

EARLY TESTING SAVES LIVES

HIV is a public health priority
Second edition



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FOREWORD

TIME TO REFOCUS ON HIV AND PUBLIC HEALTH



Lord Norman Fowler

Former Secretary of State for Health,
Vice Chair of the All-Party Parliamentary Group on HIV and AIDS

Back in the 1980s HIV and AIDS had a very high profile – and rightly so. Patients were dying. There was no cure for it. There were no drugs to treat it. That is why, as Secretary of State for Health, I mounted an extensive public education campaign using television, radio and poster advertising, and sent letters to all households.

Today the profile is nothing like as high. The assumption is that new drugs have solved the problem and that fewer people are infected. Nothing could be further from the truth. There is still no cure and, away from the public gaze, HIV has developed into one of Britain's fastest-growing health conditions.

The stigma associated with HIV has ensured that the growth of the epidemic has been silent, and effective treatment does mean there are few headline-grabbing deaths. But, make no mistake, the virus lives on. More than 90,000¹ people in the UK are living with the infection.

Each year thousands of individuals are infected, by people who are not even aware they are living with HIV themselves. Lives are being harmed, even lost, because people are being diagnosed either late or not at all. Indeed, the recent House of Lords Select Committee Report on HIV and AIDS demonstrated that the need for awareness of the risk of HIV

infection remains as great as ever.² More than two decades after the iceberg campaign, it is time we refocused on HIV.

The Halve It campaign, the first of its kind, brings all the HIV experts together – whether people living with HIV, clinicians, public sector, private sector or charities – to tackle the most serious factors involved in new infections and early deaths – late-diagnosed and undiagnosed HIV.

Instilling a culture of testing throughout the NHS and in the mind of the public will help us beat the virus. It will require leadership from the local GP's surgery to Whitehall, and at every step in between. It will also take investment – investment which will be repaid several times over through HIV infections averted.

This document sets out a path for tackling late-diagnosed and undiagnosed HIV, which is one of the most serious public health issues today. I urge everyone to work together to Halve It.

WHY SHOULD WE HALVE LATE DIAGNOSIS OF HIV?



Jenny Willott MP

Vice Chair of the All-Party Parliamentary Group on HIV and AIDS

HIV is no longer a death sentence. People living with HIV today can live long and healthy lives as long as they are diagnosed promptly and receive access to treatment.

Yet in 2010, of the 6,658 people diagnosed with HIV, 49% were diagnosed late. These people will have dramatically reduced life expectancies, some surviving for just months.

Many of these people have often had previous contact with the health services and opportunities for testing have been missed. The idea of doing a HIV test has simply not occurred to either healthcare professional or patient, despite the warning signs.

Over 60% of gay men, one of the groups vulnerable to HIV infection, are unaware of the primary symptoms of HIV.³ We need to get better at detecting the symptoms of HIV.

The later people are diagnosed, the more irreparable damage the virus does to their bodies. It's time to get better at diagnosing people quickly. More than half the people diagnosed with HIV in the UK are diagnosed late. Reducing late HIV diagnosis must be a priority for the government.

Late diagnosis costs lives. Let's Halve it by 2015.

WHY SHOULD WE HALVE UNDIAGNOSED HIV?



Pamela Nash MP

Chair of the All-Party Parliamentary Group on HIV and AIDS

There are around 22,000 people in the UK who have HIV but are unaware of their status.¹ About one in four of all HIV infections is undiagnosed.

This campaign seeks to tackle these appalling statistics. Halving undiagnosed HIV by 2015 will mean fewer new HIV infections, fewer early deaths and more money saved by the NHS at a time when every penny counts.

Once a person is diagnosed, they can receive treatment that lowers the level of virus in their body and makes them less infectious.

They also know to take the necessary precautions to avoid infecting their sexual partners.

This problem of undiagnosed HIV is too big to ignore. At a time when the Government is changing the structure of the NHS, we have a unique opportunity to design services that tackle it.

We want every decision-maker at national and local level to realise that undiagnosed HIV costs lives. Let's Halve it by 2015.

The Halve It Campaign was launched in 2010 and aims to:

Halve the proportion of people diagnosed late with HIV (with a CD4 count $<350\text{mm}^3$) by 2015.

Halve the proportion of people living with undiagnosed HIV within 2015.

EXECUTIVE SUMMARY

EARLY TESTING SAVES LIVES

According to the 2011 House of Lords Select Committee report on HIV in the UK, the current level of priority given to the prevention of HIV and AIDS is "woefully inadequate" and prevention policies need to be prioritised to combat the growing epidemic.² Indeed, it is estimated that the number of people living with HIV in the UK (diagnosed and undiagnosed) will reach 100,000 by 2012.⁴ In 2010, an estimated 26% were unaware of their condition and 49% were diagnosed after they should have started treatment, despite many having had recent contact with healthcare professionals.¹

If diagnosed early, HIV can be successfully treated and people with HIV live to near-normal life expectancies. Late diagnosis, by contrast, is associated with a greater risk of hospitalisation and AIDS-related illness, reduced life expectancy and increased cost to the NHS. It is also associated with increased onward transmission, and continued sexual risk-taking while people are unaware of their HIV-positive status.

