Halve It
EARLY TESTING SAVES LIVES.

A roadmap for eliminating late diagnosis of HIV in England

Halve It position paper

Summary briefing for local authority and NHS commissioners

A roadmap for eliminating late diagnosis of HIV in England presents the case for scaling up action to eliminate late diagnosis of HIV. It sets out key priorities for action and 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 of HIV.

Key messages:

- **Late diagnosis of HIV is the leading cause of premature death and disease among people living with HIV.** Late diagnosis is declining but remains high, and there is significant variation across populations, settings and geographical areas. Prompt diagnosis and treatment can give a normal life expectancy, prevent HIV transmission and save NHS and social care costs.

- **Late diagnosis can be reduced by increasing the number of people tested for HIV, testing people earlier in the course of their infection and increasing the frequency of testing among those at higher risk.** Individual, professional and system barriers to testing must be tackled more effectively.

- **Eliminating late diagnosis of HIV would bring significant public health benefits as well as substantial short, medium and long-term cost savings** because of lower medical costs and averted new infections. Studies have demonstrated that screening in areas of high prevalence and routine testing of people at higher risk is cost-effective

- **Evidenced-based guidelines exist and clearly set out what needs to be done; the challenge is to ensure *full* implementation** – to expand testing in line with guidelines, to disseminate effective practice and to ensure NHS and local authority (LA) commissioning drives improvement.

- **Leadership and action is needed at *all* levels:** national and local politicians and community leaders should hold local health systems to account for the joint action they are taking towards eliminating late diagnosis; medical royal colleges and specialty associations should actively engage in the drive to reduce late diagnosis and eliminate all new infections; and national and local commissioning and provider organisations should act together to plan and coordinate HIV testing across the whole system.

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 numbers 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 LAs which have high or extremely high HIV prevalence
- People diagnosed late have a 10 times higher risk of death within one year of diagnosis than those diagnosed promptly
- Most HIV is diagnosed in sexual health services but late-stage diagnosis occurs most often in hospitals (inpatients, outpatients, emergency departments and admissions units), with too many diagnoses being missed until people become seriously ill
- Gay and bisexual men are most likely to be diagnosed in sexual health services; black Africans are more likely to be diagnosed in other, mainly medical, settings
- Around 1 in 20 new diagnoses are made in non-medical settings
- The cost of HIV care in the first year after diagnosis is twice as high for those diagnosed late

* 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 350cells/mm^3 within 91 days of diagnosis

A key role for commissioners

Improved access to HIV testing, with prompt diagnosis and access to treatment, are key to reducing late diagnosis and the morbidity associated with late-stage disease. Commissioning arrangements put in place by the Health and Social Care Act 2012 divide responsibility for commissioning HIV testing between local authorities (LAs), clinical commissioning groups (CCGs) and NHS England. This has led to fragmentation and lack of clear accountability, often exacerbated by an absence of collaborative working between commissioners.

Commissioning HIV testing

- **LAs** currently commission the bulk of HIV testing, in specialist genitourinary medicine (GUM) clinics, sexual and reproductive health (SRH) services and community settings, through self-sampling and in medical settings when part of local public health initiatives (such as routine testing for new registrants in general practice). However, local authority public health spending on HIV prevention and testing has decreased over the last two years. Without specific action this situation is at risk of continuing with the future removal of the public health funding ring-fence and the growing pressures on LA budgets as a whole.

- **CCGs** are responsible for commissioning HIV testing as part of patient care in emergency departments and other CCG-commissioned hospital services, as well as termination of pregnancy services. However, the level of engagement of CCG commissioners with sexual health in some areas is disappointingly low. HIV testing when clinically indicated has the potential to reduce the costs of CCG-commissioned services by averting unnecessary

investigations, repeat visits and hospitalisations. This requires more active CCG engagement in the commissioning of HIV testing.

- **NHS England** has a key responsibility for HIV testing in general practice when clinically indicated or as part of the essential services provided under the GP contract. However, NHS England, as commissioner, does not monitor GPs' performance in relation to HIV testing. In practice, GPs vary enormously in the extent to which they offer HIV testing.

