



HIV in England: Addressing areas of unmet need and reducing the numbers of people with transmissible levels of HIV

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Foreword

We have all the tools needed to end new cases of HIV in this country by 2030 and could even be the first country to meet this global goal. However, this will only happen if we are using all the tools available to us – and know how best to deploy them.

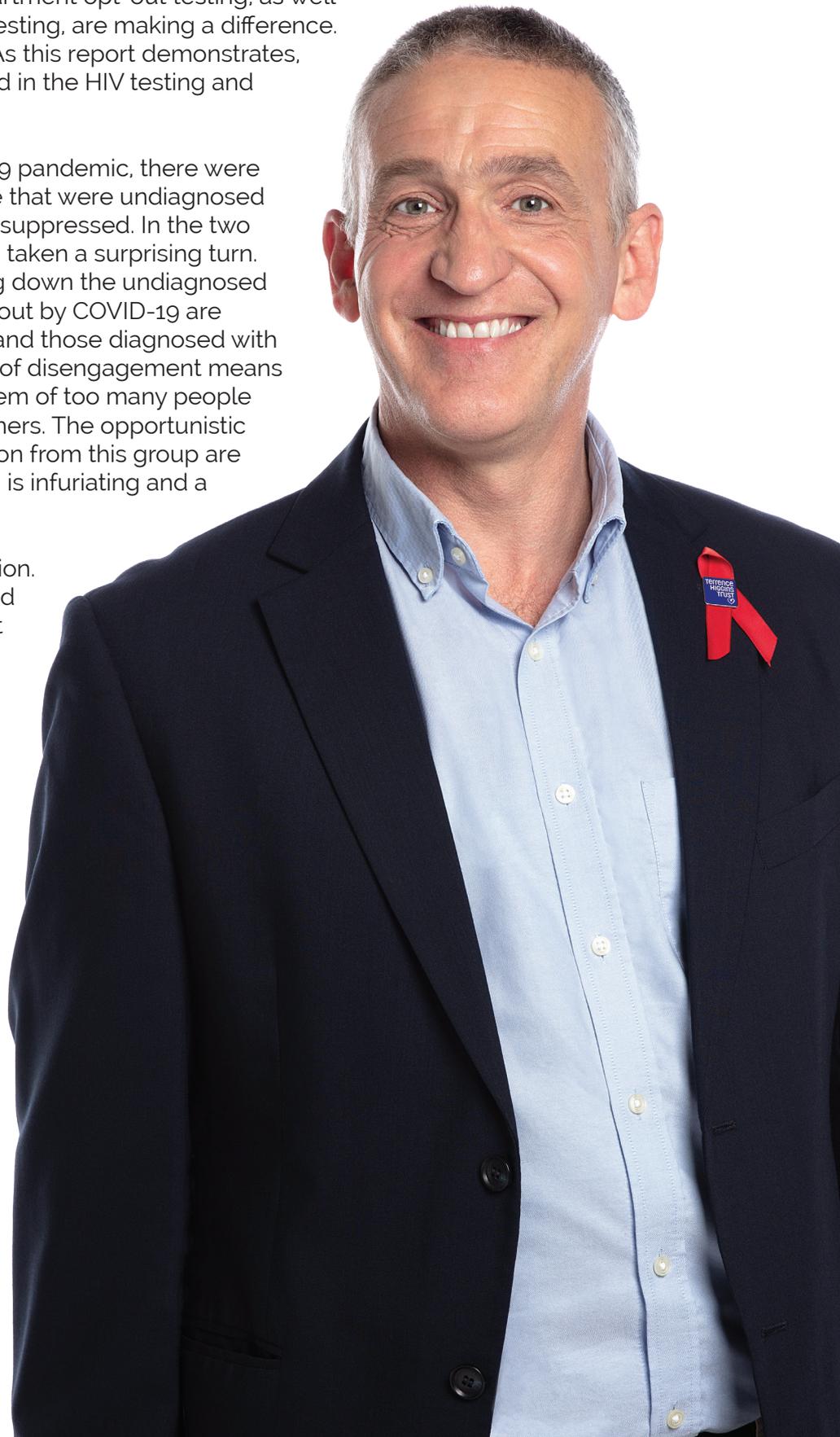
Innovations like Emergency Department opt-out testing, as well as 'Click and Collect' postal HIV testing, are making a difference. But these measures are limited. As this report demonstrates, there is still too much unmet need in the HIV testing and diagnosis system.

