective from September 2019.57

*Public awareness*

In the early years of the HIV epidemic, there were a number of high profile public awareness campaigns in the UK warning people about how you get HIV and calling for people to adopt safer sex behaviours.
However in recent years, there have been very few public HIV awareness campaigns. Even sexual health campaigns such as ‘Condom Essential Wear’ in 2009 often make no reference to HIV. In 2011, however, the government launched a new initiative called, ‘National HIV Testing Week’ that aimed to increase HIV awareness and testing among key affected populations in England, particularly men who have sex with men and black African communities in the UK. A survey following the 2016 National Testing Week found that 60% of men who have sex with men in the UK were aware of National HIV Testing Week. The campaign has also been successful in increasing the number of orders placed for HIV self-testing kits from 9,518 in 2014 to 13,527 in 2016.

**Antiretroviral treatment (ART) availability in the UK**

Over the last few years, the number of people living with HIV and accessing ART in the UK has continued to increase, from 84% in 2010 to 96% (of 91,987 people living with diagnosed HIV) in 2016. In the same year, 97% of those on ART were virally suppressed. This means the UK now meets two of the three UNAIDS 90/90/90 targets.

ART coverage across key affected populations mirrors overall treatment coverage rates with the slight exception of younger people and people who inject drugs, who have treatment coverage of 89% and 93% respectively.

In 2016, 97% of men who have sex with men, 97% of heterosexual men and women and 93% of people who inject drugs were virally supressed.

Improvements in HIV care means that people living with diagnosed HIV are growing older. In 2016, more than a third (38%) of people accessing HIV care were aged 50 and above, compared with 17% in 2007.

To ensure all people diagnosed with HIV achieve viral suppression and untransmittable levels of HIV, NHS England have implemented a new policy of immediate treatment for HIV as soon a diagnosis is made. This reflects WHO guidelines that call for the initiation of ART immediately after HIV diagnosis, regardless of CD4 count.

As a result of this the time between being diagnosed with HIV and starting ART has dropped. In 2016 76% of the people diagnosed with HIV initiated treatment within 90 days, compared to 33% in 2007. However, the waiting time varies widely between clinics.

**Civil society role in the UK**

One of the most significant civil society achievements in the UK in recent years has been in advocating for PrEP. Communities have led in pushing for PrEP to be made available in the UK, both through the National Health Service and for purchase online.

In October 2015, the community-run website www.IwantPrEPnow.co.uk was launched. It provides individuals interested in using PrEP with information on what it is and how it is taken. It also enables users to buy cheaper generic versions of the drug, which are not available to buy in the UK, through the site. It was estimated that in January 2016, 2,000 people were buying PrEP this way. In 2016, new infections among gay men fell by 21% compared to the year before, it is thought that internet access to PrEP might have been a significant contributing factor in this drop.

Furthermore, 2016 saw the National AIDS Trust successfully sue the National Health Service (NHS) for its decision to remove PrEP from the list of medicines being considered for funding. Following on from the trial, in September 2017, the NHS announced that it would launch a new
three-year trial of PrEP, to an estimated 10,000 people. The results of the study will be used to inform a potential roll-out of PrEP.

**Barriers to HIV prevention in the UK**

**Social barriers**

*Stigma and discrimination*

As in many other parts of the world, HIV-related stigma and discrimination prevent many people in the UK from accessing the services they need.

The ‘UK Stigma Index 2015’, a survey of more than 1,500 people living with HIV in the UK, found that a considerable number of people in the UK still hold stigmatising attitudes towards those living with HIV.

Around one in five people reported being excluded from family events because of their HIV status and 20% reported sexual rejection after disclosing HIV. A third of all participants feared being rejected by a sexual partner (35%) and had avoided sexual encounters (33%) in the last 12 months due to their status.

A 2014 survey among black Africans living with HIV reported that a third had been discriminated against because of their HIV status. Half of this number said they had been discriminated against by healthcare workers (including doctors, dentists and hospital staff). As a result, many do not trust in the confidentiality of health services.

“It’s amazing that despite the advances in treatment, people’s attitudes are still exactly the same.” Black African women living in London, diagnosed with HIV in 1996.

*Lack of HIV knowledge*

There is also evidence that levels of HIV knowledge among the UK public is low. A survey by the National AIDS Trust in 2014 found that only 45% of people could correctly identify all of the ways HIV is and is not transmitted, and an increasing proportion incorrectly believed it can be transmitted via routes like kissing (16%).

Talking about the need to educate the general public about HIV, Deborah Gold, Chief Executive of the National AIDS Trust said:

“It is alarming to see just how many people believe you can get HIV from kissing, sneezing, or coughing. Lack of understanding leads to stigma and discrimination towards people living with HIV.”
Structural barriers

While HIV treatment was made free to people from overseas in 2012, many migrants living with HIV in the UK face other difficulties in accessing treatment, care and support. Undocumented migrants in particular find it difficult to register with a local General Practice (GP) and are often required to prove their identity and do not understand NHS entitlement rules or how to apply for treatment.

Funding for the HIV response in the UK

In 2015 the UK government announced it intended to cut funding for HIV prevention by 50% in the financial year 2015/16 to £1.2 million. This is less than £1 for each person targeted by existing prevention programmes.

However, a campaign against the cuts led by the National AIDS Trust was successful and the overall amount spent remained more or less stable at £2.4 million.

The government cut spending on HIV prevention by 6.25% in 2016/17 to £2.25 million.

The future of HIV and AIDS in the UK

The UK has made significant progress in the provision of antiretroviral treatment over the past decade. However, gaps in HIV prevention and education mean men who have sex with men and black Africans are still at a heightened risk of HIV.

Late diagnosis rates are still too high and have an impact on individual health outcomes as well as on public health as people living with an undiagnosed infection are more likely to pass the virus on to others.

As well as better access to testing services, in order to prevent new infections, there needs to be renewed efforts to increase HIV knowledge across the country through both public campaigns and education in schools.

deaths in the UK’ [pdf]


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