Halve It is a coalition of national experts determined to tackle the continued public health challenges posed by HIV.

Our goals are to:

- Halve the proportion of people diagnosed late with HIV (CD4 count <350mm³) by 2015.
- Halve the proportion of people living with undiagnosed HIV by 2015.

We call upon all levels of government to:

- Make HIV a public health priority both locally and nationally.
 - Include HIV testing as a specific area of priority for Public Health England.
 - Ensure that late diagnosis of HIV is prioritised as an indicator in the Public Health Outcomes Framework.
- Ensure that NHS and local authorities give HIV the appropriate priority by requiring that it is systematically considered in local health needs assessments and health planning processes.
 - Implement the UK national testing guidelines⁵ and National Institute for Health and Clinical Excellence (NICE) public health guidance on HIV testing in black-African communities and in men who have sex with men.^{6,7}
 - Encourage the development and implementation of local strategies to increase HIV testing (eg testing for new GP registrants in high-prevalence areas).
 - Increase and enhance the provision of education and information provided to those groups most at risk of HIV including:
 - black-African communities
 - men who have sex with men.
- Ensure that people diagnosed with HIV have access to antiretroviral therapies known

to reduce viral loads and potential onward transmission of HIV, free of charge on the NHS.

- Offer incentives to test for HIV through the Quality and Outcomes Framework (QOF) and Commissioning for Quality and Innovation (CQUIN) frameworks in a variety of healthcare settings.
 - Strengthen the relationship between national surveillance and local reporting of HIV testing by enhancing local HIV reporting procedures and maintaining a world-class national surveillance capability.
 - Improve transparency by requiring the local Public Health Service to report back to the public on local progress in tackling late HIV diagnosis.

HIV is a public health issue that can be tackled successfully

We now have rapid and accurate tests which can be deployed by non-HIV specialists in a range of healthcare settings acceptable to the public. Evidence from NHS antenatal settings has proved that routine testing can prevent the transmission of HIV. We also have professional guidelines and recently developed public health guidance (PH33 and PH34) from NICE supporting broader testing in black-African populations and in men who have sex with men.^{6,7}

HIV prevention could deliver huge financial savings too

It is estimated that the prevention of one new HIV infection would save the public purse between £280,000 and £360,000 in direct lifetime healthcare costs.⁴ Had all of the UK-acquired infections newly diagnosed in 2010 been prevented, there would have been a saving of approximately £1.2 billion in direct healthcare costs.²

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HIV IN THE UK

People living with HIV

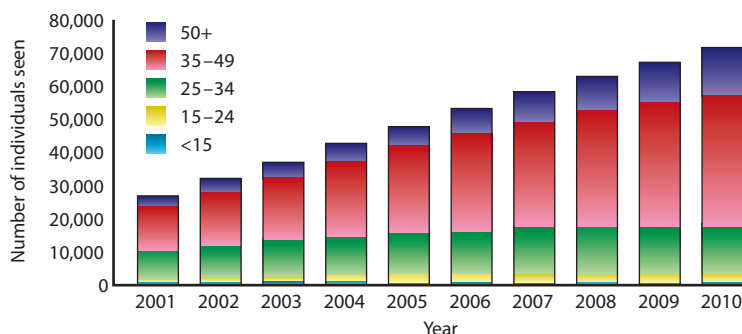
In 2010, 69,400 people were known to be living with HIV in the UK, up from 65,300 in 2009, and a three-fold increase from 2000.⁸ However, the UK has high levels of undiagnosed HIV. The Health Protection Agency estimates that the real total number of people living with the virus in the UK in 2010 was 91,500.¹

6,660 individuals were newly diagnosed with HIV in the UK in 2010;⁹ 50% of people newly diagnosed in 2010 probably acquired their infection through heterosexual contact and 45% through sex between men.¹⁰ Black Africans accounted for 33% of new HIV diagnoses in 2010.¹⁰

The numbers of people living with HIV in older age groups are increasing both in number and as a proportion of the total. In 2010, more than one in five people with HIV were 50 years of age or older, compared with one in ten in 2000 (Figure 1).¹⁰ This is due to effective antiretroviral therapy and continued transmission at older ages.¹¹

Source: Health Protection Agency (Survey of Prevalent HIV Infections Diagnosed).

Figure 1: Diagnosed HIV-positive individuals seen for care by age group, UK: 2000–2010



Late diagnosis

Late diagnosis is defined as patients with a CD4 cell count of less than 350 per mm³ within 3 months of diagnosis.¹² HIV infection reduces the number of key immune system cells called CD4 cells. A normal CD4 cell count is between 500 and 1,600 per mm³ of blood.