Immediately prior to the COVID-19 pandemic, there were roughly equal numbers of people that were undiagnosed and diagnosed but not yet virally suppressed. In the two years that have followed, this has taken a surprising turn. As quick as HIV testing is bringing down the undiagnosed number, the changes brought about by COVID-19 are seeing more people lost to care and those diagnosed with a detectable viral load. This level of disengagement means HIV is attacking the immune system of too many people and is able to be passed on to others. The opportunistic infections and onward transmission from this group are wholly preventable. This situation is infuriating and a mark of real failure.

This report is a clarion call for action. The good practice is out there and we champion it on the pages that follow. Together we can end new cases of HIV and ensure people living with HIV live well. Please make every contact count.



Ian Green
Chief Executive



Introduction

In January 2019, the then Health Secretary made ending new cases of HIV by 2030 a national priority; he was followed by his equivalent in Wales (November 2018) and by Scotland (December 2020) in making the same pledge. This built on the UK meeting the 2020 UNAIDS 90-90-90 target in 2017¹. Encouragingly, in 2020, data from the UK Health Security Agency (UKHSA) showed that England met the 2025 UNAIDS 95-95-95 targets early; 95% of people living with HIV have been diagnosed, 99% of those are on HIV treatment, and 97% of people on treatment have undetectable levels of HIV². However, the same data showed as many as 1 in 5 people living with HIV in England (19,800) have transmissible levels of virus. The Department for Health and Social Care, alongside most leading experts, agree with the HIV Commission's analysis that to be on track for 2030, there must be a reduction in new infections of 80% by 2025³.

Last World AIDS Day, the UK government laid out its plans to meet the 2030 goals. A key component was securing funding for opt-out HIV testing in emergency departments in very high HIV prevalence areas in England⁴. This was the first new funding for HIV testing in almost a decade. However, with progress come more challenges. As new infections reduce, it also becomes harder to find people living with undiagnosed HIV and certain groups continue to be disproportionately affected by HIV and late diagnosis. Moreover, a reduction in diagnoses does not tell the whole story; retention in HIV care is also crucial for achieving the end of HIV transmissions.

“If England is to achieve the 2030 goals, we must be innovative to identify and respond effectively to the high numbers of people with transmissible levels of the virus and areas of unmet need.”

- HIV Action Plan

The most recent data show that the declines in both new diagnoses and undiagnosed HIV cases have not been equal across all demographics, and unacceptable inequalities remain. This has been compounded by the COVID-19 pandemic, which significantly disrupted delivery of HIV testing and prevention. Made significantly worse by the COVID-19 pandemic was those lost to care with a 20% increase from 2019 to 2020. Most recent figures show 5,589 people living with HIV are not accessing virtual or in-person HIV care, showing a decrease compared to 2020 (7,600) but is still higher than 2019 (3,967)⁵.

If England is to achieve the 2030 goals, we must be innovative to identify and respond effectively to the high numbers of people with transmissible levels of the virus and areas of unmet need. This report examines the most recent data from the UKHSA on HIV testing, diagnoses, outcomes, and access to HIV care services in England. It also draws on current research and makes key recommendations for addressing health inequalities and achieving the 2030 goals.

1 Kirby, T., (2018), The UK reaches UNAIDS 90-90-90 targets. *The Lancet*, 392, p.2427

2 UKHSA (2021), *HIV testing, new HIV diagnoses, outcomes and quality of care for people accessing HIV services: 2021 report*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1037215/hiv-2021-report.pdf

3 HIV Commission (2020): <https://www.hivcommission.org.uk/final-report-and-recommendations/>

4 Department of Health and Social Care (2021), *Over £23 million investment to end new HIV infections by 2030*. Available at: www.gov.uk/government/news/over-23-million-investment-to-end-new-hiv-infections-by-2030

5 UKHSA (2022), *HIV testing, PrEP, new HIV diagnoses, and care outcomes for people accessing HIV services: 2022 report*. Available at: <https://www.gov.uk/government/statistics/hiv-annual-data-tables/hiv-testing-prep-new-hiv-diagnoses-and-care-outcomes-for-people-accessing-hiv-services-2022-report>