Responsibility for commissioning HIV testing in different settings

- In SRH and GUM clinics, and as part of local public health initiatives in any setting **(LAs)**
- In antenatal clinics (through the NHS Infectious Diseases in Pregnancy Screening Programme) **(NHS England)**
- In general practice when clinically indicated or requested by individual patients, where provided as part of "essential services" under the GP contract (ie not part of public health commissioned services but relating to the individual's care) **(NHS England)**
- In general practice as part of local public health initiatives, eg offering to new registrants in high prevalence areas **(LAs)**
- In "non-traditional settings", eg community outreach, home sampling **(LAs)**
- In termination of pregnancy services **(CCGs)**
- In other CCG-commissioned services (including A&E and other hospital departments) as part of patient care **(CCGs)**
- In other NHS England-commissioned services as part of patient care **(NHS England)**

Source: Public Health England (PHE). Making it work: a guide to whole system commissioning for sexual health, reproductive health and HIV. September 2014 (revised March 2015)

Working together to tackle barriers to testing

Late diagnosis can be reduced by **increasing the number of people tested for HIV, testing people earlier in the course of their infection** and **increasing the frequency of testing**, especially amongst those at higher risk. But LA and NHS commissioning bodies need to work together to address some of the key barriers to implementing the volume, frequency and timing of HIV testing required to eliminate late diagnosis. Barriers include:

People living with undiagnosed HIV 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. Also, a range of testing options that are accessible and acceptable to different population groups should be part of the commissioning package.

Health professionals in primary and secondary care often missing 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. High level commitment to embedding routine HIV testing in departmental procedures and specialty guidelines is key. 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 sexual health services.

At a system level, fragmented commissioning arrangements hindering the whole system approach required for tackling late diagnosis of HIV. The causes of late diagnosis occur across the system and to address them, whole system commissioning is important. LA and NHS commissioning bodies need to work together to clarify accountability and 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.

Variation across the country

There is regional and local variation in late diagnoses. Many of the LAs with the highest rates of late diagnosis are those with the lowest prevalence of HIV, often in rural or outer suburban areas. Conversely, late diagnosis rates are lowest in areas with higher prevalence where awareness of HIV tends to be greater and interventions are in place to increase rates of testing. However, in terms of numbers, two-thirds of late HIV diagnoses occur in the 79 LAs which have high or extremely high HIV prevalence (where at least 2 in every 1,000 adults aged 15-59 has an HIV diagnosis). Strategies to eliminate late diagnosis must therefore address both high absolute numbers and high rates of late diagnosis, with interventions designed according to local needs.

Implementing evidence-based guidance and using available tools to drive progress on late diagnosis

National guidance, based on the best available evidence of effectiveness and cost-effectiveness, is available to support further action to eliminate late diagnosis. Basic metrics to measure progress, and whole system structures and place-based initiatives, provide further opportunities to drive local prioritisation for reducing and eventually eliminating diagnosis.

But, while the tools and whole system structures already exist, further progress on late diagnosis requires:

- Political leadership to drive forward action on late diagnosis along with a commitment to eliminate the stigma that hampers action to tackle HIV at all levels
- Better prioritisation of HIV and late diagnosis in local partnership plans
- Improved collaborative working and whole system commissioning on HIV testing and late diagnosis by LA and NHS commissioning bodies
- Improved accountability for late diagnosis outcomes across the whole system
- Comprehensive implementation of the National Institute for Health and Care Excellence (NICE) guidelines on testing
- Reversal of cuts in local authority spending on HIV prevention and HIV testing

System leadership is needed more now than ever to use the tools and levers available to set off on a course which will lead to the elimination of late diagnosis of HIV.

