A roadmap for eliminating late diagnosis of HIV in England

Halve It position paper

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Executive Summary

Introduction

This position paper 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.

What is late diagnosis of HIV and why is it a problem?

The risk of death and disease is greatly increased in people diagnosed late (at a stage when the virus has already significantly damaged the immune system). 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, but the lowest proportion of diagnoses being made late, in London. Among all late diagnoses, people diagnosed very late, at the stage of advanced immunosuppression, are at highest risk of death and serious illness.

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 HIV testing at the volume, frequency and timing 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. Health professionals in primary and secondary care often miss opportunities to diagnose HIV, despite patients finding an HIV test offer in these settings acceptable. 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.

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 in areas of extremely high prevalence is cost-effective or 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 force 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 National Institute for Health and Care Excellence (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 (PHE) also makes recommendations on HIV testing in a range of services in its *HIV testing in England: 2017* report.

### 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.

### 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 priorities for action below.

### 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. Action points for each of these are presented at the end of this paper (page 57).

1. Galvanise action across local authorities (LAs), clinical commissioning groups (CCGs) and NHS England for joint planning to reduce late diagnosis of HIV.

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

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.

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

This position paper presents the case for scaling up action to eliminate late diagnosis of HIV. As the leading cause of premature death and disease among people living with HIV, late diagnosis has often seemed an intractable problem. Yet now, more than ever before, the tools we need to tackle it are within our reach.

The paper describes the evidence about where late diagnosis happens and why, what we know about how to reduce it and its associated costs, and the state of progress towards its elimination in England. 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.

_A roadmap for eliminating late diagnosis of HIV in England_ has been produced by Halve It, a coalition of agencies campaigning to eliminate late diagnosis of HIV. (See Appendix 2 for information about Halve It.)
2. HIV in England

This paper draws heavily on the following excellent and comprehensive reports. They are not referenced each time their data are used.


Just before publication of this paper, new data on HIV diagnoses in 2017 were released by PHE. They reveal a continuation of the trends described in this paper and are summarised in:

- *Trends in new HIV diagnoses and people receiving HIV-related care in the United Kingdom: data to the end of December 2017.* Health Protection Report. Volume 12, Number 32

2.1 People living with HIV

- Of around 90,000 people living with HIV in England, one in eight remains undiagnosed
- HIV is most prevalent among gay and bisexual men and black African men and women (about three-quarters of all people diagnosed)
- Most people living with HIV are in London and other large cities

**Figure 1: Estimated* number of people living with HIV (diagnosed and undiagnosed) all ages: England 2016**

*Estimates do not add up to totals and subtotals due to rounding


i. Figures in this report relate to England unless specified as UK.
In 2016, around 90,000 people were estimated to be living with HIV in England. About 12% were unaware of their infection and thus unable to access potentially life-saving treatment (Figure 1). HIV is most prevalent in gay and bisexual men and in black African heterosexual men and women. However, approximately a quarter of people living with HIV are from neither of these groups. Although people who inject drugs are at increased risk of HIV, they represent a small proportion of the epidemic in England.

The percentage of people living with HIV who remain undiagnosed has declined over the years, halving since 2010 when it was estimated to be 24%.2

People with HIV live all around the country but tend to be concentrated in urban areas, especially London, Brighton, Manchester and other large cities (Figure 2). There are now 79 local authority (LA) areas where at least 2 in every 1,000 adults aged 15-59 have been diagnosed with HIV (‘high prevalence’), and 19 where this prevalence is 5 or more per 1,000 (‘extremely high prevalence’).

Figure 2: Diagnosed HIV prevalence (per 1,000 population aged 15 to 59 years):
England, 2016

2.2 New diagnoses of HIV

- HIV diagnoses have dropped recently in gay and bisexual men, reflecting a reduction in HIV incidence

- HIV diagnoses have also declined among black Africans, mainly due to changing migration patterns, but not among white heterosexuals

There were 4,690 HIV diagnoses in England in 2016, a startling 17% decline on the 5,684 in 2015. This decline was due to a sharp decrease in diagnoses among gay and bisexual men in London and a continued gradual reduction in diagnoses among heterosexual men and women (Figure 3). This downward trend continued in 2017, with a further 17% decline in all new diagnoses since 2016.

2016 was the first year on record in which new diagnoses among gay and bisexual men declined. Public Health England (PHE) has concluded that this decline is due to reduced transmission of HIV and estimates that the annual number of actual new infections in gay and bisexual men in the UK has gone down from a peak of around 2,800 in 2010 to 1,700 in 2016.

The number of heterosexual men and women newly diagnosed with HIV in England has halved over the past 10 years, from 3,647 in 2007 to 1,598 in 2016 (Figure 4). This drop is mainly among African-born men and women, reflecting changing migration patterns as fewer people from high HIV prevalence countries come to the UK. Among white heterosexual women and men new HIV diagnoses have remained relatively stable but low, at around 750 per year in the whole of the UK over the past decade. Overall, it is estimated that about half (55%) of all heterosexual men and women diagnosed with HIV in 2016 had acquired it in the UK.
Figure 3: HIV diagnoses* by exposure group: UK, 2007 to 2016

* Data adjusted for missing exposure information


Figure 4: New HIV diagnoses* among heterosexual men and women by ethnicity: UK, 2007 to 2016

* Data adjusted for missing ethnicity information

3. Late diagnosis of HIV

3.1 What is late diagnosis of HIV and why is it a problem?

• Late diagnosis occurs when HIV has already significantly damaged the immune system

• 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 too high and there is significant variation across populations, settings and geographical areas

Late diagnosis of HIV refers to diagnosis at a stage when the virus has already significantly damaged the immune system. This can often be several years after someone has acquired HIV. The standard definition is having a CD4 count (a measure of immunity) of under <350 cells/mm$^3$ within 91 days of diagnosis.

Late diagnosis is the most important predictor of morbidity and premature mortality among people with HIV. People diagnosed late have a ten times higher risk of death within one year of diagnosis than those diagnosed promptly (see Figure 5), and 3.5 times the risk of death overall. Because of higher morbidity, late diagnosis also significantly increases treatment costs.

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 and untransmissible level. This is sometimes referred to as U=U (undetectable = untransmissible).

![Figure 5: One-year mortality rate among adults newly diagnosed with HIV by CD4 cells/mm$^3$ at diagnosis: UK, 2015](source)

3.2 Who is 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

In 2016, 2,159 (42%) of the 5,164 people newly diagnosed with HIV in the UK were diagnosed late. Late diagnosis was not distributed evenly between population groups or across the country (see Figures 6 and 7).
3.2.1 Age

Late diagnosis is more frequent in older people. In the UK in 2016, 31% (129) of 15 to 24 year-olds were diagnosed late, rising to 63% (77) of over-65s, although the greatest absolute number (702) of late diagnoses occurred in 35-49 year-olds in whom the percentage was 45%. Older people are less likely to feel at risk of HIV, or be judged to be so by healthcare providers, and therefore opportunities for earlier testing are missed. Late diagnosis is also more perilous for older people. One in fourteen people aged 50 and over who were diagnosed late in 2015 died within a year of diagnosis, compared to one in 38 among all people diagnosed late with HIV.

3.2.2 Population groups

The majority of all new HIV diagnoses occur in gay and bisexual men, so it is not surprising that there are also more late diagnoses in this population group than any other (663 late diagnoses in the UK in 2016). However, as a proportion, only 32% of all new diagnoses in gay and bisexual men were made late in the UK in 2016. This compares to 60% (413) of all new diagnoses in heterosexual men and 47% (354) of those in heterosexual women. Among black Africans the respective proportions were even higher, at 65% and 49% (139 men and 165 women diagnosed late).

Although rates of late diagnosis are highest in black Africans, recent migration to the UK does not appear to be a major reason. A 2016 British HIV Association (BHIVA) audit of people diagnosed late in the UK for which CD4 information was reported. They therefore underrepresent the true amounts. In contrast, Figure 7 uses adjusted data, giving a picture closer to the true numbers.
very late (CD4 count <200 cells/mm³) found that only 7% had arrived in the UK within the last year.11

While almost half (46%) of heterosexual women diagnosed late in 2016 were black African and only a quarter (28%) were white, among heterosexual men more were white (46%) than black African (34%) (Figure 8). A total of 192 white heterosexual men and 100 white heterosexual women were diagnosed late with HIV in 2016.12

The rate of late diagnosis was also high in people who inject drugs at 51%, but the actual numbers (41) were small.13

There is no available information about late diagnosis, and little about HIV testing and diagnosis more generally, in transgender people in the UK. However, trans women globally have an estimated HIV prevalence of 19% and a 49% greater likelihood of having HIV than the general population.14 Little is known about HIV in trans men, but there are indications their risk could also be higher than that of the general population.15 Although absolute numbers of trans people with HIV are probably small, as a group at high risk of HIV and impacted by social exclusion, their risk of late diagnosis should not be ignored.

Figure 8: Late HIV diagnoses among different population groups, by ethnicity and country of birth: UK, 2016

3.2.3 Geography

There is regional and local variation in late diagnoses. In 2016, London – where over two-fifths of all people living with HIV are resident - had the highest absolute number of residents diagnosed late but the lowest proportion of diagnoses made late at 36% (563 of the 1564 for whom CD4 count was reported). In the North of England the proportion was 42% (297/702), in the South of England 45% (267/591) and in the Midlands and East of England 47% (384/808).16

Within each region there is significant variation between local authorities (LAs), with a range nationally from 10% to 100% (though where numbers are very small, percentages mean little).17 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, despite the lower proportions, in terms of numbers two-thirds of late HIV diagnoses occur in the 79 LAs which have high or extremely high HIV prevalence.\textsuperscript{18 19}

In order to eliminate late diagnosis of HIV, strategies must address both high absolute numbers and high proportions of late diagnoses, with interventions designed according to local needs.

3.3 Very late diagnosis (advanced immunosuppression)

- Among all late diagnoses, people diagnosed very late are at highest risk of death and serious illness
- The groups most likely to be diagnosed late are also most likely to be diagnosed very late

Among people living with HIV who are diagnosed late, the highest risk of mortality and severe morbidity is in those who present with advanced immunosuppression (defined as having a CD4 count of <200 cells/mm\(^3\) within 91 days of diagnosis). In 2016, 910 diagnoses in the UK - almost a quarter (23\%) of those for whom a CD4 count was reported - fell into this category, and the proportion increased with age to 43\% (53) in the over-65s, although the absolute number (408) was highest among 35-49 year-olds.\textsuperscript{20}

Mirroring the pattern for all late diagnoses, diagnosis with advanced immunosuppression occurred in 39\% of heterosexual men, 28\% of heterosexual women, and 15\% of gay and bisexual men with a CD4 count reported. The proportion was higher in black Africans (32\%) than in other ethnic groups (18\%-29\%), and lower in London (18\%) than other regions (24\%-28\%). However, the actual numbers of people diagnosed with advanced immunosuppression reflect the overall numbers of new diagnoses, and were highest in gay and bisexual men (320), people of white ethnicity of all sexual orientations (497), and people in London (286).

3.4 Previously diagnosed late presenters

- Two-fifths of people born and diagnosed abroad present late for care in the UK
- People presenting with late-stage HIV who were previously diagnosed in the UK then lost to care have different characteristics from those who are first diagnosed late

While late diagnosis is the biggest predictor of HIV-related morbidity and mortality, a number of people who present with late-stage disease have been previously diagnosed. Some have been diagnosed in the UK but subsequently become disengaged from health services while others, diagnosed overseas, have not presented for care upon arrival in the UK.

Among people born and previously diagnosed abroad, 20\% did not access care within 1 year of arrival in the UK and 40\% had a CD4 count <350 cells/mm\(^3\) at the time of diagnosis in a UK setting. Those individuals are currently reported in statistics as late diagnoses, despite already knowing their HIV status. It will be helpful to separate the data on these individuals from those for the truly late diagnosed, as PHE is planning to do. However, for those diagnosed overseas and therefore unknown to UK HIV treatment services, the strategies for ensuring linkage to care may need to be closely aligned to those for reaching and testing the undiagnosed among migrant populations.

According to PHE data, 80\% of AIDS diagnoses occur within three months of an HIV diagnosis.\textsuperscript{21} However, an analysis of inpatients with AIDS admitted to a large HIV unit found that over half had been previously diagnosed at least six months before and had subsequently been disengaged from care for at least four months.\textsuperscript{22} These individuals had higher rates of psychiatric
comorbidities, social issues (including financial difficulties, housing issues, receipt of disability benefits and reported domestic abuse) and alcohol and substance abuse than those who were diagnosed late, and higher rates of alcohol use and injecting drug use than the broader population of people living with HIV. A larger proportion were migrants and visitors from abroad (54%) compared with those diagnosed late (34%). They were also more likely to be injecting drug users (9% vs 0%). In considering how to develop interventions to reduce late diagnosis, it is worth being aware of the different characteristics of these two groups.

Interestingly, in that study, those who were diagnosed late had had few previously reported HIV indicator conditions or co-morbidities, in contrast to the previously diagnosed who had had four times as many. The low prevalence of previous indicator conditions in the late diagnosed group suggests that an indicator condition-based testing programme might not have identified their HIV at an earlier stage. Therefore, complementary approaches based on identification of risk factors and screening in high prevalence populations, as well as indicator condition-guided testing, are important for earlier diagnosis.