In 2010, 49% of people diagnosed with HIV were diagnosed late.¹ Of these, 63% of heterosexual men, 58% of heterosexual women and 38% of men who have sex with men were diagnosed late.¹

Guidelines indicate treatment should be recommended when a patient's CD4 cell count falls to 350 cells per mm³ or lower.¹² Late diagnosis is associated with poorer prognosis and increased costs. As such, these high rates of late diagnosis present serious problems for both individuals and public health and are discussed in more detail further on in this document.

Our goal is to halve the proportion of people diagnosed late with HIV (with a CD4 cell count <350mm³) within 5 years.

Undiagnosed HIV

In 2010, an estimated 22,200 people in the UK were living with HIV but did not know it.¹ Over a quarter (26%) of all those currently living with HIV are undiagnosed.¹

These high numbers of undiagnosed infections present serious problems for both individual and public health. This is discussed in more detail further on in this document. Our goal is to halve the proportion of people living with undiagnosed HIV within 5 years.

Treatment as prevention

Scaling up HIV testing will ensure both timely diagnosis and treatment. Undiagnosed individuals will not be receiving treatment for their infection and are at greater risk of passing the infection on to others. A recent randomised clinical trial has shown that treatment with antiretroviral therapy of an HIV positive person can reduce the risk of sexual transmission of HIV to an uninfected partner by 96%.¹³

WHY DOES HALVING IT MATTER?

Reducing late diagnosis and undiagnosed infections has health benefits

- **Reducing late diagnosis and undiagnosed infection improves individual health**

HIV infection is a serious and incurable condition. Without treatment, it results in the destruction of the body's immune system and a progressive increase in illness (including blindness, heart and kidney disease, osteoporosis, some cancers and brain impairment). Some patients become wheelchair-bound or require major interventions such as hip replacement. Ultimately it can cause premature death.

The sooner HIV is diagnosed, the sooner appropriate care can begin. Antiretroviral therapy suppresses HIV replication, resulting in the reconstitution of the immune system. Thanks to combination antiretroviral therapy, the life expectancy of someone living with HIV has increased markedly over the last 15 years. Recent research shows an individual diagnosed with HIV at the age of 35 years, with prompt access to effective antiretroviral therapy, can expect to live to the age of 72 years, only a few years less than a person of the same age without HIV.¹⁴ Antiretroviral therapy also improves the psychological well-being and social welfare of HIV-positive individuals.

Scaling-up testing will ensure timely diagnosis and treatment, reduce the likelihood of progression to AIDS, improve quality of life and prolong life.

- **Reducing undiagnosed HIV means fewer new infections**

More testing for HIV increases the proportion of people who are aware of their status.

Once an individual's HIV infection has been diagnosed, they can access appropriate care. Effective treatment significantly reduces viral load and infectiousness, and thus the likelihood of transmitting HIV. Few transmissions take place when one sexual partner is HIV-positive and on antiretroviral therapy and the other is HIV-negative.

A study has shown that those living with HIV, who are aware of their condition, are more likely to take precautions (such as using condoms) to prevent transmission to partners.¹⁵ A study of newly diagnosed HIV-positive men who have sex with men reported that 76% had eliminated the risk of onward transmission 3 months after diagnosis.¹⁶ A negative HIV test, on the other hand, provides an opportunity to offer preventive education and advice and may also lead to changes in behaviour. Notification of current and former sexual partners to recommend testing and treatment is also possible following diagnosis.

Treatment during pregnancy and careful management of delivery allows women aware that they are HIV-positive to plan for HIV-free births and childcare.

More widespread testing, and earlier diagnosis and treatment (especially in areas of high prevalence and among groups at increased risk) provide a clear public health benefit by reducing onward transmission rates.

WHY DOES HALVING IT MATTER?

Reducing late diagnosis and undiagnosed infections saves money

- **Short- and long-term savings for the NHS by reducing the cost of treating individuals**

Providing routine offerings of HIV tests in primary care, hospital and community settings can be compared favourably with similar programmes for other conditions, with the cost per detected HIV infection ranging from approximately £300 to £3,800 in medical admissions, from £1,200 to £4,600 in primary care settings and from £700 to £2,600 in community settings.^{17,18} This is well within the NICE cost effectiveness parameters and compares favourably with similar programmes in other disease areas.

It has also been demonstrated that early diagnosis and early antiretroviral treatment of HIV can lead to cost savings to the NHS of £63,061 per year (in discounted incremental cost per quality adjusted life year (QALY)) when comparing treatment initiation at CD4<350 with treatment initiation at CD4<200.¹⁹

The longer someone with HIV remains undiagnosed, the more likely it is that they will require more complex and expensive treatment. A Canadian study showed that, on average, the cost of treating HIV was two-and-a-half times higher for someone diagnosed late (with a CD4 cell count ≤ 350 per mm^3) than for those diagnosed in a timely fashion in the first year.²⁰ Five years on from diagnosis, patients in both groups had similar CD4 cell counts; however, the cost of treating those diagnosed late was still 76% higher.²⁰

- **Savings for the public purse by reducing new infections**

Early diagnosis and prompt treatment can reduce onward transmission. This not only avoids illness and early deaths, but also has the potential to deliver huge financial savings. The Health Protection Agency recently estimated that the prevention of one new HIV infection saves the public purse between £280,000 and £360,000 in direct lifetime healthcare costs.¹

Had all of the 3,550 UK-acquired infections newly diagnosed in 2010 been prevented, there would have been a saving of approximately £1.2 billion in direct healthcare costs.⁴ It is noteworthy that this figure does not include additional indirect costs such as social care, time off work and cost of benefits, or any costs saved as a result of preventing further transmission.