HIV testing

HIV testing is crucial for improving health outcomes for people undiagnosed with HIV, as well as preventing onward transmission⁶. Yet the number of people tested for HIV at a sexual health service (SHS) fell by 30% between 2019 and 2020⁷, and despite a partial recovery, there were still 20% fewer people tested in 2021 (1,053,169) compared with 2019 (1,319,915)⁸. The decline in testing has not been consistent between demographics. Among gay and bisexual men, there was only a 7% decrease between 2019 and 2020, and the latest data show testing has recovered to pre-pandemic levels among this group, with a 14% increase in testing from 2019 to 2021 (an increase from 156,631 to 178,466). However, among heterosexuals, there was a 33% decrease in testing between 2019 and 2020, and these numbers have not recovered to pre-pandemic levels. Among heterosexual and bisexual women there has been a 22% reduction in testing between 2019 and 2021, and a 41% reduction among heterosexual men. This reduction is particularly acute among White heterosexual men and women (44% and 24% respectively), Black Caribbean heterosexual men and women (42% and 22%), and Indian, Pakistani or Bangladeshi heterosexual men and women (42% and 29%).

Whilst targeted HIV prevention campaigns have had considerable success among gay and bisexual men, increasing the uptake of prevention methods, including regular testing and pre-exposure prophylaxis (PrEP)⁹, the disparities in testing behaviours among other groups show the need for a different approach. We must learn lessons from COVID-19, which revealed shortfalls in targeted and symptom-based testing, highlighting that mass testing is more effective¹⁰. The evidence shows that mass HIV testing is successful, for instance opt-out testing has increased diagnoses and led to improved health outcomes among pregnant women living with HIV, and virtually eliminated vertical HIV transmission in the UK. Moreover, the Elton John AIDS Foundation (EJAF)'s HIV Testing Social Impact Bond has piloted opt-out testing in emergency departments and GPs in three south London boroughs, through which 209 individuals have been diagnosed and 256 people have been returned to HIV care¹¹. This single intervention has done more to address the health inequalities in those undiagnosed than almost any other – 40% were women, compared to 28% nationwide, and 54% are Black African, Black Caribbean or Black Other, compared to 22% nationwide.

The initial findings from the first 100 days of opt-out BBV testing in emergency departments has shown remarkable results; 102 people have been newly diagnosed with HIV, and 60 people who were lost to care have been identified. There have also been 328 new Hepatitis B diagnoses and 30 people who were lost to care identified, and 137 new Hepatitis C diagnoses, and 23 people who were lost to care identified¹². It is now time to expand opt-out testing and ensure no one is left behind in the UK's HIV response¹³. While we welcome the rollout of opt-out testing in emergency departments in very high prevalence areas in England and high prevalence areas in London, we continue to call for this to be expanded to emergency departments in all areas of high prevalence¹⁴ and GPs and other NHS settings in both categories.

6 The Lancet HIV (2017). *The role of testing in HIV prevention*. The Lancet, 4, p.e189

7 UKHSA (2021). *HIV testing, new HIV diagnoses, outcomes and quality of care for people accessing HIV services: 2021 report*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1037215/hiv-2021-report.pdf

8 UKHSA (2022)

9 NAM (2022). *What led to the fall in HIV cases in UK gay men?* Available at: <https://www.aidsmap.com/news/feb-2022/what-led-fall-hiv-cases-uk-gay-men>

10 Mbwoogge, M., (2021) *Mass Testing With Contact Tracing Compared to Test and Trace for the Effective Suppression of COVID-19 in the United Kingdom: Systematic Review*. JMIRx Med, 2, p. e27254

11 The Elton John AIDS Foundation (March 2020) *The Elton John AIDS Foundation 'Zero HIV' Social Impact Bond Final report on investment, implementation, and impact*.

12 Professor Kevin Fenton's Key Note Speech at the 2022 HIV Prevention England Conference

13 National AIDS Trust (2021). *Why we must normalise HIV testing for all*. Available at: www.nat.org.uk/blog/why-we-must-normalise-hiv-testing-all

14 DHSC (December 2021) *Local authorities with high or very high HIV prevalence (2019)*. Available at: <https://www.gov.uk/government/publications/towards-zero-the-hiv-action-plan-for-england-2022-to-2025/annex-b-local-authorities-with-high-or-very-high-hiv-prevalence-2019>

	HIV	Hepatitis B	Hepatitis C
New diagnoses	102	328	137
Lost to care	60	30	23
Number of tests	201,000	82,000 surface antigen	69,000 HCV antibody 8,200 RNA

Source: Presentation from Kevin Fenton to HIV Prevention England Conference, 30 September 2022

Despite many challenges arising from the COVID-19 pandemic, it also created opportunities for alternative service provision. As many services suspended face-to-face consultations, the uptake of online HIV testing increased. Of those who tested for HIV in 2021, 53% did so online. Online testing was especially prevalent among Black African heterosexuals, increasing by 3,212 (45%) among men and 4,819 (46%) among women between 2020 and 2021¹⁵. These figures make it even more concerning that free HIV postal testing services are not available England-wide outside of National HIV Testing Week. The HIV Action Plan claims online HIV testing is at nearly 99% coverage but the data used to make this claim are not published. It likely includes places like Lincolnshire, which only provides postal testing services for chlamydia and gonorrhoea¹⁶. Due to budget constraints, a number of postal services have limited tests available for each local authority, and services can be turned off mid-month and patients encouraged to check back at a later date.