3.5 Where are people diagnosed with HIV?

• Most people with HIV are 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 in non-medical settings

**Figure 9: New diagnoses among adult men and women (aged ≥15 years) by setting of first positive test: England 2016**

<table>
<thead>
<tr>
<th>Setting of First Positive Test</th>
<th>Men (N=3,555)</th>
<th>Women (N=1,108)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SHS or HIV Clinic</td>
<td>75.4%</td>
<td>65.9%</td>
</tr>
<tr>
<td>Inpatient</td>
<td>6.6%</td>
<td>7.3%</td>
</tr>
<tr>
<td>General practice</td>
<td>5.9%</td>
<td>6.0%</td>
</tr>
<tr>
<td>Community setting</td>
<td>4.1%</td>
<td>5.4%</td>
</tr>
<tr>
<td>Other</td>
<td>1.4%</td>
<td>1.9%</td>
</tr>
<tr>
<td>Other outpatient</td>
<td>1.0%</td>
<td>1.3%</td>
</tr>
<tr>
<td>Antenatal clinic</td>
<td>0.9%</td>
<td>1.1%</td>
</tr>
<tr>
<td>Other</td>
<td>0.6%</td>
<td>2.3%</td>
</tr>
</tbody>
</table>


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i. An HIV indicator condition is a clinical condition which can be caused by, or is more common in people with, HIV infection and therefore could indicate the presence of HIV infection.
3.5.1 Sexual health services

Although a reducing proportion of the total, the majority of HIV diagnoses are still made in sexual health or HIV clinics and the numbers attending these services continues to rise (Figure 10). Over a million people were tested for HIV in sexual health services in 2016, and 2,358 were newly diagnosed with HIV, a positivity rate of 0.2%. Among the groups at highest risk of HIV, positivity in gay and bisexual men was 1.2%, in black African people born in countries with high HIV prevalence (over 1%) it was 1%, and in black African people born in the UK only 0.2%.

Almost three in five (58%) gay and bisexual men with HIV are diagnosed in sexual health services, but the proportion is only two in five (41%) for black African heterosexuals, of whom over half are diagnosed in other medical settings.

Figure 10: HIV test offer and coverage in sexual health service (SHS) attendees eligible* for HIV testing: England 2012-2016

* Eligible SHS attendee: any patient attending a SHS at least once during a calendar year; patients known to be HIV-positive or for whom an HIV test was not appropriate, or for whom the attendance was reported as being related to sexual and reproductive health (SRH) care only are excluded. This includes England residents only.

3.5.2 General practice

6% of new diagnoses in men and 7% in women were made in general practice in 2016. HIV testing rates in practices which consistently reported data to the Sentinel Surveillance of Blood Borne Viruses (SSBBV) increased by 17% between 2014 and 2016. In extremely high prevalence areas more than twice as many tests were performed as in high prevalence areas, and about four times as many as in other areas (Figure 11). Positivity rates were 0.2% in low prevalence, 0.5% in high prevalence and 0.4% in extremely high prevalence areas.

Point-of-care tests (POCT) are not included in the above figures and it is not known how many are performed in general practice. Their use is probably more common in areas of high and extremely high prevalence where interventions have been put in place to increase HIV testing.

General practice plays an important role in diagnosing people from population groups less likely to use specialist sexual health services, notably black Africans, over half of whom are diagnosed outside sexual health settings.

Figure 11: HIV tests and positivity* in general practice** by diagnosed HIV prevalence band*** in data captured by SSBBV: England, 2014-2016

3.5.3 Hospital settings

In 2016, 7% of new HIV diagnoses in men and 9% in women were made in inpatient settings, 4% and 6% respectively in outpatient (non-antenatal) settings, and 1% in each in emergency departments (EDs). (These proportions are likely to be an underestimate, because of inaccurate data coding.23)

Based on surveillance of laboratory data from a sub-set of hospitals\textsuperscript{i}, HIV testing in hospitals increased by 17% over two years reaching 82,365 tests in 2016, and the test positivity rate was 0.6% across the different hospital settings (excluding antenatal).

3.5.4 Antenatal

5% of diagnoses in women were made in this setting in 2016. 0.03 of pregnant women screened in 2015 were newly diagnosed with HIV, down from 0.07 in 2011.

3.5.5 Non-medical settings

A small proportion (around 5%) of all new diagnoses were made in non-medical settings in 2016.

2.5% of new HIV diagnoses in men and 1.9% in women were made in community settings, where at least 20,000 tests\textsuperscript{ii} were performed with a reactivity rate\textsuperscript{iii} of 0.6% (0.9% among black Africans and 0.8% among gay and bisexual men).

A similar number of tests were performed by the national HIV self-sampling service\textsuperscript{iv}, with a ‘high reactivity’ rate of 0.7%\textsuperscript{v} (1.6% among black Africans and 0.8% among gay and bisexual men).

The number of reactive self-tests\textsuperscript{vi} in 2016 is not known, but the main UK provider sold around 26,000 kits. A pilot study\textsuperscript{vii} suggested reactivity among gay and bisexual men is similar to that for community testing and self-sampling.

Opt-out HIV testing is operating in prisons, but coverage is low. Numbers of new diagnoses from this setting account for a very small proportion of the total, as do diagnoses from blood donation services and services for people who use drugs.

\textsuperscript{i} Sentinel Surveillance of Blood Borne Virus Testing in England.
\textsuperscript{ii} This figure is based on a community survey, which may represent an underestimate of the total numbers.
\textsuperscript{iii} Reactivity rather than positivity is recorded, as a point-of-care test must be confirmed by a laboratory blood test before a positive result can be given.
\textsuperscript{iv} Self-sampling is when individuals buy or order a kit online, send a sample off to be tested and receive results from a service provider.
\textsuperscript{v} Only ‘high reactives’ are presented for the self-sampling service. All reactives are presented for community settings.
\textsuperscript{vi} Self-testing is when individuals buy a kit and perform their own test.
3.6 Where do late diagnoses occur?

- Too many diagnoses are being missed until people become seriously ill
- Late, and especially very late, diagnosis occurs most often in hospitals

An audit of individuals diagnosed with HIV with advanced immunosuppression (a CD4 count of <200 cells/mm³) found that almost a third received their diagnosis as an inpatient.²⁵ It seems probable that at least some of these were suffering from HIV indicator conditions severe enough to need hospitalisation. This is despite the fact that almost nine in ten were registered with a general practitioner (GP), so there could have been earlier opportunities for diagnosis during the several years that most of them would have been living with undiagnosed HIV.

The full list of settings where these very late diagnoses occurred was as follows (Table 1):

<table>
<thead>
<tr>
<th>Setting</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient</td>
<td>240</td>
<td>31</td>
</tr>
<tr>
<td>GUM/HIV/sexual health clinic</td>
<td>182</td>
<td>23.5</td>
</tr>
<tr>
<td>General practice</td>
<td>117</td>
<td>15.1</td>
</tr>
<tr>
<td>Outpatients (not GUM/HIV/sexual health)</td>
<td>117</td>
<td>15.1</td>
</tr>
<tr>
<td>A&amp;E (ED) or admissions unit</td>
<td>34</td>
<td>4.4</td>
</tr>
<tr>
<td>Antenatal clinic</td>
<td>21</td>
<td>2.7</td>
</tr>
<tr>
<td>Home test/home sampling</td>
<td>12</td>
<td>1.6</td>
</tr>
<tr>
<td>Community HIV test service</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>36</td>
<td>4.7</td>
</tr>
<tr>
<td>Not stated</td>
<td>6</td>
<td>0.8</td>
</tr>
</tbody>
</table>


A separate analysis of national data has shown that, in 2011-14, the vast majority of diagnoses made in medical admissions and EDs (79%), and more than half of those made in infectious disease units (66%), outpatient services (65%) and general practice (55%) were made late (CD4 <350 cells/mm³).²⁶ This suggests that testing in these settings is more often prompted by indicator conditions in people who do not suspect they have HIV, and less frequently by routine screening or testing based on risk factors (whether requested by patients or offered by healthcare professionals), which would pick up earlier infection. By contrast, in sexual health services, where people tend to seek testing because of risk behaviour, barely more than a third (36%) of diagnoses were made late.

It is encouraging that the numbers tested and diagnosed in non-HIV specialist medical settings have increased as recommended in current guidelines,²⁷,²⁸ and also that over time people have been getting diagnosed in general practice and outpatient settings at an earlier stage of infection than previously.²⁹ However, if the NICE guideline recommendations for testing in general practice and medical admissions (see pages 41 and 43) were being universally followed, a lower proportion of diagnoses in these settings would be being made late.
4. Why does late diagnosis occur?

Late diagnosis occurs when people are not tested for HIV until late in the course of HIV infection. Often, by then, opportunities for earlier testing have been missed. 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 among those at higher risk.

There are a number of barriers to implementing the volume, timing and frequency of HIV testing required. These can be broken down into 1) individual barriers, for people who may have undiagnosed HIV, 2) professional barriers, for healthcare professionals who could be offering testing, and 3) systemic and political barriers, for policy-makers and commissioners.

4.1 Individual barriers

- People living with undiagnosed HIV are not seeking testing, or not testing as frequently as needed
- Reasons for not testing include low risk perception, misinformation about HIV, fear of illness and death, and fear of people finding out
- For migrants, social exclusion and concerns relating to migration status can also hinder testing
- Stigma related to testing and to HIV itself underlies many of these barriers

* Figure 12: HIV tests as a percentage of the gay and bisexual male population*:
PHE centre, 2016

* Gay and bisexual male population derived from GP patient survey residence data and ONS mid-year population estimates. Includes gay and bisexual males aged 15-90 years old.

One reason people with HIV continue to be diagnosed late is that they do not actively seek testing or accept it when offered. This is the case for substantial numbers of people in the population groups most at risk of HIV.

Gay, bisexual and other men who have sex with men are advised to test for HIV and other sexually transmitted infections (STIs) at least annually, yet it has been estimated that in 2016 just 22% of them in England, ranging from 14% in the South West to 32% in London, actually tested for HIV in the three types of service for which this information is collected. (These are sexual health services, the national HIV self-sampling service and community settings. Data on sexual orientation of testers is not available for other settings (Figure 12).) Despite recommendations for frequent testing among gay and bisexual men, especially those who have high risk behaviour, a large number do not have repeat tests with sufficient frequency.30

Black African heterosexual men and women are advised to have a regular HIV screen if having sex without condoms with new or casual partners. In 2016, only 6% of all black Africans were tested in the three settings listed above, nine in ten of them in sexual health services31 (Figure 13). However, only 41% (341/833) of all new diagnoses in black Africans were made in sexual health services.32 33 As well as many not attending these services at all, one in five (12,030) black Africans who are offered testing in sexual health services decline the offer, and the number of women declining the offer (9,255) has increased by 52% since 2012.34

Figure 13: HIV tests among black African men and women as a percentage of the black African population*: PHE centre, 2016

* Black African population derived from census data and ONS mid-year population estimates. Includes people aged 15-64 years old.


Recent data35 suggest that, except for antenatal screening, other settings tend to diagnose at a later stage of infection. It is reasonable to assume that in those settings a higher proportion of tests arise from provider offer rather than patient request.

Clearly, people living with undiagnosed HIV are not seeking testing as much or as frequently as is needed to eliminate late diagnosis.
Among individuals at risk of HIV, a key barrier to testing is low – often incorrectly low – perception of personal risk, which may be accompanied by a good or an inadequate understanding of HIV and its transmission. Another major barrier is fear of a positive HIV test result and its consequences, which may be based on an outdated knowledge of current HIV treatment and its impact. These barriers have been reported by different groups at higher risk of HIV, including gay and bisexual men and black Africans.

HIV-associated stigma remains a significant factor in people’s experience of living with HIV and inhibits testing and prevention interventions. Stigma in the healthcare setting can be real or anticipated. In a survey of people living with HIV, 27% had avoided care when required and 40% of people had experienced at least one instance of negative treatment in a healthcare setting. Fear of disclosure is a significant deterrent to HIV testing in both healthcare and community settings, linked to stigma and fear of discrimination. Research with late-diagnosed gay and bisexual men found stigma and discrimination associated with a positive diagnosis was an important barrier, along with anxiety over the test itself and the implications of a positive diagnosis being disclosed. Such barriers may be stronger among some black African and non-national communities and are accompanied by further barriers particular to those communities, such as uncertainty about access to confidential free testing services and concerns about immigration status.

There is evidence that fear of deportation can have an effect on migrants in deterring access to healthcare. The recent sharing by NHS Digital of identifiable personal data from confidential health records with the Home Office, in order to trace individuals about possible immigration offences, had the potential to increase the number of migrants not seeking testing or treatment for HIV, with serious consequences for both themselves and the wider public health. The Government’s decision to limit this practice, following recommendations from the House of Commons Health and Social Care Select Committee, is therefore welcome.

For black Africans, media attention linking HIV with migration, alongside the impact of national migration policies, may fuel a sense of social exclusion, while the absence of African representation in decision-making processes can be a major factor preventing black Africans from testing.

For women, barriers to testing also include practical constraints such as inconvenient clinic opening times, distance from home, household or childcare responsibilities and work commitments, suggesting easier-to-access services need to be available.

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.