- **Other savings to the public purse**

People living with HIV who are not diagnosed late are also more likely to remain in work, continue to pay taxes and to participate fully in society. Relatives and friends are less likely to become carers.

Those who become aware of their HIV status earlier are better able to plan their financial future, making them less likely to require disability and unemployment benefits, as well as state-funded social care. People with HIV have limited access to financial products such as life insurance, and many currently face old age with no entitlement beyond a basic state pension.

“ ...any intervention to increase HIV testing would also incur the additional costs of treating people who are HIV-positive. These costs were considered justifiable both from a moral perspective and from the perspective of reducing transmission of the virus.

The Public Health Interventions Committee (PHIAC) of NICE

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TIME TO MOVE BEYOND SEXUAL HEALTH AND MATERNITY TESTING TO HALVE LATE AND UNDIAGNOSED HIV

Current testing practice

Most HIV testing takes place in sexual health and antenatal clinics.

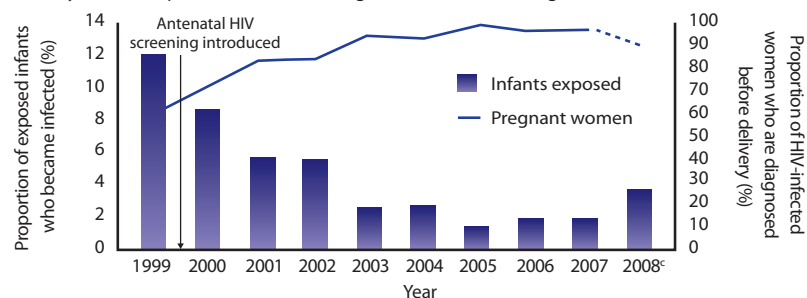
In 2009, the uptake of HIV tests reached 95% in antenatal clinics nationally and among patients tested in sexual health clinics as part of the unlinked anonymous HIV testing survey. This is a survey of residual syphilis blood samples in a sentinel network of sexual health clinics.²¹

For example, since 2000, all pregnant women have been offered HIV tests. Those testing positive are provided with a course of antiretroviral therapy, may undergo a Caesarean section and are advised not to breastfeed.

Mother-to-child transmission rates have fallen sharply as a direct result of these interventions (Figure 2), which demonstrates the key role testing can play in HIV prevention.

Source: Health Protection Agency (unlinked anonymous surveillance and National Study of HIV in Pregnancy and Childhood).

Figure 2: Estimated proportion of HIV-infected pregnant women diagnosed before delivery^a, and of exposed infants becoming infected with HIV^b: England and Scotland



- a Includes previously diagnosed and those diagnosed through antenatal testing.
- b Assumes vertical transmission rate of 26.5% in undiagnosed women and 2.2%, 1.6% and 1.1% in diagnosed women in 1999, 2000–2002 and 2003–2008, respectively.
- c These data contain reports received by the end of June 2009; 2008 estimates will improve significantly when further reports are received.

Case study – Opt-out primary care HIV testing in high-prevalence areas

In line with national guidelines, NHS Lambeth has been successfully piloting opt-out HIV testing in primary care for any new adult patient registering since December 2009. HIV testing is recommended as part of a new patient health check, regardless of sexual orientation, ethnicity, gender or age. This universal approach helps to reduce stigma among patients and staff. The results have been promising, despite some of the challenges posed by heterogeneity in clinical processes in primary care. Phase one of the project started with five large practices in Lambeth and found that 40% of the new patient registrations were accepting testing and positivity rates were 0.48% – nearly five times higher than the point at which universal testing is deemed to be cost-effective.

The project is now into phase two with 10 new practice sites in place across Lambeth and Southwark. The practices went live between March and May 2011 and all are using HIV POCT (point of care testing). The data from March until September 2011 indicates that during that period 1629 tests were performed and the testing uptake rate amongst those offered the test was 60%. Six new diagnoses have been made during this time period giving a cumulative positivity rate of 0.37% across the two boroughs. In total, 21% of the new patient registrations (7600) accepted testing and the range across the practices was (4–61%). A pilot network group has been set up with the participating practices and meets at least quarterly to share learning and best practice across the boroughs.

Dr Marie Vieu (prev Dr Murad Ruf), Jess Peck & Sarah French NHS Lambeth

Case study – Sexual Health in Practice (SHIP)

SHIP provides holistic sexual health training, aiming to work with every GP and practice nurse, and every practice, in an area. SHIP training interweaves all aspects of sexual health and includes relevant awareness such as the needs of young people, men that have sex with men, and black-Africans.