Whilst the importance of providing online testing across sexual health services is obvious, it is not a replacement for good in-clinic services and there are potential pitfalls in relying too heavily on online testing. For instance, the number of heterosexual people offered an HIV test through sexual health services declined from 83% in 2019 to 60% in 2020, and this did not improve in 2021; 38% of eligible attendees were not offered an HIV test in SHSs in 2020 and 2021¹⁷. However, this was also a substantive problem before a move to virtual appointments during COVID-19. In 2019, 34% of Black African women left specialist sexual health services without receiving a test for HIV – 15% were not even offered a test and the rest declined one when offered¹⁸. It is clear that too many opportunities to test for HIV, as well as talk about HIV prevention, are being missed.

Moreover, certain populations may face particularly acute barriers to using online healthcare services, for example those affected by homelessness, who are less likely to have access to the internet and face challenges with receiving at-home testing kits¹⁹. This is also true for students, renters and those who live in multi-occupancy homes, people who have sex outside their main relationship and younger people living with parents or grandparents. A 'Click and Collect' service can help overcome some of these barriers. Our data show that one in 10 people accessing our postal HIV testing service utilised one of the 4,000 collection sites. In particular, usage was high among those from an ethnic minority background, including 18% among Black African men, and higher among Black African men aged 35-49. Men who have sex with men (MSM) from ethnic minority backgrounds were also more like to choose 'Click and Collect'; 29% from MSM of Pakistani backgrounds, 24% from MSM of Indian backgrounds and 19% from MSM of Chinese background²⁰. All postal testing providers must learn these lessons to ensure home testing is accessible.

15 UKHSA (2022)

16 LiSH website (September 2022) <https://lincolnshiresexualhealth.nhs.uk>

17 UKHSA (2022)

18 PHE (2020). *Trends in HIV testing, new diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2019*. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/959330/hpr2020_hiv19.pdf

19 Seaview Project (2017). *An investigation into access to digital inclusion for healthcare for the homeless population*. Available at: <https://amhp.org.uk/app/uploads/2018/11/Digital-Inclusion-and-Homeless-People.pdf>

20 Terrence Higgins Trust/AIDS 2020 (July 2020) *Gathering result data for analysis and provision of follow-up support as part of a nationwide HIV self-testing service in the United Kingdom – Self testing free service final report - additional data*

New diagnoses

New HIV diagnoses in England have declined by 39% between 2017 and 2021²¹. For gay and bisexual men, new diagnoses have fallen by 53% in the same time frame. This indicates a reduction in HIV transmission within this group, likely driven by testing, treatment as prevention – people on effective treatment cannot pass on HIV – and the uptake of PrEP²². However, when disaggregating the data, it becomes clear the reduction in transmission is not representative of all gay and bisexual men. Declines in diagnoses are less apparent among those based outside of London, those of Black, Asian, and Mixed ethnicity, and those born overseas²³. Qualitative research has revealed that Black, Asian, and Latin American gay and bisexual men have experienced racism and isolation within the “gay scene” in the UK, which has hindered access to peer information and the social norms around HIV prevention, which in turn lowers attendance at sexual health services²⁴.

It is clear that we cannot succeed in achieving the 2030 goals if we do not effectively acknowledge and respond to other societal challenges, such as homophobia and racism in HIV prevention strategies. Many health promotion efforts continue to focus on the experiences of gay and bisexual men, and often only focus on disaggregated data by ethnicity for heterosexuals²⁵. More attention must be given to the intersections between sexual orientation, gender, and ethnicity as we move closer towards ending HIV transmissions in England.

Among heterosexuals, the data show a 32% decline in new diagnoses between 2017 and 2021. There has been a 39% decline in diagnoses among White heterosexuals (415 in 2017 to 252 in 2021), and a 37% decline among Black African heterosexuals (463 in 2017 to 294 in 2021)²⁶. However, the steepest decline in new diagnoses among heterosexuals overall was by 32% between 2019 and 2020. There has been minimal change in diagnoses between 2020 (491) and 2021 (459). Therefore, these data must be considered in relation to lower testing rates in 2020, suggesting the figures may be a result of reduced testing rather than reduced transmissions.