4.2 Professional barriers

- Opportunities to diagnose HIV are often missed in primary and secondary care, despite patients finding an HIV test offer in these settings acceptable

- Non-HIV specialists' reluctance to test may be based on out-of-date knowledge of HIV

- High level commitment to embedding and normalising routine HIV testing in departmental procedures, specialty guidelines and practice, is essential

- Sexual health services overall are not testing people at high risk frequently enough and are failing to test too many women, especially black African women
4.2.1 Non-HIV specialists

A number of studies have shown that opportunities to diagnose HIV are often missed in primary and secondary care. It has been clearly demonstrated that the offer of an HIV test in non-sexual health/non-HIV specialist medical settings is acceptable to patients, both those offered a screening test and especially those with an indicator condition. However, clinicians in both primary and secondary care often fail to offer a test when indicated.50

In a 2016 BHIVA audit of people diagnosed very late with HIV (with CD4 counts under 200 cells/mm³), almost half (46%) had had missed opportunities for testing and could have been diagnosed sooner.51 Missed opportunities were mainly due to clinicians not offering HIV testing rather than the individual declining. Secondary care areas mentioned for improvement were: emergency/A&E, medical admissions, haematology, gastroenterology, respiratory medicine, internal medicine and dermatology. 88% were registered with a GP but most were not diagnosed in general practice. An earlier BHIVA audit in 2010 found that the commonest missed presentations were medical conditions frequently encountered in general practice.52

An earlier review of implementation of the 2008 UK HIV testing guidelines in non-HIV specialist settings found that only an estimated 27% of patients eligible for HIV testing actually received a test. Again, this low overall level of testing was due primarily to low levels of test offer rather than low patient acceptance.53

Clinicians may be more likely to offer testing based on their perception of patients’ risk, perhaps influenced by fears of how patients will react.54 They are also influenced by clinical guidelines produced for their own specialty, but the majority of non-HIV specialty guidelines for the management of HIV indicator conditions, some of them AIDS-defining, do not include a recommendation for HIV testing.55 Clinicians from the specialties managing these conditions may be unaware of recommendations produced by HIV specialist societies or the prevalence of undiagnosed HIV among their patients.

Other barriers to testing reported by clinicians include the (erroneous) belief that lengthy counselling is required, worry about giving a positive result, lack of training, lack of knowledge of HIV and potential risk behaviours, and language barriers.56 A further commonly cited barrier in general practice is lack of time.57

Improvements in testing rates in various medical settings have been found following dedicated interventions, but it has sometimes proved challenging to maintain or continue to increase levels of testing as part of routine practice longer term. Sometimes dedicated interventions have depended on the allocation of additional staff, leaving a challenge for ongoing delivery of testing once the intervention and funding has finished.58 Despite the relatively low additional cost and time required for routine testing, commitment may not always be sufficient to prioritise HIV testing in the longer term so that it becomes truly embedded as part of mainstream practice.59 A King’s Fund review found that HIV specialists were engaging with other clinical services and primary care, but ‘increasing and normalising HIV testing in these environments was seen as a long-term proposition, which did not have the same sense of confidence about making progress’ as that observed in sexual health services.60

If we are ever to move towards the elimination of late HIV diagnosis, 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 also essential.
4.2.2 Sexual health specialists

While specialist sexual health services offer HIV testing to a much higher percentage of attenders than non-HIV specialist settings, there is still room for improvement. The numbers offered and accepting testing have grown in these settings, but 15% of black African attenders eligible for testing are still not offered a test, despite the high rate of late diagnosis in this group. More than twice as many black African women (7,511) as men (2,954) were not offered testing.\textsuperscript{51}

In ‘non-specialist’ sexual health services (sexual and reproductive health (SRH) services, young people’s services, online sexual health services, pharmacies, outreach and other community-based settings) testing is less often offered to eligible patients than in ‘specialist’ (genitourinary medicine (GUM) and integrated GUM/SRH) services, and acceptance of testing is especially low in these settings among women. Research has shown that uptake of testing is influenced by the person who offers the test.\textsuperscript{62} It may be that in services which focus more on reproductive health than STIs, some health professionals have doubts about the need for a universal HIV testing offer or lack confidence in offering testing even if an HIV test is actually appropriate; if so, they may more frequently omit the offer or be less likely to actively recommend testing than those in GUM services. As sexual health service models develop with potentially more provision by non-GUM specialists, this is an important issue to keep under review.

Only half of gay and bisexual men re-attend the same sexual health clinic in the year following an STI diagnosis, indicating that the recommendations for quarterly testing among gay and bisexual men with a higher HIV risk are currently not fully implemented.\textsuperscript{63}

Sexual health professionals already play a valuable role in diagnosing HIV promptly, but a step-up is needed 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.

4.3 Systemic and political barriers

- There is insufficient priority for tackling late diagnosis of HIV at national and local level
- Fragmented commissioning arrangements hinder the whole-system approach required
- Accountability across the system for rates of late diagnosis is lacking

Although national policy is in place with the aim of reducing late diagnosis (see Section 6, page 33), some of it has become out of date and it lacks priority. There is a deficit of political will at government level to drive forward the changes needed to eliminate late diagnosis. At local level, prioritisation and funding of HIV testing is variable. Commissioning arrangements put in place by the Health and Social Care Act 2012 divide responsibility for commissioning HIV testing between LAs, NHS England and clinical commissioning groups (CCGs)\textsuperscript{64} (Table 2). This has led to fragmentation and lack of clarity, often exacerbated by lack of collaborative working between commissioners.\textsuperscript{65}
4.3.1 Local authorities

As public health commissioners, LAs commission the bulk of current HIV testing, in specialist GUM and SRH services and community settings, via self-sampling and in medical settings when part of local public health initiatives (such as routine testing for new registrants in general practice). However, government allocations to LAs for public health were cut in-year by £200m in 2015/16 and are now being further reduced by 3.9% per annum over the five years to 2020/21, adding up to a real terms reduction of at least £600 million a year by 2020/21 on top of the original £200m.

This is happening in the context of significant reductions to LA budgets as a whole, and the combined impact is likely to be exacerbated by the removal of the public health funding ring-fence and the replacement of central government grants by funding from business rates for local public health in 2020.

The King’s Fund reported that spending on STI testing and treatment decreased by almost 4% between 2013/14 and 2015/16, with cuts set to deepen. It found clear evidence that pressure on GUM services had increased over the past few years and that patient care in some parts of the country had suffered as a result. In some areas, services had been tendered with significantly lower budgets, resulting in clinics being closed, moved to less convenient locations or operating with reduced opening hours. An NAT (National AIDS Trust) survey of LA spending on primary HIV prevention and HIV testing (excluding that provided in sexual health services) found an 11% drop in spending in England between 2015/16 and 2016/17 and, in high prevalence LAs, a decrease of almost a third (29%) over the two years from April 2015. However, the report also notes some increases in expenditure on testing and stresses the difficulty of providing an accurate picture of such expenditure from the data available.

4.3.2 Clinical commissioning groups

In view of the insufficient rates of HIV testing for people with HIV indicator conditions in non-HIV specialist settings, CCGs’ responsibility for commissioning HIV testing when part of patient care in EDs and other CCG-commissioned hospital services is crucial. However, in a recent review of sexual health, reproductive health and HIV commissioning conducted by PHE, only 44% of the small proportion of CCGs responding to the survey stated that they were responsible for commissioning ‘HIV testing when clinically indicated in CCG-commissioned services’ and 48% for ‘STI and HIV testing as part of the abortion pathway’. In addition, a much smaller number...
NHS England

A key commissioning responsibility of NHS England is the ‘essential services’ provided under the GP contract. HIV testing in general practice when clinically indicated (i.e., if a patient presents with an HIV clinical indicator condition) or when requested by individual patients, is encompassed within this. However, the wording of the contract is broad and unspecific, and 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, and the history of HIV testing being mostly performed in specialist GUM services has left many still unclear about their responsibilities in this regard and sometimes reluctant to undertake testing.

NHS England’s specialised commissioning arm is responsible for commissioning HIV treatment and care and thus bears the brunt of the higher costs of the more complex HIV care required following late diagnosis, along with CCGs, which pay for outpatient, inpatient and emergency services when individuals present with conditions associated with late-stage HIV disease. While there should be a real incentive to save those costs by investing in increased testing, the savings are not reaped by LAs which pay for the bulk of HIV testing, and this creates a potential barrier to the expansion of LA-commissioned HIV testing.

Responsibility and accountability

The fragmented responsibilities described above create the risk that no organisation or individual is accountable for outcomes across the system as a whole. This can lead to wasteful duplication, but also gaps in provision to meet local needs. The causes of late HIV diagnosis occur across the system and to address them, whole-system commissioning is important.

The King’s Fund noted that the fragmented and complex system makes it more difficult to ensure a co-ordinated process of change across HIV services in response to changing needs, and to progress areas needing concerted effort, such as HIV prevention and action to reduce stigma. In one local area on the cusp of reaching the high prevalence threshold, there was a sense that increasing prevalence was inevitable and that HIV was ‘owned’ by national bodies rather than engaging local commissioners’ attention.

Local authorities, CCGs and NHS England need to work together to prioritise the elimination of late HIV diagnosis, an outcome that will provide financial as well as public health benefits across the system as a whole.
5. 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 LAs

- Studies have demonstrated that screening in general practice and EDs in areas of extremely high prevalence is cost-effective or even cost-saving

5.1 The cost impact of late diagnosis

Late diagnosis increases the costs associated with HIV in the short and longer term. Lifetime treatment costs for someone infected with HIV at age 30 have been estimated at between £185,000 and £360,000 (potentially reducing to between £100,000 and £180,000 with the introduction of generic antiretroviral drugs). 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 because of the significant rates of morbidity linked to late diagnosis and the resulting hospital admissions. Direct medical costs remain almost 50% higher for each year after diagnosis. Reducing late diagnosis averts not only these higher treatment costs but also the social care costs associated with late-stage disease, while enabling people living with HIV to maintain healthy and productive lifestyles.

5.2 Averting the costs of new infections

Prompt diagnosis and rapid access to treatment also saves the costs of new infections by preventing HIV transmission. In 2014, based on data available in 2011, NICE estimated that, if its 2011 national 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. Since then, the evidence that treatment makes HIV untransmissible has become stronger, so NICE’s calculation may be an underestimate. Clearly, for the relatively small investment required to increase rates of testing, there is the potential for substantial savings in the short, medium and longer term if late diagnosis can be significantly reduced.

Early treatment initiation to prevent HIV transmission, known as ‘treatment as prevention’ (TasP), is deemed by NHS England to be cost-effective and probably cost-saving. However, TasP is unlikely to decrease HIV transmission at a population level unless the undiagnosed population can be substantially reduced through increasing both the coverage and frequency of HIV testing. PHE has concluded that this has been achieved among gay and bisexual men in London (see page 40): a major breakthrough which needs to be replicated more widely.

5.3 Resource implications of increasing HIV testing

NICE analysed the resource impact of implementing its 2016 testing guideline. Noting that increasing the number of people tested would increase the number diagnosed and needing treatment, it concluded that the additional costs of both testing and treatment would be offset by savings from treating people earlier rather than late or very late. There would also be savings from a reduction in the number of people with HIV arising from onward transmission.
5.4 Cost-effectiveness thresholds for routine HIV testing

HIV screening interventions are generally accepted to be cost-effective when undiagnosed prevalence in a population (and therefore its likely positivity rate) is 0.1% or above. Evidence to this effect from the USA\(^{81}\) was the basis for recommendations in UK guidance that testing should be offered routinely in medical admissions and to new registrants in general practice where local diagnosed prevalence is at least 2 per 1000.\(^{82}\) There are now 79 LAs which exceed this threshold.\(^{83}\)

European research has found HIV prevalence levels ranging from 0.3% to 4%, well over the threshold, in people with eight specified HIV indicator conditions.\(^{84}\) European guidance on indicator condition-guided testing states that individuals presenting to any healthcare setting with one of these conditions should be strongly recommended to test for HIV.\(^{85}\)

In the USA, the return on investment of a $102.3 million three-year initiative, to expand testing in populations with high prevalence of HIV, was calculated at $1.95 per dollar invested. A positive return on investment resulted when the prevalence of undiagnosed HIV was ≥1.2 per 1,000 population.\(^{86}\)
5.5 Cost-effectiveness of HIV testing interventions

A 2014 UK study modelling HIV transmission and progression showed that a targeted approach, offering annual HIV testing to people at higher risk along with one-time screening of all other adults, would be cost-effective (at £17,500 per QALY\textsuperscript{i} gained, well below established UK cost-effectiveness thresholds of £20,000–£30,000 per QALY gained).\textsuperscript{87} However, the model was developed when significant numbers of people living with diagnosed HIV were not receiving ART (and were therefore still potentially able to transmit the virus) because guidelines then recommended starting treatment at CD4 counts of 350 cells/mm\textsuperscript{3} or below.

