

# A roadmap for eliminating late diagnosis of HIV in England

*Halve It position paper*

## Executive summary

### ***A roadmap for eliminating late diagnosis of HIV in England***

presents the case for scaling up action to eliminate late diagnosis of HIV, the leading cause of premature death and disease among people living with HIV. Setting out key priorities for action, it lays down a challenge to us all – policy makers, commissioners, service providers, campaigners and people living with HIV – to work together with renewed drive to make the elimination of late diagnosis an achievable goal. It has been produced by Halve It, a coalition of agencies campaigning to eliminate late diagnosis in England.

### **Why is late diagnosis a problem?**

The risk of death and disease is greatly increased in people diagnosed late. Prompt diagnosis and treatment can give a normal life expectancy, prevent HIV transmission and save costs. Late diagnosis is declining but remains high, and there is significant variation across populations, settings and geographical areas.

In 2016, 42% of the 5,164 people newly diagnosed with HIV in the UK were diagnosed late. Late diagnosis is more frequent in older people. In absolute numbers, it affects gay and bisexual men the most.

Proportionately, it impacts heterosexual people the most, and especially black African men. There is regional variation with the highest actual number of late diagnoses, but the lowest proportion of diagnoses being made late, in London. Among all late diagnoses, people diagnosed very late, at the stage of advanced

### **Facts on HIV and late diagnosis\***

- Around 90,000 people are living with HIV in England
- About 12% remain undiagnosed and therefore unable to access life-saving treatment
- In 2016, 2,159 people newly diagnosed with HIV were diagnosed late
- The rates of late diagnosis are highest in black African men and women, though the greatest overall number of late diagnoses are in gay and bisexual men
- In 2016, 31% of 15-24 year olds were diagnosed late, 45% of 35-49 year olds, rising to 63% of over 65s
- Late diagnosis varies by region, with the highest proportion of late diagnoses seen in the Midlands and East of England (47%) and the lowest proportion in London (36%), although London has the greatest overall number of late diagnoses
- Two-thirds of late HIV diagnoses occur in the 79 local authority areas which have a high or extremely high HIV prevalence, where at least 2 in every 1,000 adults aged 15-59 has an HIV diagnosis
- Most HIV is diagnosed in sexual health services, but late-stage diagnosis occurs most often in hospitals, with too many diagnoses being missed until people become seriously ill
- People diagnosed late have a 10 times higher risk of death within one year of diagnosis than those diagnosed promptly
- The cost of HIV care in the first year after diagnosis is twice as high for those diagnosed late, with direct medical costs remaining almost 50% higher for each year after diagnosis

\* Late diagnosis of HIV refers to diagnosis at a stage when the virus has already significantly damaged the immune system. The standard definition is having a CD4 count of under 350 cells/mm<sup>3</sup> within 91 days of diagnosis

immunosuppression, are at highest risk of death and serious illness.

In contrast, people who are diagnosed promptly with HIV and receive effective antiretroviral therapy (ART) now have a normal life expectancy. They are also protected from passing HIV on to others because effective treatment reduces the virus in the body to an undetectable, untransmissible level.

Most people with HIV are diagnosed in sexual health services. Black African people are more likely to be diagnosed in other, mainly medical, settings. Around 1 in 20 new diagnoses are in non-medical settings, through community-based testing services, self-sampling and self-testing. Late, and especially very late, diagnosis occurs most often in hospitals (inpatients, outpatients, emergency departments and admissions units).