Whilst targeted interventions among White gay and bisexual men have been successful in reducing transmissions, by generating networks of information and normalising HIV prevention²⁷, this same approach should not simply be applied to other demographics. Preferences for how and where to test for HIV differ across social groups, as evidenced by the ‘Click and Collect’ service. Currently, HIV testing is predominantly offered at sexual health clinics, but certain populations, such as people of Black African ethnicity and people aged 50+ are less likely to access sexual health services in favour of their GP^{28,29}. It is necessary to shift from a focus on behaviour change and instead focus on improving institutional practices to meet the needs of diverse services users and address health inequalities³⁰.

21 New diagnosis refers to those who have been diagnosed for the first time in the UK, as opposed to those previously diagnosed abroad and recently arrived into the UK.

22 Brizzi, F., et al., (2021). Tracking elimination of HIV transmission in men who have sex with men in England: a modelling study. *The Lancet HIV*, 8: p. e440-e448

23 UKHSA (2022)

24 Nicholls, E.J., et al. (2022) Experiences of and attitudes towards HIV testing for Asian, Black and Latin American men who have sex with men (MSM) in the SELPHI (HIV SelfTesting Public Health Intervention) randomized controlled trial in England and Wales: implications for HIV self-testing. *BMC Public Health*, 22: p. 809.)

25 Nicholls, E.J., et al. (2022)

26 UKHSA (2022). HIV: annual data tables. Available at: <https://www.gov.uk/government/statistics/hiv-annual-data-tables>.

27 Nicholls, E.J., et al (2022)

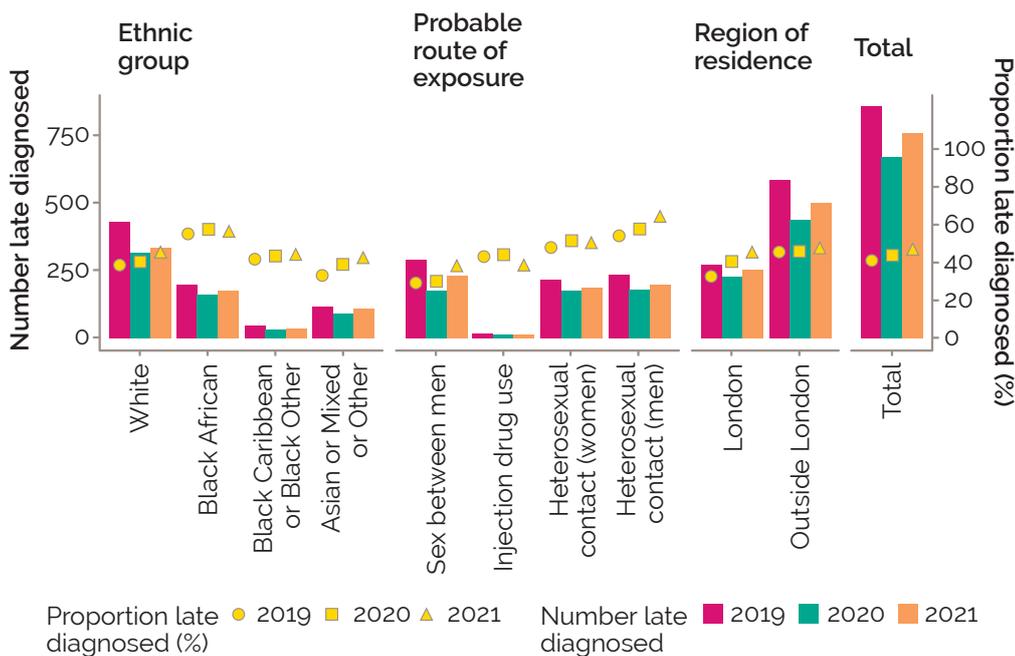
28 Seguin, M., et al. (2018) Self-sampling kits to increase HIV testing among black Africans in the UK: the HAUS mixed-methods study. *Health Technology Assessment*. 22.

29 Youssef, E., et al. (2018) Factors associated with testing for HIV in people aged ≥50 years: a qualitative study. *BMC Public Health*. 18: p. 1204.