Mathematical modelling in the USA has also shown that testing of gay and bisexual men at three-monthly intervals is cost saving in terms of new infections averted, compared to annual testing.\textsuperscript{88}

Few studies have looked in detail at the cost-effectiveness of specific HIV testing interventions in the UK, and this can be a complex exercise. One randomised controlled trial concluded that screening for HIV in primary care is cost-effective in the medium term in settings of high HIV prevalence (the study was performed in an area now classified as of 'extremely high' prevalence) because of lower healthcare costs of people living with HIV if diagnosed earlier and ongoing reductions in HIV transmission.\textsuperscript{89}

Similarly, a study in an extremely high prevalence area compared the costs of opt-out\textsuperscript{ii} testing in EDs with the costs of inpatient stays and outpatient investigations in those patients where an opportunity had been missed to test them in the ED. It concluded that opt-out HIV testing in this setting would save money before calculating additional savings from the prevention of onward transmission.\textsuperscript{90}

Mirroring this finding, a US modelling study found that screening in STI clinics and EDs was cost-effective compared with diagnosing inpatients, even when including only the benefits to index patients. When the benefits of reduced transmission to partners from early diagnosis were included, screening in settings with less-advanced disease stages was cost-saving compared with screening later in the course of infection.\textsuperscript{91}

An analysis of cost per new HIV diagnosis in four UK pilot study sites concluded that expanded HIV testing may be more cost-efficient in acute general admissions units than in general practice, because of the shorter offer time, higher patient uptake, higher HIV positivity and lower diagnostic test costs. However, HIV testing in GP settings is still an important component of expanded HIV testing because of its higher population coverage. Return on investment was found to improve with increased patient uptake rate and in areas of high HIV positivity.\textsuperscript{92}

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\textsuperscript{i} QALY = quality adjusted life year

\textsuperscript{ii} Opt-out testing means performing an HIV test after notifying the patient that the test will be done; consent is inferred unless the patient declines.
6. Policy drivers and guidance

6.1 Policy drivers

A range of policy is in place to drive the elimination of late HIV diagnosis.

6.1.1 At international level

- UNAIDS has set the **90-90-90** target as part of its strategy to end the AIDS epidemic: by 2020, 90% of people living with HIV to know their status, of whom 90% are on treatment, of whom 90% are virally suppressed.93

While already exceeding the second two targets, England still has progress to make on the first, with only 88% of infections diagnosed in 2016 (Figure 14). This should place the focus squarely on eliminating late diagnosis. The fact that London has already met the first ‘90’ provides encouragement and an indication of some of the changes needed in other parts of the country. However, in London and around the country, the focus also needs to be on reaching the first ‘90’ for each of the population groups most affected by HIV, not just for gay and bisexual men.

**Figure 14: The continuum of care in England, 2016**


6.1.2 At national level

- The Department of Health’s (DH)’s *A framework for sexual health improvement* (2013) states the need to ‘continue to tackle HIV through prevention and increased access to testing to enable early diagnosis and treatment’.94

- The *Public Health Outcomes Framework* (PHOF) sets out desired outcomes and indicators for public health improvement and protection which LAs must consider when carrying out their public health functions. These include indicators for late diagnosis of HIV (‘people presenting with HIV at a late stage of infection’) and antenatal HIV screening coverage.95

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i. Since January 2018, Department of Health and Social Care (DHSC)
• PHE’s *Health promotion for sexual and reproductive health and HIV. Strategic action plan, 2016 to 2019*, which sets out its approach to improving the public’s sexual and reproductive health and reversing the HIV epidemic, gives clear priority to decreasing HIV incidence in the populations most at risk and reducing rates of late and undiagnosed HIV in the most affected communities.96

• In addition, there are broader national policies which emphasise the primacy of prevention and early diagnosis, not specifically of HIV, such as the *Five Year Forward View* (2014), published by NHS England with NHS partner organisations, which sets out a radical vision for a better NHS and urges ‘a radical upgrade in prevention and public health’ and a reduction in health inequalities.97

Taken together these policy documents provide some support for national and local efforts to eliminate late HIV diagnosis, but their force is limited. The DH *Framework* was published at a time when guidelines recommended treatment initiation at a CD4 count of 350 cells/mm³ and the sale of self-testing kits was still illegal. It needs updating with a greater focus on current challenges and opportunities, and it would be stronger if its ‘ambitions’ were replaced with measurable outcomes. The PHOF late diagnosis indicator is useful but its impact is weakened by the fact that its prioritisation at local level is discretionary. PHE’s *Strategic action plan* is a statement of its own priorities; it may create a trickle-down effect on PHE’s partners, but it is not in itself a driver for action across the system. The *Five Year Forward View* makes no mention of HIV or sexual health, unlike other key areas of public health, and as the engagement of CCGs and NHS England with the challenge of late diagnosis is currently very limited, it is debatable how great its impact can be in driving priority within the NHS for eliminating late HIV diagnosis.

### 6.1.3 At regional or supra-local level

• Sustainability and transformation partnerships (STPs) have been set up across 44 designated areas in England, focused over five years on improving quality and developing new models of care, improving health and wellbeing, and improving efficiency of services. STPs are intended to facilitate collaboration and shared planning across a geographical footprint – ‘place-based planning’. The plans cover all aspects of NHS spending, as well as focusing on better integration with social care and other LA services.98

• Integrated care systems (ICSs) are a further development, building on the work of the STPs and the establishment of the Greater Manchester Combined Authority whereby all the NHS organisations and LAs in Greater Manchester signed a landmark agreement in 2015 with the Government to take charge of health and social care spending and decisions in the city region.99 ICSs have evolved from STPs and take the lead in planning and commissioning care for their populations and providing system leadership. They bring together NHS providers and commissioners and LAs to work in partnership in improving health and care in their area.100

The collaborative approach of STPs and ICSs offers the potential for addressing the barriers described above arising from the fragmented commissioning arrangements for HIV and sexual health. 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. Only seven of the 44 current sustainability and transformation plans make any mention of HIV, and of these just two refer to diagnosis (halving late diagnosis is a specific outcome for one) and one to screening.101 The Greater Manchester Population Health Plan also prioritises HIV, with a significant focus on reducing late diagnosis.102
6.2 Evidence-based guidance

The 2016 NICE guideline, *HIV testing: increasing uptake among people who may have undiagnosed HIV*, based on the best available evidence of effectiveness and cost-effectiveness, makes recommendations for HIV testing in all areas of England, with additional recommendations for further testing in areas with a ‘high’ HIV prevalence (ie a diagnosed local prevalence of 2 or more per 1000 adult population) and ‘extremely high’ HIV prevalence (a diagnosed local prevalence of 5 or more per 1000). The recommendations are under four headings:

1. **Offering and recommending testing in different settings**, with specific recommendations for testing in specialist sexual health services, secondary and emergency care, GP surgeries, prisons and community settings;

2. **Increasing opportunities for testing**, focusing on point-of-care testing, self-sampling, repeat testing, people who decline a test and partners of people who test positive;

3. **Promoting awareness and uptake of testing**, with recommendations on the content of materials and interventions and how they should be targeted, and methods of raising awareness;

4. **Reducing barriers to testing**, covering communication in medical settings, staff skills and behaviour, and referral pathways following positive and negative test results.

The *UK National Guidelines for HIV Testing 2008* (currently being reviewed and updated) complement the NICE guideline, advising that people should be offered and encouraged to accept HIV testing in a wider range of settings and that patients with specific indicator conditions should be routinely recommended to have an HIV test. The guidelines state that any doctor, nurse or midwife should be able to offer and obtain consent for testing.

In its *HIV testing in England 2017* report, PHE makes recommendations on HIV testing for a range of services (see box, page 36). Specific recommendations are also made about frequency of HIV testing for different groups at higher risk.

The recommendations in these three guidance documents are broadly in line with each other and based on the epidemiology and evidence of effectiveness. There is consensus on the steps needed to increase uptake of testing and reduce late diagnosis. The challenge lies in implementation and ensuring the barriers to this are recognised and overcome. Responsibility rests with NHS commissioners as well as LAs, and with non-HIV specialists as well as HIV specialists.
Public Health England recommendations

1. Sexual health services should consider how they can ensure that:
   - all gay and bisexual men are offered and recommended regular (ie annual) HIV tests
   - all gay and bisexual men at high risk of HIV acquisition (eg a recent anogenital STI diagnosis), are offered and recommended frequent (ie every 3 months) HIV tests
   - all black African men and women are offered and recommended regular HIV tests
   - HIV partner notification improves for heterosexuals and gay and bisexual men
   - all other attendees are offered and recommended to have HIV tests

2. General practices and secondary care in high and extremely high prevalence areas should consider how they can ensure that they offer and recommend HIV testing to patients in line with NICE recommendations.

3. Commissioners should consider how they can ensure that people at higher risk of HIV acquisition have access to a range of testing options including community testing and self-sampling.

4. Providers of health services to patients with hepatitis B and C, tuberculosis and people who inject drugs should consider how they can ensure that all patients are offered and recommended to have HIV tests.

5. Providers of HIV testing in prisons should consider how they can ensure that HIV testing is implemented and monitored effectively.

6. Antenatal service providers and blood, tissue and organ donation services should continue to maintain current high levels of HIV testing

7. Progress towards eliminating late HIV diagnosis

7.1 Effectiveness of interventions

Late diagnosis has been gradually decreasing over many years due to a range of interventions to expand the reach of HIV testing. It can be hard to measure the direct impact on the number or rate of late diagnoses of particular interventions, especially when they are relatively small scale and target a wide population, because the majority of people tested, even in higher prevalence populations, will not have HIV. However, interventions which can be shown to increase testing in populations at highest risk are likely to be effective, and the higher the positivity rate (the proportion of tests which are positive) the more effective an intervention can be deemed to be.

The positivity rate usually reflects the prevalence in the population being tested. The chart below shows how positivity in different settings compares, based on national testing and diagnosis data (Figure 15). All the settings in the chart achieve a positivity rate well above the accepted threshold for cost-effectiveness.

**Figure 15: Number of people tested in order to diagnose one positive/reactive by service type, 2016**

<table>
<thead>
<tr>
<th>Service type</th>
<th>Number of people tested</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-sampling</td>
<td>139</td>
</tr>
<tr>
<td>Secondary care</td>
<td>175</td>
</tr>
<tr>
<td>Community settings</td>
<td>181</td>
</tr>
<tr>
<td>General practice (High prevalence areas)</td>
<td>217</td>
</tr>
<tr>
<td>General practice (Extremely high prevalence areas)</td>
<td>228</td>
</tr>
</tbody>
</table>


A high positivity rate is likely to be found if testing is targeted at:

- People with risk factors for HIV (notably gay and bisexual men, black Africans, people from countries with high HIV prevalence, sexual partners of people with diagnosed HIV and others whose behaviour places them at higher risk)
- People in local areas where there is a high prevalence of HIV
- People with HIV indicator conditions

An effective approach to testing needs to reach people at risk who have never tested before or who have not tested in the last year. For those at highest risk, testing should be three-monthly.
Such approaches will detect the most cases of HIV and should continue to be prioritised. However, they are not sufficient for eliminating all late diagnoses, especially as indicator conditions sometimes do not appear until a significantly advanced stage of HIV disease. There is no ‘magic bullet’ for finding everyone with undiagnosed HIV before they present with severe illness. People who end up being diagnosed late are spread through the population and around the country without all sharing unifying characteristics that would render them susceptible to targeting as a group. Innovative approaches are needed to pick up those at risk of falling through the net before they reach such a late stage. For example, social media campaigns could be designed not to exclude people who may have been at exposed to HIV but do not fit the profile of the groups at highest risk (such as white heterosexuals who travel abroad), and HIV testing could be intensified in health services used by heterosexual women, such as those providing contraception. The essence of an effective approach is to combine testing services and interventions which reach different parts of the undiagnosed population and thus are complementary.

7.2 Effective and promising interventions

The section below describes progress with HIV testing which could contribute to the eventual elimination of late diagnosis in different settings. It identifies some recent interventions notable for either their proven effectiveness or their innovation.

7.2.1 Testing in specialist sexual health services

- A model of high volume, high frequency testing and rapid access to treatment, along with provision of pre-exposure prophylaxis (PrEP), has led to a reduction in HIV incidence among gay and bisexual men at five clinics in London

- The model should be analysed for success factors that can be replicated in clinics with different characteristics and for learning relevant to reducing late diagnosis

- Partner notification is highly effective and has increased, and there is room for innovation for further improvement

Service modernisation

In the face of funding and commissioning pressures, sexual health clinics are experiencing major changes. Capacity is stretched and waiting times have increased in many services\(^\text{[106]}\) meaning potential delays and lack of access for people seeking HIV testing. On the other hand, new technology has enabled services to innovate, for example by using online access to self-sampling, electronic reminders for clinicians to offer, or patients to request, repeat testing, and automated clinics designed to improve screening for asymptomatic HIV.\(^\text{[107]}\)

Frequent testing is of crucial importance, especially for those at high risk of HIV, because it can
identify new infections early enough to prevent or reduce further transmissions. (In the first weeks of infection, around seroconversion, viral load is very high and transmission most likely.) Among gay and bisexual men tested for HIV in sexual health services (of which there were 104,000 in 2016), the positivity rate fell dramatically from 2.3% in 2012 to 1.7% in 2015 and, even more sharply, to 1.2% in 2016\textsuperscript{108}, resulting in a 17% drop in new diagnoses between 2015 and 2016. This decline was not evenly spread; it was twice as high in five London clinics which account for over a quarter of all new HIV diagnoses in gay and bisexual men in England.\textsuperscript{109} Innovation in the design of care pathways for frequent HIV testing and rapid access to treatment in these services, along with use of pre-exposure prophylaxis (PrEP), has been shown to have a major impact on HIV incidence in gay and bisexual men (see Case study 1, page 40). The level of testing frequency in these ‘steep fall’ clinics was higher than in other clinics which do not seem to have reached the tipping point for large reductions in new infections.