### Why does late diagnosis occur?

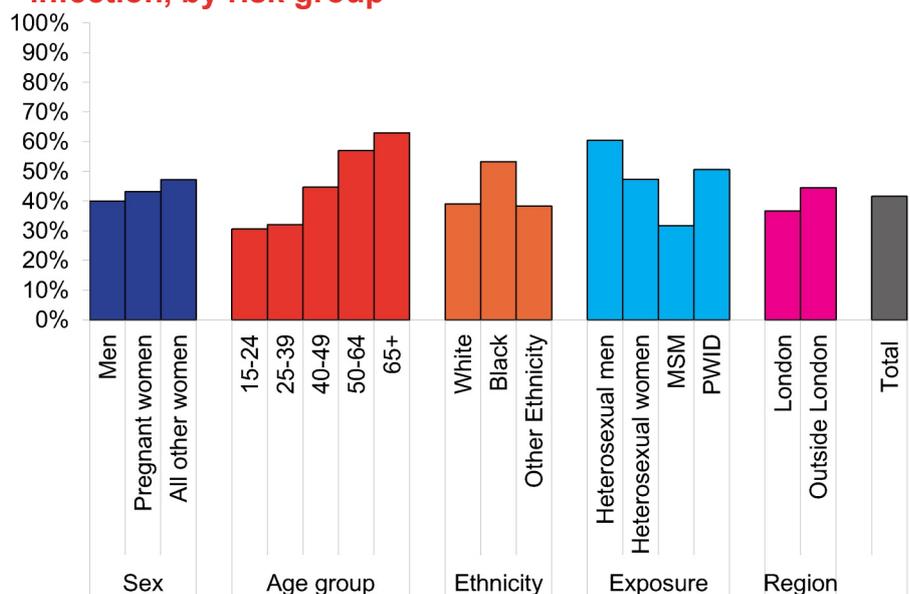
There are a number of barriers to implementing the volume, frequency and timing of HIV testing required to eliminate late diagnosis:

**People living with undiagnosed HIV** are not seeking testing as frequently as needed or at all because of factors including low risk perception, misinformation about HIV, fear of illness and death, fear of people finding out, social exclusion, concerns relating to migration status, and the stigma related to testing and to HIV itself. To eliminate late HIV diagnosis, information and services that address these barriers for the communities most at risk are essential, in order to increase their motivation and willingness to test, and to do so more frequently.

**Health professionals in primary and secondary care** often miss opportunities to diagnose HIV, despite patients finding an HIV test offer in these settings acceptable. There must be better knowledge and understanding of HIV among non-HIV specialists and a sea-change in their approach to HIV testing. And while sexual health professionals already play an essential role in diagnosing HIV promptly, more needs to be done to grasp the current challenges of promoting repeat testing for all groups and overcoming barriers to testing offer and uptake in women, especially in non-GUM (genitourinary medicine) sexual health services.

**At a system level**, fragmented commissioning arrangements hinder the whole system approach required, accountability across the system for rates of late diagnosis is lacking, and there is insufficient priority for tackling late diagnosis of HIV. The causes of late diagnosis occur across the system and to address them, whole system commissioning is important. Local authorities (LAs), clinical commissioning groups (CCGs) and NHS England need to work together to prioritise elimination of late HIV diagnosis, an outcome that will provide substantial cost savings as well as public health benefits across the system as a whole.

**Proportion of HIV diagnoses made at a late stage of infection, by risk group**



Source: Brown AE et al. *Towards elimination of HIV transmission, AIDS and HIV-related deaths in the UK – 2017 report*. Public Health England

## Cost-effectiveness of timely HIV diagnosis

Eliminating late diagnosis of HIV would bring substantial savings in the short, medium and long-term, because of lower medical costs and averted new infections. Prevalence levels at which routine HIV testing is cost-effective are

found in people with a number of HIV indicator conditions, and in the general population resident in 79 local authorities. Studies have demonstrated that screening in general practice and emergency departments (EDs) in areas of extremely high prevalence is cost-effective or even cost-saving.

