

EARLY TESTING SAVES LIVES

HIV is a public health priority



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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 80,000 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 either being diagnosed late or not at all. 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 patients, 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 disease. 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

People living with HIV today can prevent their condition from turning into AIDS and live into old age as long as they are diagnosed promptly and treated appropriately. Yet in 2009, just 30 days after their diagnosis, 426 individuals had already progressed to AIDS. These people will have dramatically reduced life expectancies, some surviving for just months rather than years.

Most of these people who are diagnosed late have had previous contact with the health services and opportunities for testing have been missed.

The idea of doing an HIV test has simply not occurred to either healthcare professional or patient, despite the warning signs.

The later people are diagnosed, the more irreparable damage the virus does to their bodies. More than half of people diagnosed with HIV in the UK are diagnosed late. It's time to get better at diagnosing people quickly.

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

WHY SHOULD WE HALVE UNDIAGNOSED HIV?



David Cairns 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 do not know it. About 1 in 4 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 reviewing how the NHS works, we have a unique opportunity to design services that tackle it.

Undiagnosed HIV costs lives. Let's Halve It by 2015.

Halve the proportion of people diagnosed late with HIV (with a CD4 count $<350\text{mm}^3$) within 5 years

Halve the proportion of people living with undiagnosed HIV within 5 years

EXECUTIVE SUMMARY

EARLY TESTING SAVES LIVES

At the end of 2008, a total of 83,000 people in the UK were HIV-positive.¹ Of these, an estimated 27% are unaware of their condition and 55% 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 onwards transmission, and continued sexual risk taking while people are unaware of their HIV-positive status.

Halve It is a new 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 $<350\text{mm}^3$) within 5 years.
- Halve the proportion of people living with undiagnosed HIV within 5 years.

We call upon all levels of government to:

- Make HIV a public health priority both locally and nationally.
 - Include HIV as a specific area of priority in the new public health White Paper and include levels of HIV in the calculation of the public health premium.
- Ensure the Health Service (whether the NHS or the Public Health Service) gives HIV the appropriate priority on the ground by requiring that it is systematically considered in local health needs assessments and health planning processes.
 - Implement the forthcoming National Institute for Health and Clinical Excellence (NICE) public health guidance on HIV testing by encouraging 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:
 - Men who have sex with men, and
 - Black-Africans.
 - Ensure that people diagnosed with HIV have access to antiretroviral therapies known to reduce viral loads and potential onward transmission of HIV.

- Offer healthcare practices 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 and levels of new infection.

HIV is a public health issue that can be tackled successfully

We now have rapid and accurate tests which can be deployed by non-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 draft public health guidance from NICE supporting broader testing.

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.¹ And that, had all of the UK-acquired infections newly diagnosed in 2008 been prevented, there would have been a saving of approximately £1.1 billion in *direct* healthcare costs.¹

HALVE IT COALITION MEMBERS

Dr Anthony Nardone

Health Protection Agency (observer)

David Yirrell

Scottish HIV and AIDS Group (observer)

Deborah Jack

National AIDS Trust

Francis Kaikumba

African Health Policy Network

Hong Tan

London Sexual Health Programme

Dr Ian Williams

British HIV Association

Baroness Joyce Gould

Independent Advisory Group on Sexual Health and HIV (observer)

Kay Orton

HIV Services and Sexual Health Promotion, Department of Health (observer)

Lisa Bright

Gilead Sciences Ltd

Dr Martin Fisher

British Association for Sexual Health and HIV

Dr Murad Ruf

NHS Lambeth

Nathaniel Ault

National HIV Nurses Association

Professor Nick Bosanquet (Chair)

Imperial College London

Paul Ward

Terrence Higgins Trust

Dr Philippa James

Sex, Drugs and HIV Group of the Royal College of General Practitioners

Dr Philippa Matthews

Islington Primary Care Trust (PCT)

Rob Walton (Secretariat)

Wisper Public Affairs

Ruth Lowbury

Medical Foundation for AIDS and Sexual Health

Dr Simon Edwards

British Association for Sexual Health and HIV

Dr Valerie Delpech

Health Protection Agency (observer)