The five ‘steep fall’ London clinics have characteristics such as a central location, large size and a concentrated local LGBT community, which have enabled them to develop a service model for gay and bisexual men designed to facilitate fast and repeated access to testing and treatment (gay-friendly, patient-led, automated clinic technology). In order to achieve a similar impact on HIV incidence among gay and bisexual men around the country, it will be important to analyse the success factors from these clinics and how they can be replicated elsewhere, including in clinics which do not share the same characteristics.

In comparison with gay and bisexual men, HIV transmission dynamics and service use patterns are very different among black African heterosexuals and other groups at higher risk of HIV. Consideration should be given to what can be learnt from the ‘steep fall’ clinics in order to develop innovative service models which will be equally effective in reducing HIV incidence and late diagnoses in these groups. In addition, it should be noted that while the ‘steep fall’ clinics focused on frequency and promptness of testing among a group of engaged service users, success in reducing late diagnosis will also mean testing people who have never, or not recently, tested for HIV, may be unaware of their risk and are not engaged with sexual health services. This will require different service models but the same focus on understanding the underlying factors and implementing actions that directly address these.

**Partner notification**

An important role of sexual health services is partner notification (PN).\textsuperscript{i} Of all HIV testing interventions, PN has the highest positivity rate (3.9% in 2016). The number of people tested in specialist sexual health services as a result of HIV PN increased by 43% between 2012 and 2016.\textsuperscript{110} During this period, PN activity may have been stimulated by a rising awareness of the potential impact of PN due to a number of developments:

- a National AIDS Trust report published in 2012 highlighting the ‘missed opportunity’ of HIV PN\textsuperscript{111}
- a national audit of HIV PN in 2013 which found a staggering 21% prevalence of newly diagnosed HIV among tested contacts and one contact newly diagnosed for every 10 index cases, but also concluded that one in three possibly HIV-positive contactable contacts may have remained undiagnosed\textsuperscript{112}
- new standards for HIV PN published in 2015\textsuperscript{113}

In view of the proven effectiveness of PN, it should be further developed. One innovative recent approach was an interactive digital contact slip for anonymous PN, developed to alert partners of an index patient via text or email that they should visit a clinic, with details of a local testing service provided via the website. The tool enables providers to track which partners have been tested. When the tool was trialled with testing providers, the positivity rate was an impressive 16.7%, confirming the potential for PN to play an important role in the elimination of late HIV diagnosis.\textsuperscript{114}

\textsuperscript{i} Partner notification is the practice of notifying the sexual partners of a person who has been newly diagnosed with HIV (or other STI) that they may have been exposed to the infection.
**Case study 1**

**Steep fall in HIV diagnoses at five London sexual health clinics**

A 17% fall in new HIV diagnoses in gay and bisexual men in England between October 2014–September 2015 and October 2015–September 2016 was focussed in five London clinics which experienced a 32% decline. The fall seen at these five clinics coincided with accelerated treatment at diagnosis and a substantial increase in HIV testing, particularly repeat testing. The volume of HIV tests across London combined with rapid treatment following diagnosis at the five ‘steep fall’ clinics is now likely to have reached a level that decreases the number of men with transmissible levels of virus thereby reducing transmission. In contrast, although attendances by gay and bisexual men increased in other clinics inside and outside London along with a general decline in time to starting treatment, the volume and frequency of testing and the reduction in time from diagnosis to treatment were not sufficient to have this effect elsewhere.

If HIV testing of gay and bisexual men at high risk of HIV is intensified and wide-scale immediate ART, as observed within the London ‘steep fall’ clinics, is replicated elsewhere, it is probable that a substantial reduction in HIV transmission among gay and bisexual men could be achieved nationally.

The use of PrEP among gay and bisexual men with high risk behaviour, although limited at this stage, will also have contributed to the fall in new diagnoses. Should the promise of the PrEP Impact Trial in England be realised promptly, then a very large reduction in HIV transmission in gay and bisexual men may be attained.

More recent data from one of the five clinics, which diagnoses half of all the HIV in gay and bisexual men in London, shows that recent HIV infections among gay and bisexual men using its services fell by around 90% in three years. The number of new HIV diagnoses went down from 60-70 a month at the end of 2015 to ten in September 2017. Factors leading to the decline are multiple, including frequent HIV testing, early diagnosis and rapid treatment initiation, support for PrEP use, and fast treatment of STIs which can increase the risk of HIV transmission.

Sources: Graph and text adapted from Brown AE, Mohammed H, Ogaz D, Kirwan PD, Yung M, Nash SG et al. Fall in new HIV diagnoses among men who have sex with men (MSM) at selected London sexual health clinics since early 2015: testing or treatment or pre-exposure prophylaxis (PrEP)? Euro Surveill 2017;22(25):pii=30553, and Alcorn K. How a London clinic reduced new HIV infections by 90% and why more European cities can do the same. NAM aidsmap, 26 October 2017.

Graphs reproduced under Creative Commons license
7.2.2 Testing 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

- Increasing testing in general practice in all areas, especially where prevalence is low, remains a challenge and needs different approaches

Most interventions aiming to increase HIV testing in general practice have taken place in areas with high or extremely high HIV prevalence, where there are likely to be significant numbers of patients with undiagnosed HIV on each practice list. Interventions which have increased rates of diagnosis have usually included training for GPs and practice nurses. Findings have been mixed as regards i) the respective benefits and feasibility of screening, such as for all patients at new registration checks, versus testing based on risk assessment and recognition of clinical indicator conditions, and ii) the need for financial incentives.

The RHIVA2 study in Hackney, East London, found that promotion of opt-out rapid testing in general practice led to increased and earlier diagnosis of HIV. An extensive primary care education programme carried out as part of local initiatives in South West London resulted over a five-year period in a 184% increase in HIV diagnoses in primary care and other non-sexual health settings and diagnoses being made earlier.

SHIP (Sexual Health in Practice) offers training in sexual health clinical skills. In Haringey, North East London, it significantly increased testing rates without financial incentives. Positivity rates were substantially higher than that found in pilots of screening in London, suggesting that the training nurtured and supplemented complex clinical skills, thus prompting the offer of testing to those most likely to have HIV. Updated data (submitted for publication), showed that GP HIV testing rates in Haringey rose 600% over six years.

In Brighton, multiple initiatives in primary care and community settings, including training for primary care doctors and nurses, simplification of testing processes and support from an HIV testing liaison health adviser, improved the recognition and diagnosis of HIV. Over a 12-year period, there was a decrease in the rate of late diagnosis in such settings from 89.5% to 42.0%.

The size of the general practice workforce presents a major challenge when it comes to changing practice across the board. With over 7,000 GP practices and 33,000 GPs nationally, local, time-intensive interventions such as training sessions have limited reach, and in lower prevalence areas would be unlikely to be prioritised by busy GPs even if offered. While interventions with GPs and their staff such as those described above have been shown to increase rates of HIV testing and new diagnoses in areas of high or extremely high prevalence, different approaches are needed to raise the awareness, understanding and confidence of GPs in other areas so they are able to fulfil the universal NICE guideline recommendation for testing in response to symptoms or risk factors.

### NICE recommends

- GP surgeries should offer and recommend HIV testing to everyone who has not previously been diagnosed with HIV and who has either symptoms that may indicate HIV or specified risk factors

- In areas of high and extremely high prevalence, also offer and recommend HIV testing to all new registrants with the practice and to everyone undergoing blood tests for another reason who has not been tested in the previous year

- In areas of extremely high prevalence, consider HIV testing opportunistically at each consultation based on clinical judgement.

Source: NICE guideline [NG60] HIV testing: increasing uptake among people who may have undiagnosed HIV. 2016
Case study 2
Engaging GPs in HIV testing in an area of extremely high HIV prevalence

A GP HIV Champion was appointed in Southwark, South East London, in May 2017 to promote testing ‘from GPs to GPs’. The project set out to win GPs’ hearts and minds and promote changes that reduce stigma and are sustainable.

Enablers:
• Primary care usually happy to follow guidelines
• Driven by comparative performance indicators
• Powerful wish to avoid missing a serious diagnosis
• Strong will to improve public health

Barriers:
• Outdated knowledge of HIV
• Struggling surgeries
• No financial incentives for HIV testing
• Non-engagement – ‘not my role’
• HIV stigma – worried about patient reaction
• Medico-legal concerns

Approach:
• Engaging – meeting clinicians at each practice and offering targeted intervention, presenting at CCG, locality forums and Vocational Training Scheme meeting for GP registrars
• Supporting system change – Removal of check box in lab requests requiring counselling for HIV test, adding prompts to practice IT system, phlebotomist to include HIV test in bloods for new patient checks, patient information leaflet at new patient registration
• Collaborating – creating audit tool to analyse late HIV diagnosis as a significant event

Early results:

<table>
<thead>
<tr>
<th>Surgeries visited (9)</th>
<th>HIV tests 01.09.16 - 27.10.16</th>
<th>HIV tests 01.09.17 - 27.10.17</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>254</td>
<td>306</td>
<td>+52 (+20%)</td>
</tr>
<tr>
<td>Surgeries not visited (30)</td>
<td>823</td>
<td>694</td>
<td>-129 (-16%)</td>
</tr>
</tbody>
</table>

Lessons learnt:
• Main difficulty is engaging with practices
• Initial good response to powerful message ‘GPs have a key role in ending HIV epidemic’
• Keep it simple – routine test well accepted and easier to implement than targeted testing
• Collaboration between surgeries – sharing resources, strategies and software warnings helps build a pro-active testing community

Adapted from: Dr Jonty Heaversedge and Dr Cristina Guallar. HIV testing. Presentation, BHIVA autumn conference, November 2017
7.2.3 Testing in secondary care

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

- A simplified pathway for consent compatible with standard clinical pathways increases test uptake

- HIV testing levels for people with tuberculosis (TB) are now very high, but those for people with hepatitis B and C need improvement

**Routine testing on admission and in emergency departments**

In recent years a number of opt-out testing initiatives in EDs and AMUs have shown success. Most of the 17% increase in HIV testing in hospitals between 2014 and 2016 took place in EDs where numbers more than doubled, reflecting local testing initiatives and studies. The challenge now is to refine, roll out and sustain successful methodologies in line with the NICE guideline.

In a 2009 pilot study, routing HIV testing was introduced for all patients admitted to an AMU in Leicester, a high prevalence area. The percentage of eligible patients tested increased from 3.7% to 22% after the one-year pilot, and there were four times as many HIV diagnoses. A similar initiative in a London AMU in a high prevalence area in 2011 resulted in the testing rate rising from 33% to 41% in three months.

Both AMU studies showed that a routine opt-out HIV testing policy can be delivered by frontline medical staff in an acute setting with no extra resource requirement beyond laboratory costs, and that such a policy identifies new HIV patients who would not otherwise have tested and reduces late diagnosis. The London study concluded that policy ownership by nurse champions, with the HIV team as background advisors, was key to achieving and sustaining high test rates. However, the highest levels of testing coverage achieved remained well below 50%, making it likely that a significant number of people with undiagnosed HIV in the AMU were remaining undiagnosed. One of the studies observed that blood samples had often already been taken in the ED and were not repeated in the AMU, limiting the amount of routine HIV testing that could be done in the latter.

Better testing rates have been achieved in EDs. In a 2012 pilot study in a busy London teaching hospital, whereby patients having serological testing were offered an HIV test by ED clinical staff, 48% were offered testing of whom 65% accepted. The study demonstrated that routine HIV testing in the ED is feasible and acceptable. However, the authors concluded that to make HIV testing effective and part of routine clinical care, considerable clinical leadership, staff training and additional resources are required.

**NICE recommends**

- In secondary and emergency care, offer and recommend HIV testing on admission to hospital, including emergency departments, to everyone not previously diagnosed who has either symptoms that may indicate HIV or specified risk factors

- In areas of high prevalence, also offer and recommend HIV testing on admission to everyone not previously diagnosed with HIV who is undergoing blood tests for another reason

- In areas of extremely high prevalence offer and recommend HIV testing on admission to everyone who has not previously been diagnosed with HIV

- Routinely offer and recommend an HIV test to everyone attending their first appointment at services providing treatment for hepatitis B, hepatitis C, lymphoma and tuberculosis.

Source: NICE guideline [NG60] HIV testing: increasing uptake among people who may have undiagnosed HIV. 2016
Addressing the challenge of sustaining a consistent offer of testing by busy frontline staff, a simplified consent pathway was introduced in the ED of a large teaching hospital. This achieved significantly higher rates of testing and clearly reduced late diagnoses (see Case study 3).

Case study 3
A simplified consent pathway increases routine HIV testing uptake in the ED

In an extremely high prevalence area of London, a simplified consent pathway for routine HIV testing was introduced in the ED of a large teaching hospital (Guy’s and St Thomas’), designed to work seamlessly with standard clinical pathways.

Standard blood order sets were re-configured, with HIV pre-selected, and all ED attenders already having a blood test were tested for HIV unless they opted-out. Posters about routine HIV testing were prominently displayed and clinicians gave patients an information leaflet without initiating pre-test discussion. Reactive results were followed up by a dedicated new HIV diagnosis team, with recall for confirmatory testing by the HIV service. The initiative was supported by ED clinical champions and the HIV testing pathway was taught at all new staff inductions. The ED team received weekly reports on testing rates and new diagnoses, including feedback to individual clinicians on their testing practice.