Cost impact of late diagnosis	Resourcing increased HIV testing
If a person is diagnosed late the cost of HIV care in the first year after diagnosis is twice as high as for those diagnosed earlier, due to significant rates of morbidity and hospital admissions. Direct medical costs remain almost 50% higher for each year after diagnosis. Reducing late diagnosis averts higher treatment costs and social care costs associated with later-stage disease	The National Institute for Health and Care Excellence (NICE) analysed the resource impact of its 2016 testing guidance, concluding that the additional costs of testing and treatment would be offset by savings from treating people earlier and from reduced onward transmission
Averting costs of new infections	Cost effectiveness of routine HIV testing and testing interventions
In 2014, NICE estimated that if its testing guidance were implemented fully, 3,500 cases of onward transmission could be prevented in the next five years, saving the NHS more than £18 million a year in treatment costs  NHS England has deemed early treatment to prevent HIV transmission ('treatment as prevention') as cost-effective and probably cost saving	HIV screening interventions are cost-effective when undiagnosed prevalence in a population is 0.1% or above  A targeted approach of offering annual HIV testing to people at higher risk along with one-time screening of all other adults has been modelled and calculated to be cost-effective  Screening in general practice and EDs in areas of extremely high prevalence is cost effective and even cost saving

## Policy drivers and guidance

A number of international and national policy documents provide support for efforts to eliminate late diagnosis, but their impact is limited. For sustainability and transformation partnerships (STPs) and integrated care systems (ICSs), the public health benefits and long-term cost savings to be gained from prompt HIV diagnosis and access to treatment should provide a strong incentive for investment once resources are pooled (under ICS arrangements) and goals for improving health and wellbeing are shared. However, HIV is not a priority for most STPs at present.

The 2016 NICE guideline, *HIV testing: increasing uptake among people who may have undiagnosed HIV* makes

recommendations for HIV testing in all areas of England, with additional recommendations for further testing in areas of high and extremely high HIV prevalence. The *UK National Guidelines for HIV Testing* advise testing in a wide range of settings and the routine offer and recommendation of testing for patients with specific HIV indicator conditions. Public Health England also makes recommendations on HIV testing in a range of services.

## Progress towards eliminating late HIV diagnosis

Late diagnosis has been gradually decreasing over many years and this has been due to a range of interventions to expand the reach of HIV testing. The challenge now is to refine, roll out and sustain successful methodologies in line with the NICE guideline.

Guidance	Metrics	Collaborative models/ partnerships
<ul style="list-style-type: none"> <li>• NICE Guideline <i>HIV Testing: increasing the uptake among people who may have undiagnosed HIV</i> (2016)</li> <li>• NICE Quality Standard <i>HIV Testing: encouraging uptake</i> (2017)</li> <li>• <i>UK National Guidelines for HIV Testing</i> (2008)</li> <li>• PHE <i>HIV Testing in England</i> (2017)</li> </ul>	<ul style="list-style-type: none"> <li>• Public Health Outcomes Framework (PHOF) late diagnosis indicator</li> <li>• PHE's Sexual and Reproductive Health Profile indicators</li> <li>• NICE's threshold of diagnosed prevalence for additional action on testing in areas designated with high or extremely high prevalence</li> </ul>	<ul style="list-style-type: none"> <li>• Sustainability and transformation partnerships (STPs)</li> <li>• Integrated care systems (ICSs)</li> <li>• Fast-Track Cities Initiative to end AIDS</li> <li>• Social investment partnerships</li> </ul>