SHIP also offers resources and support (eg pregnancy testing kits and help with computer template development).

SHIP works with over 85% of practices in Birmingham and a number of practices in the West Midlands. SHIP HIV training has a focus on opportunistic testing of those at risk (as identified through risk assessments, including sexual history taking) and diagnostic testing (ie of people with HIV-associated symptoms and conditions).

SHIP uses a range of measures to assess effectiveness. A recent pilot in Haringey PCT surveyed 'whole practice' HIV testing rates before and after holistic training with individual practitioners. Currently rates have increased by 150% and we aim to reach sustained increases of 500–600% as we train more and more practitioners.

Judith Mullineux, ship.bham.nhs.uk

TIME TO MOVE BEYOND SEXUAL HEALTH AND MATERNITY TESTING TO HALVE LATE AND UNDIAGNOSED HIV

Testing beyond sexual health and antenatal clinics

Several prominent bodies have concluded that issues such as late-diagnosed and undiagnosed HIV can only be tackled if testing is performed in a wider range of settings than sexual health and antenatal clinics.

In 2007, the UK Chief Medical Officers wrote to healthcare professionals, including GPs, urging them to offer and recommend an HIV test to their patients if they may have been exposed to HIV infection.²² In 2008, the British HIV Association, the British Association for Sexual Health and HIV and the British Infection Society published guidelines and recommendations on testing for HIV.⁵

In 2010, The Department of Health proposed late diagnosis of HIV as an indicator for the Public Health Outcomes Framework.²³

In March 2011, NICE issued guidance on increasing the uptake of HIV testing among black-Africans and men who have sex with men.^{6,7}

In September 2011, the House of Lords Select Committee on HIV and AIDS concluded that prevention policies need to be prioritised to combat the epidemic and testing was identified as a key component of any prevention efforts.²

Further to this, the House of Lords report was supported by the government response in October 2011. The response welcomed existing guidance on HIV testing; agreed that HIV testing should be a part of local HIV prevention strategies; accepted the need to capture more data on local HIV testing; confirmed that HIV testing should be within the competence of all doctors and nurses; and advised that it would ask the National Screening Committee to provide advice on routine testing of HIV in high prevalence areas.²⁴

They all reached similar conclusions – we must scale up HIV testing to include general practice and other settings.

The UK national guidelines for HIV testing 2008 (prepared jointly by the British HIV Association, the British Association for Sexual Health and HIV and the British Infection Society)

HIV tests should be offered and encouraged in a much broader range of settings including genitourinary medicine (GUM) or sexual health clinics, antenatal and pregnancy termination services, drug dependency programmes, and healthcare services for those with tuberculosis, hepatitis B, hepatitis C and lymphoma.

They should be considered for all men and women registering with GPs and all general medical admissions in areas where diagnosed HIV prevalence exceeds two per 1,000 of the population. This was the case in 37 English local authorities in 2009.

HIV testing should be routinely offered and recommended to all patients presenting with immuno-compromised conditions associated with HIV, with a sexually transmitted infection, all sexual partners of those known to be HIV-positive, all men who have sex with men, women who have sex with bisexual men, patients reporting a history of injecting drug use, all men and women from countries of high prevalence and all sexual contacts of individuals from countries of high prevalence.

NICE draft guidance 2011

“Halve It” welcomes the testing guidance published by NICE on HIV testing in in black African communities and among men who have sex with men in England.^{6,7} We hope that this guidance is a catalyst to wider testing in a broad range of healthcare and community settings. We firmly believe that the early diagnosis of HIV is of significant benefit to both personal and public health. We look forward to its full implementation.

NICE public health guidance:

PH33: Increasing the uptake of HIV testing to reduce undiagnosed infection and prevent transmission among black African communities living in England⁶

The recommendations of the NICE public health guidance for black African communities include:

- Involving communities and promoting testing
- Planning services – developing a strategy and commissioning services in areas of identified need
- Reducing barriers to HIV testing for black African communities
- Offering and recommending an HIV test in healthcare settings
- HIV referral pathways

PH34: Increasing the uptake of HIV testing to reduce undiagnosed infection and prevent transmission among men who have sex with men⁷

The recommendations of the NICE public health guidance for men who have sex with men include:

- Promoting HIV testing among men who have sex with men
- Primary and secondary care: offering and recommending an HIV test
- Outreach: providing rapid point-of-care tests

Gilead UK & Ireland Fellowship programme

The Gilead UK & Ireland Fellowship Programme has provided grants to 50 locally-based HIV testing initiatives over the last 3 years. The aim of the Programme is to support the development and dissemination of best practice in HIV testing. The following projects received funding from the Gilead UK & Ireland Fellowship Programme.

Case study – HIV testing in primary care

The project was based at an inner city practice, the largest in central Manchester with a practice population of 18,000 patients. Patients were offered HIV tests as part of a new patient health check which included testing for hepatitis B and C and screening for cholesterol and diabetes. Two hundred and fifty seven patients were screened over a ten month period with a 66% uptake for HIV tests. A total of four newly diagnosed patients were found.