- 70% testing rates were achieved and sustained (rising from 2.9%)
- Patients rarely chose to opt-out
- New diagnoses were 0.3% of those tested (well above the cost-effectiveness threshold)
- Inpatient episodes fell by 15%
- Over half of newly diagnosed patients had previously attended the ED when the opportunity to diagnose HIV had been missed
- Almost a quarter of new diagnoses had HIV seroconversion (very early infection)

By detecting HIV which had previously been missed as well as seroconversions, this initiative must have been successful at reducing late diagnoses. It appears to have overcome the barriers which have prevented high test offer and uptake in other studies.

Source: Paparello J, Hunter L, Betournay R, Doctor J, Larbalestier N. Reducing the barriers to HIV testing – a simplified consent pathway increases the uptake of HIV testing in a high-prevalence population. Presentation, 22nd annual conference of BHIVA, 2016. Additional data from Dr Nick Larbalestier and Dr Laura Hunter.
Routine testing in services for people with indicator conditions

Testing for HIV in hospital services for people with specific indicator conditions has been variable. Around half of people newly diagnosed with hepatitis B and C were tested for HIV between 2010 and 2014, with the proportions varying between settings (Table 4).

Table 4: HIV testing within 6 months in those positive for HBsAg or anti-HCV: England 2010-2014

<table>
<thead>
<tr>
<th></th>
<th>Secondary care</th>
<th>General practice</th>
<th>Sexual health services</th>
<th>Positivity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hepatitis B</td>
<td>40%</td>
<td>45%</td>
<td>58%</td>
<td>2.4%</td>
</tr>
<tr>
<td>Hepatitis C</td>
<td>50%</td>
<td>41%</td>
<td>54%</td>
<td>1.9%</td>
</tr>
</tbody>
</table>


Testing rates for people with notified TB are much more comprehensive. In 2016, 93% of people with notified TB (for whom testing information was available) were tested, an increase from 88% in 2012. 3.8% of notified TB cases were co-infected with HIV.\(^{125}\)

In 2010 it was reported that half of all TB patients in London were not offered an HIV test.\(^{126}\) A subsequent randomised controlled trial in London introduced staff training and patient information leaflets to TB clinics which already had a universal HIV testing policy, and the same two interventions plus the introduction of a universal testing policy to clinics which had been testing selectively. Baseline testing levels were higher in the clinic already doing universal testing (89%) than in the ones doing selective testing (76%), but testing offer and coverage increased significantly in both trial arms. The study concluded that the implementation of a policy of universal testing, combined with supportive information, has the potential to positively impact on the levels of testing in TB clinics.\(^{127}\)

7.2.4 Testing in antenatal services

- Antenatal screening has nearly eliminated vertical transmission\(^i\) of HIV and kept late diagnosis lower in women than heterosexual men
- Screening coverage has grown to almost 100%

The NHS Infectious Diseases in Pregnancy Screening Programme recommends

- Midwives and healthcare professionals should offer and recommend testing to all pregnant women as part of their antenatal care.


Universal antenatal HIV screening, part of the Infectious Diseases in Pregnancy Screening Programme\(^{128}\), has now reached 98% coverage of pregnant women and rates of newly diagnosed HIV had declined to 0.03% by 2015.\(^{129}\) As well as almost eliminating vertical transmission of HIV in the UK, this programme has helped to keep the rate of late diagnosis lower in women than men. Perhaps because of the benefits of antenatal screening for their child, pregnant women much more rarely decline screening than women offered testing in other settings. It is also likely that the continuing rise in coverage is because screening has become increasingly normalised for staff and patients.

\(^i\) The term ‘vertical transmission’ refers to transmission from a mother to her baby
7.2.5 Testing in the community

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

- Models and learning from innovative projects should be disseminated

Community testing initiatives are usually local and relatively small-scale, run by voluntary organisations or other providers within local communities such as pharmacies, and as such their impact on rates of late diagnosis is necessarily limited. However, because they often reach people at high risk who do not get tested elsewhere, they complement testing in other settings and can still have an impact on late diagnosis.

In the first cohort of PHE HIV Prevention Innovation Fund projects (see Case study 4), the three which focused on HIV testing in community settings achieved positivity rates of 0.4%, 1.6% and 3.5% (although some positive results were in people who had already been diagnosed). Getting a specific community on board (and influencing them to have a test) was felt to be more effective if key influencers from the community were involved, for example if the project leads and volunteers were members of the same community or if leaders in the community came forward for testing. The complexity of gaining engagement in communities where HIV-related stigma may be high means interventions needed sufficient time to become established and outcomes would probably have improved beyond the one-year span of each project.130

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**NICE recommends**

- Providers of community testing services (including outreach and detached services) should set up testing services in:
  - areas with a high prevalence or extremely high prevalence of HIV, using venues such as pharmacies or voluntary sector premises (for example, those of faith groups)
  - venues where there may be high-risk sexual behaviour, for example public sex environments, or where people at high risk may gather, such as nightclubs, saunas and festivals.

Source: NICE guideline [NG60] HIV testing: increasing uptake among people who may have undiagnosed HIV. 2016
7.2.6 Testing in the home

• User satisfaction with self-sampling and self-testing is high

• HIV self-sampling has extended the reach of HIV testing to people who have never before tested, especially gay and bisexual men and white heterosexuals

• The potential to increase the reach of self-sampling in black African communities should be explored

• Many buyers of self-test kits have never tested before and the majority are from non-metropolitan areas, but there is no information about test results

• Providing self-tests through an online service has been successful at reaching gay and bisexual men at high risk especially those not testing frequently enough

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Case study 4
HIV Prevention Innovation Fund - providing learning for community HIV testing

The HIV prevention innovation fund is run by PHE to support voluntary sector organisations to reduce the impact of HIV through innovative interventions targeting groups most affected by HIV. PHE seeks to fund projects which have the potential to be replicated and scaled-up, strengthen local partnership working, and impact on national and local prevention practice. Offering proof of concept for a range of innovative approaches, each project contributes to the evidence base around reducing the impact of HIV.

Learning that could inform new community testing initiatives is provided from four projects in the evaluation of the first cohort:

• **HIV testing in the workplace** ran health and wellbeing events, providing health checks including HIV testing, for low waged and migrant workers in workplaces from the East Midlands to the South East.

• **Let’s stop HIV** ran events in London to raise awareness and offer HIV testing to Latin American communities in which a high level of stigma attaches to HIV.

• **Talk and Test** offered point-of-care testing (POCT) to gay and bisexual men and black African communities in community settings across Greater Manchester.

• **Testing Faith** trained faith leaders in Luton, Bradford, Leeds and London about HIV and supported them to develop simple sexual health plans for their congregations and to hold events at which people were offered HIV testing.

The second cohort included projects to engage transgender communities in HIV testing in sex-on-premises venues, sell HIV self-testing kits through vending machines at saunas for gay and bisexual men, train pharmacists and offer HIV testing in community pharmacies, run drop-in sessions with HIV testing and referral in drug and alcohol treatment services, and undertake one-to-one outreach, workshops, HIV testing and support in a hostel for refugees.

**HIV self-sampling**

The main provider of self-sampling is the National HIV Self-Sampling Service (NHSSS), established by PHE in 2015 to standardise provision and offer LAs an ‘off-the-shelf’ option to commission for their local population. The service offers a low-cost HIV testing service (at £933 per reactive test) that can complement current service provision to key populations.\(^{131}\)

The NHSSS has had more take-up from gay and bisexual men and white heterosexuals than from black Africans, who made up fewer than one in ten users in 2016. The service has succeeded in extending the reach of testing, with almost a third of users not having tested before and a further third having last tested over a year ago. It has also successfully targeted people at higher risk of HIV, as evidenced by a reactivity rate of 1.1% (of which ‘high reactivity’ is 0.7%).\(^ {132}\)

The potential to increase the reach of self-sampling to more black Africans should be explored.

**HIV self-testing**

As self-testing is performed in private and not reported, it is impossible to know how many tests have been done since the sale of self-test kits was legalised in 2014.

However, a three-month online self-testing service was piloted by Terrence Higgins Trust and promoted especially to gay and bisexual men. Feedback from users showed that self-testing was reaching men with behaviours which put them at high risk of HIV, many of whom had either never tested before (one in five users) or were not testing frequently enough – more than a third had last tested over a year ago. Perhaps surprisingly, given the convenience of self-testing for those who have to travel long distances to testing services, over 90% of users were urban. Reported reactivity was 0.9%, comparable to self-sampling.\(^ {133}\)

Data from the initial year’s sales of the first HIV self-testing kit on the UK market showed a different user profile. Over a quarter of users were female, and over two-thirds were from ‘non-metropolitan’ locations. Half had never tested before. Both the pilot and a Biosure satisfaction survey found self-testing to be very popular, with 97-98% of users saying they would use it again.\(^ {134}\)

In a recent survey of UK women not diagnosed with HIV, but who had experienced concern about HIV, almost half said they would like to test themselves at home.\(^ {135}\)

There is a need to know more about the use of self-testing among people other than gay and bisexual men, in order to find new ways of extending the reach of testing to those at risk. Given the levels of stigma and fear of disclosure in some African and other non-national communities, the privacy of self-testing might have particular appeal. However, for people who may be isolated and vulnerable, rapid linkage to care following a reactive result is especially important and self-sampling may be more appropriate.

**NICE recommends**

- Consider providing self-sampling kits to people in groups and communities with a high rate of HIV
- Ensure that people know how to get their own self-sampling kits, for example, by providing details of websites to order them from.

Source: NICE guideline [NG60] HIV testing: increasing uptake among people who may have undiagnosed HIV. 2016
7.2.7 Testing in prisons and other places of detention

- Opt-out testing in prisons has started but is not yet fully implemented
- Data so far indicate that the prison population has a high HIV prevalence of over 2 in 1000

An opt-out blood-borne virus testing programme for all new prison receptions was recently launched, but preliminary data for 2016/17 indicate that only 17.5% of new receptions and transfers were tested. 942 positive tests were reported – a positivity rate of 2.5% - but many were in people who already knew they had HIV. Data quality will improve, but the high positivity rate among those tested, even if it reflects diagnosed as well as undiagnosed HIV prevalence, indicates the importance of achieving full implementation of the programme in order to diagnose all HIV in prison as early as possible.

There is little published information on any HIV testing in other places of detention, such as immigration removal centres.

7.2.8 Public education

- Social media has enabled national public education to reach beyond traditional geographical boundaries for publicity and advertising
- National and local campaigns should be complementary

Commissioned at national level by PHE, HIV Prevention England (HPE) delivers public education campaigns, as well as online services, local activities and policy work. One of its aims is to increase HIV testing to reduce undiagnosed HIV and late diagnoses. Its campaigns use a social marketing approach and are designed to complement locally commissioned prevention in areas of higher prevalence. One campaign (It Starts with Me) aims to increase knowledge, improve attitudes and significantly encourage uptake of protective behaviours including testing. National HIV Testing Week (NHTW) promotes HIV testing to communities which are most affected by HIV in the UK.

Notably, by using social media the campaign is able to extend its reach beyond the geographical boundaries which often constrain conventional media communications – in 2016 it claimed a reach of 8.5m people through these channels, of whom 20,000 ordered a postal testing kit over a two-month period. The programme’s impact summary for 2012-16 reported that over 45,000 people were tested, about two-thirds by postal testing and the rest by local delivery partners, with 753 NHTW events and roughly 615 people diagnosed. Evaluation of NHTW in 2016 found that 89% of gay and bisexual men and 83% of black Africans recalled having seen, heard or read an HIV-related message around the time of NHTW and two-thirds of organisations agreed NHTW increased their capacity to impact their community or clients, mainly through raising awareness of the importance of HIV testing and delivering more HIV tests.

The national campaign is designed to be complemented by activity at local level. Some areas commission local public education campaigns, such as the London HIV Prevention Programme, jointly funded by almost all the 33 boroughs. A series of media campaigns with a core common brand (‘Do it London’) have included outdoor advertisements, digital social promotion and targeted press coverage, complemented by community-focused campaigns tailored towards black Africans and gay and bisexual men. The campaign has very prominently promoted HIV testing and has
formed a backdrop for the decline in new HIV diagnoses among gay and bisexual men seen in 2016.  

It is very difficult to prove that public education campaigns have had a direct impact on rates of diagnosis or health outcomes, but they can play a significant role in raising public awareness, setting the climate within which testing and other interventions take place, and getting health education messages to people who may not be in touch with health services or community organisations.

### 7.2.9 Place-based initiatives

- Fast-Track Cities and Social Impact Partnerships offer promising models for collaboration to increase support and investment in high prevalence areas for increasing HIV testing and diagnosis

Place-based initiatives bring together commissioners, providers and the public across a (smaller or larger) local area to share goals and sometimes pool resources. STPs and ICSs (see page 34) are an example, as is the Greater Manchester devolution model. Two innovative HIV-specific initiatives in Brighton and London – Fast-Track City status and a Social Impact Partnership (see Case studies 5 and 6) – aim to radically improve outcomes and, while still unproven, should be watched for signs of success which could be replicated in other parts of the country. The same applies to Greater Manchester, where the ambition to eradicate HIV has been prioritised within its Population Health Plan 2017-2021, with a significant focus on reducing late diagnosis (see Case study 7).

**Case study 5**

**Fast-Track City status to galvanise local action on HIV**

In 2017, Brighton & Hove became the first Fast-Track City in the UK and agreed to work towards ‘zero new HIV infections, zero HIV-related deaths and zero HIV stigma’.