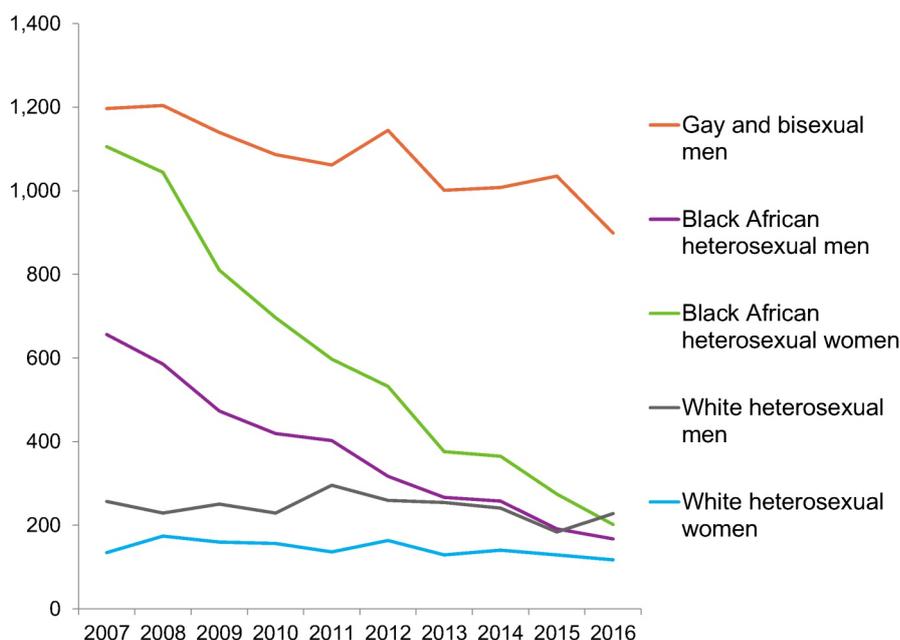
## Action required to move towards eliminating late diagnosis of HIV

Eliminating late diagnosis of HIV will result not only in reduced mortality and morbidity but also significant cost savings. However, policy designed to drive a reduction in late diagnosis has limited impact while fragmented commissioning arrangements undermine the incentives for investment and the erosion of public health funding continues. There are evidence-based guidelines which make clear what needs to be done, but they are far from universally followed and the challenge now is for implementation.

Leadership at all levels is needed. National and local politicians and community leaders can speak out to encourage HIV testing and hold local health systems to account for the action they are taking and the outcomes arising. Medical royal colleges and specialty associations can publicly endorse the drive both to reduce late diagnosis and to eliminate all new infections, highlighting the important role their members need to play.

An overarching requirement is political leadership along with a commitment to eliminating the stigma that hampers action to tackle HIV at all levels. The actions recommended in this paper should form part of a government strategy for eliminating HIV, echoing the UNAIDS goal of zero new infections and zero AIDS-related deaths by 2030. The adoption of such a strategy would provide a facilitative context for implementing the following priorities for action.

### Adjusted\* number of people diagnosed late by exposure group: UK, 2007 to 2016



\* Adjusted for missing CD4 count at diagnosis

Source: Brown AE et al. *Towards elimination of HIV transmission, AIDS and HIV-related deaths in the UK – 2017 report*. Public Health England

## Priorities for action: 2018 – 2023

Four key priorities for action are recommended as the first phase on a course to eliminate late diagnosis of HIV by 2030.

### 1. Galvanise action across LAs, CCGs and NHS England for joint planning to reduce late diagnosis of HIV

Whole system approaches are needed to reduce late diagnosis of HIV, where priorities, goals and resources are shared and actions are coordinated. The establishment of STPs and ICSs provides new opportunities for coordination between all commissioners and closer working with providers in a geographical area.

Action required	With leadership from
Use STPs, and ICSs where established, to plan and coordinate the commissioning of HIV testing across the whole system, according to local epidemiology and NICE guidance	LAs, CCGs, NHS England, provider organisations
Collate and disseminate data relevant to late HIV diagnosis at STP/ICS level, to enable benchmarking and analysis	PHE <sup>i</sup>
Involve providers and the public, including people living with HIV, in commissioning decisions	LA commissioners, CCGs, STPs, NHS England
Develop and share evidence that investment in HIV testing saves costs	PHE
Disseminate learning from whole system approaches to eliminating late HIV diagnosis, including STPs, ICSs, Fast-Track Cities, Social Investment Partnership	PHE, ADPH <sup>ii</sup> , LGA <sup>iii</sup> , NHS England, EJAF <sup>iv</sup>
Raise awareness of local councillors and national parliamentarians who can push for local action to tackle late HIV diagnosis	National and local HIV organisations, LGA
Hold local commissioners and providers to account	MPs, local councillors, people living with HIV, PHE