30 Leitch, S., et al., (2020) Black Lives Matter in health promotion: moving from unspoken to outspoken. *Health Promotion International*, 36: p. 1160-1169

Late diagnoses

Late diagnosis is defined as having a CD4 count of less than 350 cells/mm³ where there is no evidence of recent seroconversion³¹ which may result in a transient decline in CD4 cell count. Late diagnosis of HIV can have serious consequences for the individual, such as opportunistic illnesses, an elevated risk of mortality within a year of diagnosis, and an increased likelihood of onward transmission. Late HIV diagnoses remain unacceptably high in the UK. In 2021, 46% of all new diagnoses in England were at a late stage of infection – an increase from 41% in 2019 and 44% in 2020. Heterosexual men and women showed the highest rates of late diagnosis at 63% and 50% respectively, compared with 37% of gay and bisexual men. Late diagnosis was also more prevalent among people of Black African ethnicity at 56%, and older people - 59% for those aged 50-64 and 73% for those aged 65+³². A key contributing factor to late diagnosis is missed opportunities to test³³.



UKHSA (2022). HIV: annual data tables.

To reduce late diagnosis and overcome missed testing opportunities, research calls for late HIV diagnoses to be categorised as a serious incident requiring investigation³⁴ – another recommendation of the HIV Commission. Alternative solutions include the expansion of opt-out testing, particularly to regions where late diagnosis is most prevalent, such as Bolton (50%) and Wolverhampton (47%)³⁵. Opt-out testing has thus far proved successful and is a step towards addressing health inequalities. In London hospitals, where it has been piloted, those diagnosed were more likely to be heterosexual, women, people of Black ethnicity, and people older than those diagnosed in sexual health clinics³⁶.

31 The stage at which the immune system starts reacting to HIV and antibodies become detectable and give an HIV-positive test result.
 32 UKHSA (2022). HIV: annual data tables. Available at: <https://www.gov.uk/government/statistics/hiv-annual-data-tables>
 33 HIV Commission (2020). 'Test, test, test' – the clear message from the HIV Commission. Available at: <https://www.hivcommission.org.uk/2020/12/18/test-test-test-the-clear-message-from-the-hiv-commission>
 34 Chadwick, D.R. and A. Freedman (2019) Treating late HIV diagnosis as a patient safety issue in the UK. *The Lancet HIV*. 6: p. e346-e348.
 35 Office for Health Improvement and Disparities (2021). *Sexual and Reproductive Health Profiles*. Available at: <https://fingertips.phe.org.uk/profile/sexualhealth>
 36 Terrence Higgins Trust (2022). *HIV testing when blood is taken in A&E launched in London hospitals*. Available at: <https://www.tht.org.uk/news/hiv-testing-when-blood-taken-ae-launched-london-hospitals>

Lost to care

Progress towards the 2030 goals is not irreversible – people may stop taking their treatment, disengage with care and develop detectable viral loads. Therefore, we must be cautious about drawing conclusions from the 95-95-95 targets, which assume that once diagnosed and linked to care, people stay in care and remain virally suppressed. However, in 2021, one in 10 people living with HIV had a detectable viral load – around 19,800 people. We know 5,150 of those are undiagnosed, and 7,250 people are diagnosed but not linked to care. In 2021, an estimated 5,589 people were lost to follow-up, compared with 7,600 in 2020 and 3,967 in 2019³⁷. While these figures may be partly attributed to the COVID-19 pandemic as evidenced by the high number lost to follow-up in 2020, it is still considerable and worrying, and it is unclear whether HIV clinics have the resources to substantially reverse this figure.

As the EJAF report highlights, there are tried and tested ways for returning people to care; in total their Social Impact Bond (SIB) re-engaged 256 people to care³⁸. Opt-out testing played an important part, returning 53 people to care. Of these, 81% had a CD4 count of less than 350 and a serious risk of developing AIDS-defining illnesses. This initiative will have prevented both HIV-related deaths and huge costs to the NHS resulting from patients presenting at hospital with late-stage HIV and opportunistic infections. However, most of their number – 153 people – were found by HIV clinic audit and recall. This is a 'time-consuming intervention' but necessary – 63% of those found via this method had a CD4 count of less than 350. In many cases people required intensive repeated contact to establish a rapport, needing support such as food or travel vouchers, and potentially meeting in a community HIV clinic to avoid the possibility of being recognised. It cost under £3,000 per person to re-engage patients to care through HIV clinic audit – a third of the cost of returning someone to care through opt-out testing. Worryingly, EJAF found 'commissioners had a perception that this activity was already funded through HIV clinic contracts, but the reality is that HIV staff capacity within SIB providers did not allow sufficient resource for this, nor was it included in job plans.'