The Fast-Track Cities initiative (FTCI) is a global partnership launched to accelerate and scale up local HIV responses. Cities around the world with high HIV prevalence have signed up and negotiations are ongoing to recruit more. Focused on translating global goals, objectives and targets into local implementation plans, the FTCI is meant to build upon and strengthen existing HIV-specific and -related programs to attain the UNAIDS 90-90-90 targets. The FTCI supports Fast-Track Cities with process and oversight, monitoring and evaluation, programme interventions, communications and resource mobilisation.

The Brighton and Hove health and wellbeing board, which brings together the LA and CCG with representatives of NHS England and Healthwatch, agreed to put a plan in place to achieve the Towards Zero work, including a broad and thorough public engagement campaign, working closely with HIV community organisations in the city.

In January 2018, London also became a Fast-Track City, with the ambition of cutting rates of new HIV infection in the capital and eliminating discrimination and stigma associated with the condition.

By providing a framework for coordinating the efforts of all partners in a city, accessing international networks of support and learning, and holding leaders to account for progress, Fast-Track City status could galvanise and focus a city-wide response to the challenge of late HIV diagnosis.

**Sources:** [UN/IAPAC Fast-Track Cities](https://www.unaids.org/en); [Brighton and Hove Health & Wellbeing Board paper on Fast-Track Cities Initiative](https://www.brightonandhove.gov.uk); [Mayor of London press release](https://www.london.gov.uk)
Case study 6
An innovative model for place-based investment to increase HIV diagnosis

On World AIDS Day 2017, the Lambeth, Southwark and Lewisham HIV Testing and Care Programme was launched in three London boroughs which have some of the highest levels of HIV infection in the UK. With funding from the Elton John AIDS Foundation (EJAF), the programme will pilot the world’s first Social Impact Bond (SIB) designed to tackle HIV. The aim is to dramatically reduce HIV transmission in South East London by bringing additional investment to fund the commissioning of new evidence-based interventions to address local health needs.

A Social Investment Partnership (based on the SIB model) will be developed, supported by a grant from the Big Lottery Fund. The partnership brings together all local stakeholders in Lambeth, Southwark and Lewisham involved in the commissioning of the HIV care pathway (LAs, CCGs, NHS England and PHE), although it is intended in time to expand to cover the footprint of the area’s STP. The partnership will work with HIV service providers to identify ways of using additional resources to commission innovative interventions to increase HIV testing in high risk groups as well as improving access to HIV treatment and retention in care. The interventions will be delivered across a range of settings according to need and are likely to include primary care, acute care and voluntary and community sector providers. In particular, commissioners will look to see how current work can be supported, enhanced or developed to facilitate improved HIV outcomes, with a focus on sustainability.

A Special Purpose Vehicle (SPV) will manage the commissioning of interventions, targets will be set against HIV testing and treatment baseline data and a contract will be established between the relevant parties. A payment by results model will be determined (which outcomes, what level of improvement, what payment).

The project will be initially funded by private investors such as EJAF, other foundations, and impact investing funds. The financial return for investors will be linked to the achievement of two cost-saving outcomes: diagnosing new cases of HIV and re-engage patients who have dropped out of HIV care.

If found to be successful in achieving its intended outcomes, the Social Investment Partnership could provide a model for fostering innovation and improving outcomes which would contribute towards the elimination of late HIV diagnosis in other high prevalence areas.

Sources: EJAF press release; staff of LB Lambeth and Lambeth CCG - personal communication.
Case study 7
A city-region approach to eradicating HIV within a generation

Greater Manchester is working upon an ambition to end all new transmissions of HIV within a generation. This is a whole system approach, with commissioners, providers, North West PHE and others working together to develop the transformation application to the Greater Manchester Health & Social Care Partnership (GMHSCP). Activities have included workshops with a variety of stakeholders and strong public and patient engagement, including focus groups with key most-at-risk communities and people living with HIV.

Through this collaborative and co-produced approach, the programme aims to deliver a range of interventions to end all new transmissions of HIV, including scaling up HIV testing, particularly through community settings and home sampling postal kits. An online membership scheme for people most at risk of acquiring HIV gives them access to a range of bespoke interventions tailored around individual need, such as:

- individual face-to-face support focusing on behaviour change, underpinned and informed by a sexual health and wellbeing needs assessment
- free postal access to condoms, lube and home sampling kits
- a text reminder service for testing, aiming to increase test frequency
- intensive support, one-to-one and through peer-led support groups, for people living with HIV who may be at risk of not adhering to medication and have complex needs.

Key components of the development of this programme of work have focused on system leadership, the service user voice and a robust cost-benefit analysis.

The ambition regarding ending all new transmission of HIV within a generation is captured in the GMHSCP Population Health Plan Summary.

Source: Rob Cookson, LGBT Foundation - personal communication

7.2.10 Education and training for health professionals

- Training interventions can be effective but are usually small-scale

- To educate the primary and secondary care workforce so as to deliver the NICE guideline requires high level action from the leadership of the medical and healthcare professions

Training for the existing workforce

Most interventions to increase HIV testing in medical settings have included training for staff who will be offering testing. While some training is specific to the intervention (eg making a routine offer of testing in the ED), some is designed to impart a broader range of knowledge and skills to improve clinical diagnosis and communication with patients (eg SHIP for GPs and practice nurses).

Training is time-intensive and, apart from short sessions tied to dedicated testing interventions, it is probably unrealistic to expect most non-HIV specialists to dedicate significant time to face-to-face training on HIV. Brief, online educational resources are likely to have a better reach but still face the challenge of learner interest and prioritisation. Where training is linked to specific testing interventions, it may be difficult to roll it out at scale.
There is therefore a need to explore what educational interventions could have impact at scale. The medical Royal Colleges, especially Royal College of General Practitioners (RCGP), and specialty associations are in a position to play a key role, as are membership bodies for nurses and the Faculty of Sexual and Reproductive Healthcare (FSRH) which has a large membership of GPs and nurses with an interest in SRH.

**Education for the future workforce**

Undergraduate and postgraduate education needs to equip healthcare professionals entering the workforce with the knowledge and skills to provide HIV testing in line with current guidelines.

Since all doctors undergo undergraduate training it could be argued that a consistent approach to HIV testing in this curriculum is particularly important. However, there is no consistent approach, with universities each setting their own curriculum. The same applies to the undergraduate nurse curriculum, which includes no mandatory HIV training. In 2005, BASHH with a number of other organisations, developed a consensus definition of core learning outcomes in sexual and reproductive health and HIV for medical undergraduates, intended for use both in influencing curriculum planners and policy-makers, and as a standard against which to measure current sexual health education provision in medical schools. However, there has been no development of competencies specific to HIV testing within the curriculum since that call. In a 2009 BASHH survey of recent medical graduates, only 43% felt they could conduct an appropriate HIV pre-test discussion and 59% felt they could recognise clinical indicators suggestive of HIV, leading the authors to conclude that ‘lack of skill in discussing HIV testing, risk assessment and recognition of possible HIV presentations must be addressed’.

The curriculum for core medical trainees, which is followed by all junior doctors pursuing training in medicine, includes ‘HIV and AIDS including ethical considerations of testing’ in the required Infectious Diseases knowledge base along with applied competencies which include ‘elucidat[ion of] risk factors for the development of an infectious disease including contacts, travel... and sexual history’. It also includes the competency to ‘outline the principles of, and interpret’ HIV testing. While it is helpful that medical trainees are expected to be able to identify risk factors, there is no mention of HIV indicator conditions — a key area of knowledge for the elimination of late HIV diagnosis. The curriculum for GP trainees contains more detail but focuses more on counselling and advice than the actual offer and provision of HIV testing. The RCGP curriculum acknowledges ‘suggestions’ to test for HIV in primary care in high prevalence areas but since publication of these competencies, NICE has made strong recommendations for testing in primary care in its HIV testing guideline. In this and other respects, the RCGP curriculum is in need of updating.

The curricula for medical students, as well as for junior doctors in general practice and other specialties, should contain minimum requirements for coverage of HIV in relation to indicator conditions and risk factors and be up-to-date in their recommendations about HIV testing.

**7.2.11 Serious incident reporting and look-back exercises**

- Serious incident reporting and root cause analysis can identify reasons for late diagnosis and stimulate improvement across the whole patient pathway

An important way that health professionals can review their practice and learn how to improve it is through exercises such as serious incident reporting and look-back. In general practice, significant event audit fits in with the requirements for professional revalidation and Care Quality Commission inspection. Such exercises can also be useful for commissioners to understand better where people with undiagnosed HIV may be within their local populations and where service improvement is needed to address this.
7.3 Metrics to drive and measure progress

A range of useful indicators are monitored and reported by upper and lower tier LA in PHE’s Sexual and Reproductive Health Profiles. These should be used by local commissioners to provide a picture of local need and performance.

Two key metrics are used in policy and guidance, as follows.

7.3.1 Indicator to drive local prioritisation

NICE guidance on increasing uptake of HIV testing (in line with the UK national guidelines for HIV testing) uses a threshold of diagnosed prevalence to differentiate action recommended within each LA area (see page 35). A diagnosed prevalence of 2 per 1,000 population is designated as ‘high’ and 5 per 1,000 as ‘extremely high’ prevalence, each bringing additional recommendations for HIV testing.

Using diagnosed prevalence has helped to concentrate effort in the areas where the need is greatest and the most impact can be achieved. As NICE’s committee discussions during development of its 2016 guideline recorded: ‘Two-thirds of late HIV diagnoses occur in high-prevalence and extremely-high-prevalence LAs. This means that if this guideline is successfully applied in high- and extremely-high-prevalence areas, it could potentially affect two-thirds of late diagnoses nationally.’146

Case study 8
Serious incident reporting as a strategy for reducing late HIV diagnosis

Serious incident reporting (SIR) was used in two areas of the South West (Bristol, and Bournemouth and Poole) to identify and address reasons for late HIV diagnoses across the patient pathway. Case notes were reviewed in batches for missed opportunities for earlier diagnosis using a root-cause analysis tool. Actions resulting included increasing awareness of indicator conditions, HIV education days within primary care, and initiatives to increase testing within hospital specialties. The Royal College of Emergency Medicine was successfully lobbied to change HIV testing recommendations.

On a strategic level, measures were undertaken to ensure late diagnosis remained a priority action within each LA.

Since enhanced testing was introduced in Bournemouth and Poole late diagnosis has decreased from 50 to 32% and testing increased by 5-6% in general practice and hospital settings. A key aspect of the study was recognising that the SIR process should relate to the entire patient pathway and involve the whole health community, with consideration of the issue at a senior level thereby informing population testing strategies.

The study authors conclude that SIR may be part of an effective strategy to prevent late diagnosis of HIV which would have important benefits for individual and population health. The SIR protocol can be requested from Norah.O'Brien@phe.gov.uk.

That being said, late diagnosis still occurs in all parts of the country and the high proportion of diagnoses made late in many low-prevalence areas leads to avoidable morbidity and mortality, higher treatment costs and more transmission of HIV, which in the longer term could raise local prevalence. Local authorities should therefore still benchmark their performance using the late diagnosis indicator and take appropriate steps to lower their number of late diagnoses.

### 7.3.2 Indicator to measure progress

It is important that local areas can benchmark and be held to account for their progress in reducing late diagnosis.

The key tool for this is the Public Health Outcomes Framework (PHOF), which uses as the indicator ‘people presenting with HIV at a late stage of infection’. Some refinements are needed to improve the data for this measure and give a more accurate picture of local performance. PHE is currently developing enhanced surveillance to address these.

- There needs to be clarity between genuine late diagnosis and presentation with late stage infection by people who have been previously diagnosed. In this regard, the number of people previously diagnosed overseas at the time of first presentation for care in the UK should be separately identified.

- The indicator is measured using CD4 count <350 cells/mm³ within 91 days of diagnosis, yet CD4 count can drop markedly around the time of seroconversion in very early infection, sometimes below 350 cells/mm³. These diagnoses also need to be separately identified.

Currently, benchmarking is done using the proportion of all new diagnoses which are made late. However, as the total number of annual new diagnoses declines, the same actual number of late diagnoses will constitute a larger proportion of the total. In order to get a clear picture of local progress over time, as well as the relative scale of the problem between areas, there is therefore a need to pay more attention to actual numbers of late diagnoses. For example, the rate of late diagnoses per 1,000 or 10,000 population could be reported.

The definition of ‘late diagnosis’ with reference to a CD4 count of <350 cells/mm³ was adopted based on a now superseded threshold for initiating antiretroviral therapy. It has become a somewhat arbitrary cut-off point, though for measuring progress, monitoring trends and benchmarking it remains a very useful tool. However, by encompassing people who are still living relatively healthy lives alongside those experiencing imminently life-threatening conditions, a focus on this fairly broad category alone may hide issues that need to be addressed where the problem is most acute. Alongside ‘late diagnosis’, serious attention should therefore be paid in local needs assessment and planning to diagnoses with a CD4 count of <200 cells/mm³, a measure of advanced immunosuppression. PHE has the data to report on this and identify it as a priority.
8. 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, fragmented commissioning arrangements currently undermine the incentives for investment in HIV testing, and severe financial pressures on LAs and the NHS continue to erode funding. Existing policy designed to drive a reduction in late diagnosis has limited impact on national and local decision-makers in the context of many other pressing priorities.