i. Public Health England

ii. Association of Directors of Public Health

iii. Local Government Association

iv. Elton John AIDS Foundation

## 2. Embed HIV testing in primary and secondary care to prevent late diagnosis

A quarter of people with HIV in England are not diagnosed until they reach a stage of advanced immunosuppression, despite having lived unknowingly with HIV for several years and often having previously presented to a range of healthcare settings. Identification of risk factors, screening in high prevalence populations and indicator condition-guided testing are all important for earlier diagnosis. NICE has produced clear, evidence-based guidance which, if implemented comprehensively, could radically reduce the number of infections diagnosed late. The higher costs of treating late-diagnosed HIV, compared to those diagnosed promptly, along with the costs arising from additional new infections, make a compelling case for CCGs, NHS England and LAs to invest the relatively small amounts of funding necessary to embed HIV testing in primary and secondary care as recommended by NICE.

Action required	With leadership from
Commission testing in primary and secondary care according to NICE guideline	LA commissioners, CCGs, NHS England
Establish local CQUINs (Commissioning for Quality and Innovation) as an incentive to improve rates of HIV testing in secondary care settings	CCGs, STPs, ICSs
Integrate HIV testing into standard protocols in relevant non-HIV specialist settings	NHS provider organisations, GPs, testing laboratories
Integrate HIV testing with hepatitis C testing programmes, and with blood-borne virus and syphilis testing in primary care	LA commissioners, CCGs, GPs
Provide high level endorsement and guidance/standards for each specialty/professional group	RCGP <sup>i</sup> , RCP <sup>ii</sup> , specialty associations
Nationally, develop a standard look-back methodology for HIV late diagnosis and locally, undertake standardised look-back exercises, feeding back findings to services where diagnoses were missed and to local commissioners	BHIVA <sup>iii</sup> , HIV specialist clinicians
Use findings from look-back exercises to inform commissioning of testing and health professional training	LA commissioners, CCGs
Set targets/indicators and provide regular data to monitor and benchmark progress	PHE with relevant specialty bodies
Update curricula for medical students and specialty/GP trainees, ensuring minimum requirements in relation to HIV and HIV testing are included	GMC <sup>iv</sup> , medical schools, HEE <sup>v</sup> , LETBs <sup>vi</sup> , Royal Colleges, specialty associations
Develop and disseminate appropriate training and educational materials for non-HIV specialist clinicians	RCGP, FSRH <sup>vii</sup> , BHIVA, BASHH <sup>viii</sup>
In high and extremely high prevalence areas, consider commissioning a GP HIV testing champion, obtaining HIV prevalence data at GP practice or neighbourhood level to refine targeting by practice, and including a key performance indicator (KPI) on GP practice dashboards to encourage benchmarking between practices and CCGs	LA commissioners, CCGs

i. Royal College of General Practitioners

ii. Royal College of Physicians

iii. British HIV Association

iv. General Medical Council

v. Health Education England

vi. Local Education and Training Boards

vii. Faculty of Sexual and Reproductive Healthcare

viii. British Association for Sexual Health and HIV

### 3. Increase the diversity of testing opportunities available for key populations, especially black Africans, people from countries of high HIV prevalence, and gay and bisexual men

To detect more cases of undiagnosed HIV and reduce late diagnosis, it is a priority to continue to increase the numbers of people who test for HIV on a repeated basis, according to their exposure to risk. Although sexual health services currently diagnose the majority of new HIV, they do not meet the needs of everyone who wants or needs HIV testing and their capacity is limited. An increasing range of other settings and technologies for HIV testing, which are both acceptable to users and cost-effective, are now available. The key is to ensure a range of testing options are commissioned, to meet the full range of needs and to ensure they are provided in ways that are accessible and acceptable to different population groups.