Through primary care audit and recall, 45 people were re-engaged in care, and 51% had a CD4 count of less than 350. This activity had a higher cost associated – less than £10,000 per person. EJAF report that, 'different federations employed different methods. One federation had a person in the management team contact people who had disengaged, whilst others filtered the HARS list and then contacted the individual surgery to engage the person. Response rates were broadly similar for each method.' However, neither of these methods, nor any primary care re-engagement, is currently commissioned within existing contracts.

Lastly, EJAF used the voluntary, community and social enterprise (VCSE) sector to influence people to re-engage 'through their role as trusted contacts' and found a further five people - 40% of whom had a CD4 count of less than 350 - for less than £10,000 per person returned to care.

When opt-out testing in London was funded in December 2021, there was talk of 10% being earmarked for re-engagement of care, potentially through in-clinic and community programmes run in partnership with the VCSE. So far, little has come of these proposals, which must be reviewed.

EJAF found that reasons for disengagement included fear of HIV stigma and very challenging lives - we know from research that people living with HIV are twice more likely than the general public to be living in poverty. Regarding stigma, people living with HIV reported to the HIV Commission that they were most likely to experience HIV-related stigma from a healthcare professional. Despite all the work involved and the very real health risk, 'some people refused to be re-engaged, citing fears of HIV stigma in their community, or denial of their status.'

³⁷ UKHSA (2022)

³⁸ The Elton John AIDS Foundation (March 2020) *The Elton John AIDS Foundation 'Zero HIV' Social Impact Bond Final report on investment, implementation, and impact.*

Missing data

Data on HIV testing, diagnoses, and access to prevention and treatment is crucial for identifying areas of unmet need or areas where there is slower progress. However, we must also remain cautious of how much we rely on data; whilst numbers can inform us of where disparities are they cannot tell us much about the complex social, cultural, and political contexts in which they exist³⁹. Moreover, data may not always be accurate or complete, which means that the needs of certain populations are not visible.

This is particularly relevant for sex workers where there is a lack of reliable data. Following a data request to UKHSA, we were informed that 42% of the records (1992 – 2022) have missing information on sex work and there is no available data on sex worker clients.

In the current cost of living crisis, which has seen more people turn to sex work for income⁴⁰, we must be prepared to understand and respond to their specific HIV and sexual health needs, including access to PrEP. The first step to achieving this is by collecting accurate and detailed data, which will allow us to understand how sex workers of different genders, age, and ethnicity are affected by HIV, as well as data about their clients.

Outside of the EJAF SIB, there is minimal data available on those lost to care. The lesson from south London suggests they are more likely to be heterosexual, women, people of Black ethnicity, older and experiencing poverty. Data in this area must be collected and analysed to drive a relentless strategy of re-engagement and drug adherence.

Quality of life

To successfully end HIV transmissions in the UK, we must not only focus on expanding HIV testing, but also continue to work towards improving the quality of life for people living with HIV. Although HIV treatment now means that people can live long and healthy lives, public attitudes have not progressed alongside these developments. People living with HIV continue to experience stigma and discrimination, and health and social services often fail to provide adequate care.

Patients have reported experiencing stigma due to low levels of HIV literacy among non-HIV health professionals, in particular providers of mental health services⁴¹. People living with HIV are twice more likely to experience feelings of depression and anxiety than the general public, and more than 1 in 3 have been diagnosed with a mental health condition. However, support services are failing to meet their needs; 40% of HIV clinics do not have access to a psychological or mental health professional within their multidisciplinary teams (MDTs)⁴².

There are similar concerns within social care. People aged 50+ living with HIV now represent almost half of all people accessing HIV care. A lack of coordinated healthcare, low levels of knowledge among staff in care homes, and polypharmacy are issues that threaten the welfare of older people living with HIV. Avoiding the anxiety for people living with HIV accessing social care, stopping further stigmatisation in this new setting and acknowledgement that people in care homes may be sexually active, must be a priority in our efforts to reach the 2030 goals⁴³.