Yet there is evidence about what works and there are evidence-based guidelines which make clear what needs to be done. The guidelines are far from universally followed, especially by health professionals in non-HIV specialist settings and by individuals most likely to be exposed to HIV. The challenge now is for implementation – to expand HIV testing in line with the guidelines, to disseminate demonstrably effective practice in a way that is relevant to areas with different local conditions and to ensure NHS and LA commissioning drives improvement.

Locally and nationally, advocacy is needed for the prioritisation and investment that will allow such improvement to happen. An overarching requirement is political leadership along with a commitment to eliminating the stigma that hampers action to tackle HIV at all levels.

8.1 Political and system leadership

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 practical steps outlined in the Priorities for action below.

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.

8.2 Stigma

The stigma associated with HIV and, by extension, with HIV testing is insidious, affecting the attitudes of health professionals and policy-makers, people at risk of HIV and the wider population. There can be particular stigma within communities most affected by HIV, inhibiting not only testing uptake but also information-seeking behaviour in a context where myths and misinformation often lie behind a failure to seek testing. At its worst, stigma can lead to discrimination, ostracism and violence. Stigma may inhibit GPs and other non-HIV specialist clinicians from offering an HIV test, for example because of unfounded assumptions about a patient’s lack of risk or a fear of causing offence.

Stigma will be weakened when people of influence, such as politicians, celebrities, community and faith leaders, speak out to correct misinformation, counter negative stereotypes and support people living with HIV, as well as stressing the importance of testing and seeking care. The voices of people living with HIV themselves must, too, be heard and amplified. The more HIV testing is normalised, the less its uptake will be impeded by stigma. The elimination of HIV-related stigma must be a key plank of a government strategy to eliminate late HIV diagnosis and new HIV infections by 2030.
8.3 Priorities for action, 2018-2023

An effective strategy for eliminating new HIV infections and late diagnoses by 2030 will result in an ever-decreasing prevalence of undiagnosed HIV. Accordingly, it will be necessary to take stock and adjust priorities periodically in order to ensure the most effective and cost-effective approaches are implemented. The four key priorities for action set out below are therefore recommended for the next five years, as the first phase on a course to eliminate late diagnosis of HIV by 2030. They address the diversity of the HIV epidemic in England.

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

The commissioning of HIV testing has been plagued since 2013 by fragmentation which can result in a lack of shared goals and priorities, and mismatched or non-existing involvement from some parts of the system. Gaps in commissioning can arise, leading to inequalities in access to testing for local populations. 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.

<table>
<thead>
<tr>
<th>Action required</th>
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<tbody>
<tr>
<td>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</td>
<td>LAs, CCGs, NHS England, provider organisations</td>
</tr>
<tr>
<td>Collate and disseminate data relevant to late HIV diagnosis at STP/ICS level, to enable benchmarking and analysis</td>
<td>PHE</td>
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<tr>
<td>Involve providers and the public, including people living with HIV, in commissioning decisions</td>
<td>LAs, CCGs, NHS England, STPs</td>
</tr>
<tr>
<td>Develop and share evidence that investment in HIV testing saves costs</td>
<td>PHE</td>
</tr>
<tr>
<td>Disseminate learning from whole system approaches to eliminating late HIV diagnosis, including STPs, ICSs, Fast-Track Cities, Social Investment Partnership</td>
<td>PHE, ADPH, LGA, NHS England, EJAF</td>
</tr>
<tr>
<td>Raise awareness of local councillors and national parliamentarians who can push for local action to tackle late HIV diagnosis</td>
<td>National and local HIV organisations, LGA</td>
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<tr>
<td>Hold local commissioners and providers to account</td>
<td>MPs, local councillors, people living with HIV, PHE</td>
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i. ADPH = Association of Directors of Public Health
ii. LGA = Local Government Association
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.

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<th>Action required</th>
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<tr>
<td>Commission testing in primary and secondary care according to the NICE guideline</td>
<td>LA commissioners, CCGs, NHS England</td>
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<tr>
<td>Establish local CQUINs (Commissioning for Quality and Innovation) as an incentive to improve rates of HIV testing in secondary care settings</td>
<td>CCGs, STPs, ICSs</td>
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<tr>
<td>Integrate HIV testing into standard protocols in relevant non-HIV specialist settings</td>
<td>NHS provider organisations, GPs, testing laboratories</td>
</tr>
<tr>
<td>Integrate HIV testing with hepatitis C testing programmes, and with blood-borne virus and syphilis testing in primary care</td>
<td>LA commissioners, CCGs, GPs</td>
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<tr>
<td>Provide high level endorsement and guidance/standards for each specialty/professional group</td>
<td>RCGP, RCP, specialty associations</td>
</tr>
<tr>
<td>Nationally, develop a standard look-back methodology for late HIV diagnosis and locally, undertake standardised look-back exercises, feeding back findings to services where diagnoses were missed and to local commissioners</td>
<td>BHIVA, HIV specialist clinicians</td>
</tr>
<tr>
<td>Use findings from look-back exercises to inform commissioning of testing and health professional training</td>
<td>LA commissioners, CCGs</td>
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<tr>
<td>Set targets/indicators and provide regular data to monitor and benchmark progress</td>
<td>PHE with relevant specialty bodies</td>
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<tr>
<td>Update curricula for medical students and specialty/GP trainees, ensuring minimum requirements in relation to HIV and HIV testing are included</td>
<td>GMC, medical schools, HEE, LETBs, Royal Colleges, specialty associations</td>
</tr>
<tr>
<td>Develop and disseminate appropriate training and educational materials for non-HIV specialist clinicians</td>
<td>RCGP, FSRH, BHIVA, BASHH</td>
</tr>
<tr>
<td>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</td>
<td>LA commissioners, CCGs</td>
</tr>
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</table>

i. RCP = Royal College of Physicians  
ii. GMC = General Medical Council  
iii. HEE = Health Education England  
iv. LETB = Local Education and Training Board  
v. BASHH = 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

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. Some people prefer the convenience and privacy of self-sampling or the autonomy of self-testing, others feel more comfortable taking a test in a supportive setting within their community and many will happily accept a test offered as part of a routine new patient registration in general practice although they would not have sought one out. 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.

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<tr>
<td>Actively disseminate learning from HIV Prevention Innovation Fund testing projects and other innovative local projects</td>
<td>PHE</td>
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<tr>
<td>Scale up work with organisations and leaders in most-at-risk communities</td>
<td>LA commissioners, local HIV organisations</td>
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<tr>
<td>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</td>
<td>LA commissioners, STPs, ICSs</td>
</tr>
<tr>
<td>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</td>
<td>LA commissioners</td>
</tr>
<tr>
<td>Involve community pharmacy in promoting and providing HIV testing, whether on site or via the provision of self-sampling and self-testing kits</td>
<td>LA commissioners</td>
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<tr>
<td>Set up and signpost pathways into care for people using self-testing</td>
<td>LA commissioners, local HIV organisations, HIV treatment services</td>
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<tr>
<td>Use social media to correct misinformation and promote testing, including repeat testing, to individuals at risk in extremely high, high and low prevalence areas</td>
<td>HPE</td>
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<tr>
<td>Encourage repeat testing and increase the offer of HIV testing, especially to women, in SRH services</td>
<td>FSRH, SRH service providers</td>
</tr>
<tr>
<td>Further develop partner notification, using innovative approaches and technologies to extend its reach</td>
<td>BASHH, BHIVA, HIV, GUM and SRH service providers, LA commissioners</td>
</tr>
<tr>
<td>Work with HIV organisations and other stakeholders to ensure any new Memorandum of Understanding on processing information requests for tracing immigration offenders is drafted so as not to deter people from HIV testing in any way</td>
<td>NHS Digital, DHSC, Home Office</td>
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i. DHSC = 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 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 (see page 40) 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.

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<tr>
<td>Undertake an investigative evaluation involving interviews with people diagnosed late, to improve understanding of factors resulting in late diagnosis</td>
<td>PHE</td>
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<tr>
<td>Undertake a national analysis of late diagnosis by LA and by GUM/sexual health clinic, identify where significant downturns in late diagnosis have occurred and analyse the reasons</td>
<td>PHE</td>
</tr>
<tr>
<td>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</td>
<td>PHE with BASHH and BHIVA</td>
</tr>
<tr>
<td>Explore how the learning from the ‘steep fall’ clinics can be used to develop new service models for other high-risk communities, especially black Africans, to achieve a similar impact</td>
<td>PHE, BASHH, BHIVA, HIV community organisations</td>
</tr>
<tr>
<td>Disseminate the learning from the four points above to commissioners, providers and community organisations</td>
<td>PHE, BASHH, BHIVA, NAT</td>
</tr>
<tr>
<td>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</td>
<td>LA commissioners, sexual health service leads, CCGs</td>
</tr>
<tr>
<td>Make these changes a priority locally for commissioning</td>
<td>Local councillors, HWBs(^i), DsPH(^ii)</td>
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<tr>
<td>Set targets/indicators to measure and benchmark progress</td>
<td>PHE with BASHH, BHIVA and community-based service providers</td>
</tr>
<tr>
<td>Integrate relevant messages in education campaigns and materials for gay and bisexual men, black Africans and other communities affected</td>
<td>HPE, local public health teams, community organisations</td>
</tr>
</tbody>
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i. HWB = health and wellbeing board  
ii. D(s)PH = director(s) of public health
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Appendix 1

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Consultant
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Appendix 2

The Halve It campaign

The Halve It campaign was launched in 2010 as a broad-based coalition with the dual goals of halving late diagnosed and undiagnosed HIV. Operating primarily across England, it aimed to influence policy and practice at national, regional and local level.

In 2017-18, following a halving in the rate of undiagnosed HIV (from 24% to 12%) the coalition decided to focus on late diagnosis, where a much smaller decline had occurred (from 50% to 42%) and to review the future role of the campaign. This position paper was drafted, taking stock of the current status of late HIV diagnosis and setting out the action now required to eliminate it.

In 2018, it was decided that the campaign had run its useful course in its current form. The position paper is therefore its legacy to the organisations and individuals who will continue to advocate and work towards the elimination of late HIV diagnosis. It is intended to be a key reference document and campaigning tool.

The full paper and summary briefings can be found at halveit.org.uk.

Halve It members included:
African Health Policy Network (AHPN)
All Party Parliamentary Group (APPG) on HIV & AIDS
British Association for Sexual Health & HIV (BASHH)
British HIV Association (BHIVA)
Elton John AIDS Foundation (EJAF)
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LGBT Foundation
Martin Fisher Foundation (MFF)
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National HIV Nurses Association (NHIVNA)
NAZ
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Sophia Forum
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Halve It observer members included:
Department of Health and Social Care (DHSC)
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London HIV Prevention Programme (LHPP)
National Institute for Health and Care Excellence (NICE)
Public Health England (PHE)
Scottish HIV & AIDS Group (SHIVAG)
Appendix 3

Glossary of acronyms

A&E: Accident and emergency
AIDS: Acquired immune deficiency syndrome
ADPH: Association of Directors of Public Health
AMU: Acute medical admissions unit
ART: Antiretroviral therapy
BASHH: British Association for Sexual Health and HIV
BHIVA: British HIV Association
CCG: Clinical commissioning group
DH: Department of Health
DHSC: Department of Health and Social Care
D(s)PH: Director(s) of public health
ED: Emergency department
EJAF: Elton John AIDS Foundation
FSRH: Faculty of Sexual and Reproductive Healthcare
FTCI: Fast-Track Cities Initiative
GMC: General Medical Council
GMHSCP: Greater Manchester Health and Social Care Partnership
GP: General practitioner
GUM: Genitourinary medicine
HEE: Health Education England
HIV: Human immunodeficiency virus
HPE: HIV Prevention England
HWB: Health and wellbeing board
ICS: Integrated care system
IT: Information technology
LA: Local authority
LETB: Local Education and Training Board
LGA: Local Government Association
LGBT: Lesbian, gay, bisexual and transgender
MP: Member of Parliament
NAT: National AIDS Trust
NHS: National Health Service
NHTW: National HIV Testing Week
NICE: National Institute for Health and Care Excellence
NHSSS: National HIV Self Sampling Service
PHE: Public Health England
PHOF: Public Health Outcomes Framework
PN: Partner notification
POCT: Point-of-care test
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>PrEP</td>
<td>Pre-exposure prophylaxis</td>
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<tr>
<td>QALY</td>
<td>Quality adjusted life year</td>
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<td>RCGP</td>
<td>Royal College of General Practitioners</td>
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<td>RCP</td>
<td>Royal College of Physicians</td>
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<tr>
<td>SHIP</td>
<td>Sexual Health In Practice</td>
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<td>SHS</td>
<td>Sexual health service</td>
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<td>SIB</td>
<td>Social Impact Bond</td>
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<td>SIR</td>
<td>Serious incident reporting</td>
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<td>SRH</td>
<td>Sexual and reproductive health</td>
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<td>SSBBV</td>
<td>Sentinel Surveillance of Blood Borne Viruses</td>
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<tr>
<td>STI</td>
<td>Sexually transmitted infection</td>
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<tr>
<td>STP</td>
<td>Sustainability and transformation plan/partnership</td>
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<tr>
<td>TasP</td>
<td>Treatment as prevention</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
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A roadmap for eliminating late diagnosis of HIV in England

Halve It position paper

Written by Ruth Lowbury

October 2018

halveit.org.uk