The project found that routine testing for blood-borne viruses is acceptable to primary care patients, as shown by the high uptake rate. This project also helped to raise awareness among our clinicians about blood-borne virus screening

Dr Archana Griffin, Robert Darbshire Practice, General Practice, Central Manchester

Case study – Screening for HIV as Routine Practice (S.H.A.R.P)

Through local targeted educational sessions highlighting the UK HIV testing guidelines & clinical indicator conditions, the S.H.A.R.P project aimed to identify more HIV cases in both primary and secondary care through routinely screening newly registered patients between the ages of 18-60 and to increase diagnostic HIV testing in patients of any age presenting with clinical indicator conditions of HIV/AIDS. Over a period of 4 months, 61 hospital doctors, 55 GPs and 13 practice nurses received group or individual training on HIV testing and clinical indicator conditions. Within 4 months of initiating SHARP training, nine new HIV diagnoses were made, compared to two new HIV diagnoses in the preceding 6 months.

The SHARP initiative aimed to promote increased opt-out and diagnostic HIV testing in non-specialist settings; following educational sessions the project observed an initial increase in rates of HIV testing of medical admissions and observed a steady increase in primary care testing.

Dr Stephen Dawson, Garden Clinic, Berkshire East Sexual Health Centre

WORKING WITH HEALTHCARE PROFESSIONALS TO HALVE LATE AND UNDIAGNOSED HIV

Missed opportunities

A study in black-Africans undertaken prior to NICE guidance on testing showed that in the year leading up to the diagnosis of HIV in 263 people, of whom 49.8% presented with advanced disease, 76% saw their GP, 38% had been seen in an outpatient service and 15% had been inpatients.²⁵ In addition, while primary care is extremely well utilised by this high-risk population, HIV testing had not been discussed for 82.4% of the black-Africans who accessed GP services in the year prior to HIV diagnosis.²⁵ The researchers conclude that black-Africans are accessing health services but clinicians are failing to use opportunities effectively for diagnosing HIV infection.

Key healthcare professionals are missing the signs of HIV. These missed opportunities for diagnosis are a threat to individuals and to public health. The publication of the new NICE guidance on HIV testing^{6,7} represents an unprecedented opportunity to address this issue, but the NICE guidance alone will not be enough to drive this change in clinical practice and this will need to be supporting with GP training programmes, incentives and targets.

Why general practice could help to Halve It

Most people are registered with a GP, with patients seeing their GP on average three or four times per year. There is good evidence to suggest that groups of people at greatest risk of infection and those already HIV-positive but undiagnosed (including some with relevant symptoms) access general practice.

With the right training, targets and incentives, GPs and practice nurses could be ideally placed to provide HIV testing for patients living in areas with high HIV prevalence, patients in high-risk groups and patients with symptoms or conditions that indicate possible HIV infection. It must be recognised, however, that many HIV-associated conditions are also commonly encountered in HIV-negative people. Furthermore, GPs can only operate within the constraints of the primary healthcare system.

Historically GPs have been encouraged to think of HIV testing as a specialised service offered in sexual health clinics. This is a view that needs to change. Any doctor or nurse should be able to offer a patient an HIV test. It is now generally accepted that pre-test counselling is not required.

The Chief Medical Officers, the UK National Guidelines for HIV Testing and NICE's recent guidance all suggest a greater role for GPs in testing. The Sex, Drugs and HIV Group of the Royal College of General Practitioners is currently looking at ways to encourage GPs to carry out more HIV testing, in accordance with these recommendations.

Why do people not ask for HIV tests?

Many people currently avoid HIV testing because of the stigma it attracts. Misconceptions around the kinds of individuals for whom testing is appropriate are common.

Regular offers of testing in general practice and other healthcare settings would help to normalise the practice, defuse notions of otherness and encourage understanding that HIV is just one of a range of causes of ill-health that should be considered when someone is at risk. Removing the stigma from HIV testing would reduce late diagnosis in groups at particular risk such as women, black-Africans, and men who have sex with men.

Barriers to testing within general practice

A workshop with GPs and practice nurses held in Manchester in 2010 identified the main barriers to carrying out more HIV testing within general practice as:

- time (or lack of)
- need to arrange follow-up for results
- fear of having to tell a patient of a positive result
- confusion about effect on insurance
- difficulty bringing the subject up and how to word it
- stigma surrounding positive diagnoses
- confidentiality
- language barriers

Participants also identified the following opportunities for overcoming barriers and promoting testing within general practice:

- waiting room messages and advertising
- normalising testing by offering it to everyone
- offering tests when taking smears, providing contraception, giving travel advice, at asthma clinics and during sexual health screening
- improving awareness among staff, including receptionists
- having patient leaflets that identify the risks
- clarifying the insurance position in leaflets

The researchers conclude that black-Africans are accessing health services but clinicians are failing to use opportunities effectively for diagnosing HIV infection... Key healthcare professionals are missing the signs of HIV. These missed opportunities for diagnosis are a threat to individuals and to public health.