Evidence-based guidance relevant to eliminating late diagnosis

- NICE guideline *HIV Testing: increasing the uptake among people who may have undiagnosed HIV* (2016)
- NICE Quality Standard *HIV Testing: encouraging uptake* (2017)
- *UK National Guidelines for HIV Testing* (2008)
- PHE *HIV Testing in England: 2017 report* (2017)

Cost-effectiveness of timely HIV diagnosis

Cost impact of late diagnosis: 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 each year after diagnosis

Averting costs of new infections: 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

Resourcing increased HIV testing: 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

Cost-effectiveness of routine HIV testing and testing interventions: (i) HIV screening interventions are cost-effective when undiagnosed prevalence in a population is 0.1% or above (ii) 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 been calculated to be cost-effective (iii) Screening in general practice and emergency departments in areas of extremely high prevalence is cost-effective and even cost-saving

Metrics to drive and monitor progress

- PHE's Sexual and Reproductive Health Profile indicators
- Public Health Outcomes Framework (PHOF) late HIV diagnosis indicator
- NICE's threshold of diagnosed HIV prevalence for *additional* action on testing in areas designated with high or extremely high prevalence

Effective or promising testing interventions

In specialist sexual health services

- A model of high volume, high frequency testing and rapid access to treatment, along with the use of preexposure prophylaxis (PrEP), has led to a significant reduction in HIV incidence among gay and bisexual men
- Partner notification is highly effective, with the highest positivity rate of all HIV testing interventions

In general practice

- Interventions in general practice in higher prevalence areas, with training to support a routine test offer or enhancement of clinical skills, have increased testing and earlier diagnosis

In secondary care

- Introducing routine opt-out testing in acute medical admissions units and emergency departments has increased rates of diagnosis with minimal extra costs

In the community

- Innovative projects developed in community settings have been successful at engaging marginalised communities and diagnosing people who would not otherwise access testing

In the home

- HIV self-sampling has been successful in extending the reach of HIV testing to people who have not been tested previously

Collaborative models for whole system action

- Sustainability and transformation partnerships (STPs)
- Integrated care systems (ICSs)
- Fast-Track Cities Initiative to end AIDS
- Social investment partnerships

Key priority areas and recommended action for LA and NHS commissioning bodies

1. 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 even resources are shared and actions are coordinated. The establishment of STPs, as well as their development in some areas into 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
Involve providers and the public, including people living with HIV, in commissioning decisions	LA commissioners, CCGs, STPs, NHS England
Disseminate learning from whole system approaches to eliminating late HIV diagnosis, including STPs, ICSs, Fast-Track Cities, Social Investment Partnership	PHE, ADPH[i], LGA[ii], NHS England

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. This is an unacceptable failure of medical care leading to avoidable mortality, morbidity and extended periods of infectivity when new transmissions can occur. 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 that 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.

i. ADPH = Association of Directors of Public Health
ii. LGA = Local Government Association

Action required	With leadership from
Commission testing in primary and secondary care according to the 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 with hepatitis C testing programmes, and with blood-borne virus and syphilis testing in primary care	LA commissioners, CCGs
Use findings from look-back exercises to inform commissioning of testing and health professional training	LA commissioners, CCGs
In high and very 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

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.

In order 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 not only once but on a repeated basis, according to their exposure to risk. Although sexual health services currently diagnose the majority of new infections, 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
Analyse local populations at risk 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
Scale up work with organisations and leaders in most-at-risk communities	LA commissioners
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
Further develop partner notification, using innovative approaches and technologies to extend its reach	LA commissioners

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 PHE, 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 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
Work with national agencies (PHE[i], BASHH[ii], BHIVA[iii]) 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, CCGs
Make these changes a priority locally for commissioning	Local councillors, HWBs[iv], DsPH[v]
Integrate relevant messages in education campaigns and materials for gay and bisexual men, black Africans and other communities affected	Local public health teams

i. Public Health England
ii. British Association for Sexual Health and HIV
iii. British HIV Association
iv. Health and wellbeing boards
v. Directors of public health

*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**. The production of this briefing was funded by an educational grant from Gilead Sciences Ltd. Gilead had no editorial control.*