Veronica Oakeshott

All-Party Parliamentary Group on HIV and AIDS

Zoë Sheppard

National HIV Nurses Association

HIV IN THE UK

People living with HIV

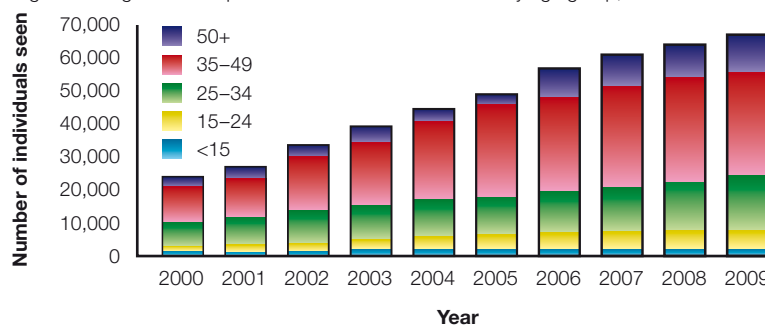
In 2009, 65,319 people were *known* to be living with HIV in the UK, up from 61,110 in 2008, and almost a three-fold increase from 2000.² However, the UK has high levels of undiagnosed HIV. The Health Protection Agency estimates that the real total number of people living with the virus in the UK in 2008 was 83,000.¹

An estimated 6,630 individuals were newly diagnosed with HIV in the UK in 2009.² Over half of people newly diagnosed in 2009 (54%; 3,560) probably acquired their infection through heterosexual contact and 42% (2,760) through sex between men.² Africans accounted for 38% of new HIV diagnoses in 2009.²

The numbers of people living with HIV in older age groups are increasing both in number and as a proportion of the total. In 2009, almost one in five people with HIV were 50 years of age or older, compared with one in ten in 2000 (Figure 1).² This is due to effective antiretroviral therapy and continued transmission at older ages.³

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

Figure 1: Diagnosed HIV-positive individuals seen for care by age group, UK: 2000–2009²



Late diagnosis

Late diagnosis is defined as patients with a CD4 cell count of less than 350 per mm³ within 3 months of diagnosis.⁴ 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 2008, 55% of people diagnosed with HIV were diagnosed late.¹ Of these, 66% of heterosexual men, 61% of heterosexual women and 43% 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.⁴ 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 2008, an estimated 22,400 people in the UK were living with HIV but did not know it.¹ Over a quarter (27%) of all those currently living with HIV are undiagnosed.¹

Undiagnosed individuals will not be receiving treatment for their infection and are at greater risk of passing the infection on to others. 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.

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 found 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.⁵ 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.⁶ 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.⁷ 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, 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**

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.⁸ 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.⁸

- **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 2008 been prevented, there would have been a saving of approximately £1.1 billion in direct healthcare costs.¹ 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

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.

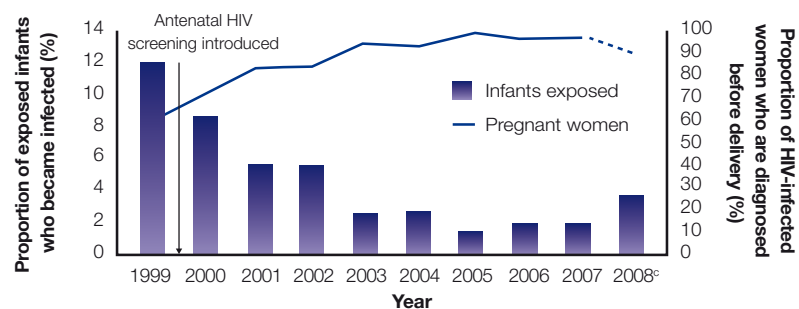
In 2008, the uptake of HIV tests reached 95% in antenatal clinics nationally and 93% among patients tested in sexual health clinics as part of the unlinked anonymous HIV testing survey. This is a survey of residual syphilis blood samples in a sentinel network of sexual health clinics.¹

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 at one of five large practices. HIV testing is recommended as part of a new patient health check, regardless of sexual orientation, ethnicity or age. This universal approach helps to reduce stigma among patients and staff.

Results are very promising with around 40% of 3,937 patients accepting the test, nearly 1,500 patients knowing their status and several newly diagnosed patients having been successfully provided with care.