39 Biruk, C. (2018) *Cooking Data: Culture and Politics in an African Research World*. Duke University Press.

40 English Collective of Prostitutes (2022). *Evening Standard: Cost of living crisis 'pushing more women into sex work'*. Available at: <https://prostitutescollective.net/evening-standard-cost-of-living-crisis-pushing-more-women-into-sex-work>

41 National AIDS Trust (2021). *HIV and Mental Health: Improving generic NHS talking therapy services for people living with HIV in England*. Available at: https://www.nat.org.uk/sites/default/files/publications/NationalAIDS_Trust_IAPT_Report_FINAL.pdf

42 APPG on HIV/AIDS (March 2020) *The Missing Link: HIV and mental health*. Available at: <https://www.chiva.org.uk/files/1115/8394/4622/TheMissingLinkWebversion.pdf>

43 Terrence Higgins Trust (2022). *Growing Older with HIV Strategy Summary Review*.

Conclusion

Although there is evidence that England is making progress towards ending HIV transmissions by 2030, it is clear that this progress is not equal across all demographics and unacceptable inequalities remain. In particular, those of Black, Asian, and Mixed ethnicity, older people, and heterosexual people are less likely to uptake HIV testing and more likely to be diagnosed late. Importantly, research indicates that this does not simply require behavioural change, but a need to develop more accessible services that effectively consider the intersections between gender, age, ethnicity, and sexual orientation in their institutional practices.

Opt-out testing is a promising development, which is a move towards ending missed opportunities to test. However, opt-out testing needs to be implemented in full to identify the remaining undiagnosed cases of HIV, reach those who are not routinely accessing sexual health services and re-engage the diagnosed into care. The latter will be more effective if commissioned alongside audit and recall methods in HIV clinics, in primary care and with VCSEs.

Finally, stigma, discrimination, and a lack of coordination between health and social care services remains a barrier to good quality of life for people living with HIV.

Recommendations

1 Opt-out testing

- a) To reduce rates of late diagnoses and to overcome missed opportunities to test, expand HIV opt-out testing in the following ways:
 - In line with 2020 BHIVA/BASHH/BIA guidance⁴⁴, to all admissions to hospital emergency departments in very high HIV prevalence areas, not just those already undergoing blood tests for another reason.
 - In line with 2016 NICE guidance⁴⁵, all emergency departments in high prevalence areas outside London to introduce 'HIV testing on admission to hospital, including emergency departments, to everyone who has not previously been diagnosed with HIV and who is undergoing blood tests for another reason.'
 - Roll out opt-out HIV testing in GPs and other NHS services in very high and high HIV prevalence areas, as described in the HIV Commission's 'testing traffic light' chart⁴⁶.
- b) To reduce late diagnosis, consider the adoption of opt-out HIV testing in areas with higher-than-average late diagnosis rates.

2 Online postal HIV testing

- a) Year-round postal HIV testing available in all areas of England, for all groups and demographics.
- b) All postal HIV testing providers should offer 'Click and Collect' services to increase access.

3 Data collection

- a) Collect more disaggregated data on transactional sex to understand how sex workers of different ages, genders and ethnicity, and their clients are affected by HIV.

4 Healthcare services

- a) Make all late diagnoses a serious incident requiring investigation.
- b) NHS/ICS commissioners must ensure HIV clinic audit and recall capacity is funded in HIV clinic contracts to resource the re-engagement of people into HIV care. Furthermore, they should consider contracting primary care and the VCSE sector to support return to care activities.
- c) Improve the integration of health and social care services to enhance quality of life for people living with HIV, in particular older people. This should include a psychological or mental health professional within HIV clinic multidisciplinary teams.

5 Stigma reduction

- a) Increase focus on intersectional issues that shape experiences of stigma and discrimination, such as the intersections between gender, sexual orientation, ethnicity, and age.
- b) Implement mandatory HIV awareness and stigma reduction training for professionals in health and social care systems.

44 BHIVA/BASHH/BIA (2020) *British HIV Association/British Association for Sexual Health and HIV/British Infection Association Adult HIV Testing Guidelines 2020*

45 NICE (December 2016) *HIV testing: increasing uptake among people who may have undiagnosed HIV*. Available at: <https://www.nice.org.uk/guidance/ng60>

46 HIV Commission (2020). *'Test, test, test' – the clear message from the HIV Commission*. Available at: <https://www.hivcommission.org.uk/2020/12/18/test-test-test-the-clear-message-from-the-hiv-commission>

About Terrence Higgins Trust

We are the UK's leading HIV and sexual health charity.

Our current strategy includes:

- working to end new transmissions of HIV in the UK by 2030
- supporting people to live well with HIV
- challenging the stigma associated with HIV and with poor sexual health
- delivering high quality services.

We do this by supporting people living with HIV and ensure their voices are heard, providing testing services for HIV and other sexually transmitted infections, and helping the people using our services to achieve good sexual health.

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