Action required	With leadership from
Actively disseminate learning from HIV Prevention Innovation Fund testing projects and other innovative projects	PHE
Scale up work with organisations and leaders in most-at-risk communities	LA commissioners, local HIV organisations
Analyse local vulnerable populations and undertake needs assessments and equity audits of access to local HIV testing services, working with community leaders to overcome barriers to access	LA commissioners, STPs, ICSs
Commission self-sampling and promote to black African people and other communities most affected by HIV, exploring and addressing any barriers to take-up, especially in areas not close to other testing services	LA commissioners
Involve community pharmacy in promoting and providing HIV testing, whether on site or via the provision of self-sampling and self-testing kits	LA commissioners
Set up and signpost pathways into care for people using self-testing	LA commissioners, local HIV organisations, HIV treatment services
Use social media to correct misinformation and promote testing, including repeat testing, to individuals at risk in extremely high, high and low prevalence areas	HPE <sup>i</sup>
Encourage repeat testing and increase the offer of HIV testing, especially to women, in sexual and reproductive health (SRH) services	FSRH, SRH service providers
Further develop partner notification, using innovative approaches and technologies to extend its reach	BASHH, BHIVA, HIV, GUM and SRH service providers, LA commissioners
Work with HIV organisations and other stakeholders to ensure any new memorandum of understanding (MoU) on processing information requests for tracing immigration offenders is drafted so as not to deter people from HIV testing in any way	NHS Digital, DHSC <sup>ii</sup> , Home Office

i. HIV Prevention England

ii. Department of Health and Social Care

#### 4. Interrogate data and use available evidence to produce tailored, highly effective and cost-effective interventions

The UK has excellent epidemiological data to understand the HIV epidemic and benefits from support for its interpretation from Public Health England, but some unanswered questions about late diagnosis remain. The recent drop in new HIV diagnoses among gay and bisexual men provides proof of concept for an innovative approach which resulted in a significant reduction in new HIV infections and their associated costs. This approach was informed by an understanding of the factors driving HIV transmission in a particular population and used a combination of measures to address these directly. Late diagnosis presents a different challenge but, in the same way, a deep understanding of the characteristics of people who are diagnosed late, the factors that drive late diagnosis and the levers available to tackle these should be applied to the development of new, highly effective and cost-effective interventions.

Action required	With leadership from
Undertake an investigative evaluation involving interviews with people diagnosed late, to improve understanding of factors resulting in late diagnosis	PHE
Undertake a national analysis of late diagnosis by local authority and by GUM/sexual health clinic, identify where significant downturns in late diagnosis have occurred and analyse the reasons	PHE
Analyse which elements of the London 'steep fall' experience with gay and bisexual men are relevant to clinics with different characteristics and in other geographical areas	PHE with BASHH and BHIVA
Explore how the learning from the 'steep fall' clinics can be used to develop new service models for other vulnerable communities, especially black Africans, to achieve a similar impact	PHE, BASHH, BHIVA, HIV community organisations
Disseminate the learning from the four points above to commissioners, providers and community organisations	PHE, BASHH, BHIVA, NAT <sup>i</sup>
Work together on changes to local services to create or replicate a steep fall in late diagnoses, including greater use of new technology to increase capacity	LA commissioners, sexual health service leads, CCGs
Make these changes a priority locally for commissioning	Local councillors, DsPH <sup>ii</sup> , HWBs <sup>iii</sup>
Set targets/indicators to measure and benchmark progress	PHE with BASHH, BHIVA and community service providers
Integrate relevant messages in education campaigns and materials for gay and bisexual men, black Africans and other communities affected	HPE, local public health teams, community organisations

i. National AIDS Trust

ii. Directors of Public Health

iii. Health and Wellbeing Boards

*The Halve It position paper, A roadmap for eliminating late diagnosis of HIV in England, along with this and other summary briefings can be found at: [halveit.org.uk](http://halveit.org.uk). The production of this briefing was funded by an educational grant from Gilead Sciences Ltd. Gilead had no editorial control.*