WORKING WITH HEALTHCARE PROFESSIONALS TO HALVE LATE AND UNDIAGNOSED HIV

Overcoming barriers to testing

The proposed public health outcomes framework indicator on late-diagnosed HIV, in combination with UK national testing guidelines and NICE public health guidance on reducing undiagnosed HIV in men who have sex with men and among black African communities,^{6,7} will encourage local commissioners and providers of HIV testing to look more broadly at HIV prevalence and to take appropriate steps to address it through expanded testing and linkage to care.

Healthcare professionals in primary care undoubtedly have many different jobs and targets to meet; however, the need for HIV testing to become a greater priority in general practice is clear.

The Department of Health's public health outcomes framework indicator to reduce the proportion of persons presenting with HIV at a late stage of infection will be vital to incentivise healthcare services to scale up HIV testing in the UK.

The Quality and Outcomes Framework (QOF) has been successfully used to encourage general practice to meet national targets by the provision of financial incentives. Rewarding practices through the QOF for carrying out more HIV tests is likely to be one of the most effective means of increasing, widening and normalising testing.

Making patients more aware of their right to request HIV testing through their GP would also improve uptake.

Commissioning by GP consortia will be the key policy direction for the future with opportunities to develop local programmes. This is especially relevant for HIV, where much of the burden arising from late diagnosis for patients and services is localised, such as in the cities of Brighton, London and Manchester.

More training for GPs in offering HIV testing is needed. There also needs to be more focus on improving access to testing across a range of settings, such as community-based testing services.

Department of Health pilot studies

The Department of Health (DH) has funded pilot projects to try out new approaches to routine HIV testing for adults in primary and secondary care in areas of high prevalence for HIV infection. Settings include general practice, hospital admission units, emergency departments and an acute care unit.

The projects, in London, Brighton and Leicester, will assess the feasibility and acceptability, to patients and staff, of providing an HIV test as part of the routine care services offered to all adult patients. The pilots will support the implementation and development of the 2008 UK National Guidelines for HIV Testing.

The DH has also funded three projects in London and Sheffield working with community-based organisations for men who have sex with men, and black African communities – the groups most at risk of HIV in the UK, working in partnership with NHS services. The Health Protection Agency published findings from these eight pilots in an interim report in December 2010.

Case study – Testing in acute general medicine

The routine offer of an HIV test as part of normal clinical care for patients admitted through general medicine in Brighton was introduced in August 2009, initially as part of a DH-funded pilot.

During the first 6 months, 1,413 patients were tested for HIV. The routine offer was highly acceptable to patients with an uptake rate of over 90%. Three new infections were identified during the pilot and one transmission to an uninfected partner was probably avoided.

The success of the pilot has led to routine testing of all emergency hospital admissions (not just general medicine) agreed between the hospital trust and the PCT as part of the commissioning process.

Dr Martin Fisher and Nicky Perry, Brighton and Sussex University Hospitals

Case study – Community testing

Barking PCT funds a community HIV testing clinic aimed at local black-African communities, a group at high risk of HIV in this area of London. The clinic is operated by Terrence Higgins Trust nurses and staff with community outreach done by Widows and Orphans, a local African support organisation.

Situated just off the high street in a discreet community setting, the clinic operates every Saturday afternoon, a time identified as convenient by those the service is aimed at, and tests up to 12 people per session. Rapid HIV testing is offered along with referrals into local community support, specialist advice and Newham Hospital.

Over a quarter of those attending the clinic have never been to any other sexual health service.

Terrence Higgins Trust

Case study – Strengthening commissioning performance to reduce late diagnosis of HIV

London PCTs and NHS London have agreed to a local performance indicator to reduce late diagnosis of HIV by 50% (from 2004–2005 baseline) over 3 years. This means that each PCT has set plans that are performance managed by NHS London.

A commissioning toolkit for local use outlining examples of best practice is updated each year by the London Sexual Health Programme and the Health Protection Agency. This has increased HIV testing in primary care, community and acute settings. The work is also based on an HIV prevention pathway that aims to get people diagnosed early and to reduce onward transmission of HIV through referral to HIV treatment, one-to-one counselling in line with NICE guidelines, the Positive Self-Management Programme (HIV Expert Patients Programme) and increased HIV testing in non-GUM settings, eg tuberculosis, accident and emergency, and general medical admissions.

This toolkit can be accessed from www.londonsexualhealth.org

Hong Tan, London Sexual Health Programme Director

LOOKING AHEAD

The new NHS and Public Health England: an opportunity to Halve It

The White Paper ‘Equity and Excellence: Liberating the NHS’ and the Public Health White Paper ‘Healthy lives, healthy people: Our strategy for public health in England’ herald an increase involvement in public health by local authorities.^{26,27}

Public health is likely to become a joint responsibility of Public Health England and local Health and Wellbeing Boards. While funding for public health will be decentralised wherever possible, there will need to be coordination between the relevant institutions of the NHS and local authorities. This offers new opportunities to ensure that HIV testing is high on the agenda of these bodies, and remains there.

There are also opportunities for these bodies to become more proactive and innovative in their approaches to HIV testing and to expand testing by other healthcare providers such as pharmacies, non-governmental organisations and the prison and probation service. Pilot studies in hospital accident and emergency departments have also had good results.

“Halve It” urges the prioritisation of the indicator to reduce the proportion of persons presenting with HIV at a late stage of infection in the Public Health Outcomes Framework. Late diagnosis is the single most important factor associated with HIV-related morbidity and mortality (CD4 count $<350\text{mm}^3$) in the UK. It is vital to ensure that the late diagnosis of HIV is retained as an indicator in the Public Health Outcomes Framework.

The Commissioning for Quality and Innovation (CQUIN) payment framework, which makes a small proportion of the income of local healthcare providers dependent on achieving locally agreed quality improvement and innovation goals, could

be used as a means of incentivising the expansion of testing in some of these settings.

Using local diagnosed HIV prevalence as part of the calculation of the new public health premium would also provide incentives to test and would maintain a true reflection of public health burden in an area.

There is also a need for more training for GPs and other healthcare professionals likely to offer an HIV test. Further clarity on how Public Health England will work with key local stakeholders is required, in particular, directors of Public Health, local authorities and local Health and Wellbeing Boards (the key local policy coordinators of the future), to ensure opportunities are developed for local GP training programmes and community testing initiatives. This is especially relevant for HIV, where much of the burden arising from late diagnosis for patients and services is localised, such as in the cities of Brighton, London and Manchester.

While the “Halve It” coalition supports the overall vision of the White Papers, we believe that there should be more clarity on the roles and accountabilities of the many different institutions involved in the provision and management of HIV services. Under the current proposal, we are concerned that, without clear accountabilities, the local provision of testing in England may become fragmented, jeopardising the much-needed implementation of NICE’s recommendations and national testing guidelines.

CQUIN could be a means of incentivising the expansion of HIV testing.

CONCLUSION AND RECOMMENDATIONS

TOGETHER WE CAN HALVE IT

Making HIV a public health priority both locally and nationally will save lives and money. This document shows that early diagnosis reduces onward transmission and that each transmission averted saves the public purse over £280,000 in direct health costs alone,¹ with the cost per detected HIV infection ranging from just over £2,000 to just under £4,000.¹⁸ Had all of the UK-acquired infections newly diagnosed in 2010 been prevented, there would have been a saving of approximately £1.2 billion in direct healthcare costs.⁴

The figures are stark and we can do better. More than a quarter of those currently living with HIV are undiagnosed and, of those who are diagnosed, more than half are diagnosed too late.¹

There is an urgent need for a new approach, which must include wider testing in primary care and other settings. Testing for HIV must become a regular mainstream activity, free of stigma, if we are to halve current levels of late and undiagnosed HIV.

There is an urgent need for a new approach, which must include wider testing in primary care... Testing for HIV must become a regular mainstream activity, free of stigma, if we are to halve late and undiagnosed HIV.

Good guidelines already exist from the leading professional bodies and NICE to increase testing. Incentives and support should be put in place to ensure that these are implemented by commissioners and providers; and that healthcare professionals are aware of their recommendations and trained to deliver them.

Until such a comprehensive approach is adopted, stories of missed opportunities for diagnosis will continue to be widespread, at great individual and public cost.

As the NHS and Public Health Services evolve, all the relevant players – local communities, commissioning consortia, the NHS commissioning board, local authorities and public, private and third-sector health providers – must work together to tackle HIV.

CONCLUSION AND RECOMMENDATIONS

TOGETHER WE CAN HALVE IT

Our goals are to:

- Halve the proportion of people diagnosed late with HIV (CD4 count <350mm³) by 2015.
- Halve the proportion of people living with undiagnosed HIV by 2015.

We call upon all levels of government to:

- Make HIV a public health priority both locally and nationally.
 - Include HIV testing as a specific area of priority for Public Health England.
 - Ensure that late diagnosis of HIV is prioritised as an indicator in the Public Health Outcomes Framework.
- Ensure that NHS and local authorities give HIV the appropriate priority by requiring that it is systematically considered in local health needs assessments and health planning processes.
 - Implement the UK national testing guidelines and NICE public health guidance on HIV testing in black-African communities and in men who have sex with men.
 - Encourage the development and implementation of local strategies to increase HIV testing (eg testing for new GP registrants in high-prevalence areas).
 - Increase and enhance the provision of education and information provided to those groups most at risk of HIV including:
 - black-African communities
 - men who have sex with men.
- Ensure that people diagnosed with HIV have access to antiretroviral therapies known to reduce viral loads and potential onward transmission of HIV, free of charge on the NHS.
- Offer incentives to test for HIV through the QOF and CQUIN frameworks in a variety of healthcare settings.
 - Strengthen the relationship between national surveillance and local reporting of HIV testing by enhancing local HIV reporting procedures and maintaining a world-class national surveillance capability.
 - Improve transparency by requiring the local Public Health Service to report back to the public on local progress in tackling late HIV diagnosis.

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