The positivity rate in this pilot is 0.48% – nearly five times higher than the point at which universal testing is deemed to be cost-effective.

Dr Murad Ruf and Jess Peck, NHS Lambeth

Case study – Sexual Health in Practice (SHIP)

SHIP provides holistic sexual health training, aiming to work with every GP and practice nurse, 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 (for example 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 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.⁹

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.¹⁰

In September 2010, NICE issued draft guidance on increasing the uptake of HIV testing among men who have sex with men¹¹ and Black-Africans in England.¹²

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 43 English local authorities in 2008.

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 2010

Local strategies should be developed to encourage individuals to consider testing, drawn up in consultation with local voluntary organisations and community members. These should pay particular attention to groups who are less likely to access services.

Community engagement is regarded as particularly important in Black-African communities. Community members should be recruited and trained to act as 'health champions' and 'role models'. Programmes should address

misconceptions about testing and treatment, promote the benefits of early diagnosis and tackle HIV-related stigma. Some Black-Africans see HIV testing in sexual health clinics as stigmatising, complicated and time-consuming. There should be an emphasis on providing testing in other settings.

Interventions promoting testing to men who have sex with men should be encountered in venues or on websites that facilitate sex between men. Testing should also be offered in venues where high-risk sexual behaviour between men occurs.

Gilead UK & Ireland Fellowship programme

The Gilead UK & Ireland Fellowship programme has provided grants to 28 locally based HIV testing initiatives over the last 2 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 – Educating primary care providers

A pilot study across East London explored whether training would increase awareness and knowledge of HIV among primary care clinicians, and subsequently increase the number of tests offered.

A questionnaire was given to 26 GPs and three practice nurses before and after they attended an HIV education course.

Before the training, attendees performed an average of one test per month. This increased to four per month following the course. Before, barriers to testing cited by participants included a lack of knowledge about the symptoms of HIV and a lack of clarity around the benefits to patients of knowing their HIV status. None of these issues were considered to be barriers following the course.

Dr Jane Hutchinson, Barts and the London NHS Trust

Case study – Acute admissions point of care testing

Researchers at University College London set out to determine whether a model that is effective in New York is an acceptable and feasible tool in reducing late diagnoses of HIV in London. This involved asking people already waiting in an acute admissions unit to watch a video that provided information on risk reduction and point of care testing.

Of the 282 patients approached in the acute admissions unit, 140 agreed to watch the video. Of these, 138 had a rapid HIV test performed and three tested HIV-positive. Of those who watched the video, 96.7% felt HIV testing in this setting was appropriate, 89.9% liked receiving the information via video and 92.3% felt the health advisor facilitated the testing process.

The research team concluded that HIV testing in an acute medical setting for people already waiting, facilitated by an educational video and dedicated staff, is acceptable, feasible and effective.

Dr Fiona Burns, Dr Simon Edwards and Dr Mike Brown, University College of London Hospital, London

Case study – Rapid HIV testing service

A rapid HIV testing service called SORTED is offered by the 56 Dean Street HIV and sexual health clinic in Soho, London.

The clinic is situated in a prime location for London's gay community. Patients do not feel 'outed' when entering the clinic as it has an inconspicuous entrance.

The clinic is open 6 days a week, including four evenings. Results are guaranteed within an hour. Promotional activities include advertising on Gaydar radio, the Gaydar website and in the gay press, and posters at Leicester Square tube station.

In 2008, 12,062 HIV tests were performed and this figure rose to 18,112 in 2009. The number of new HIV diagnoses in these years was 166 and 224, respectively.

Dr Macky Natha and Marco Rossi, 56 Dean Street

WORKING WITH HEALTHCARE PROFESSIONALS TO HALVE LATE AND UNDIAGNOSED HIV

Missed opportunities

A study in Black-Africans 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.¹³ 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.¹³ 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.

Why general practice could help to Halve It

Most people are registered with a GP, with patients seeing their GP on average three to four times per year. There is good evidence to suggest 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 draft guidance all suggest a greater role for GPs in testing. The Sex, Drug 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 men who have sex with men, Black-Africans and women.

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

If HIV testing becomes a national priority in the next year, many of the barriers to individuals requesting/taking tests and healthcare professionals actively promoting tests can be overcome, thus saving lives and money.

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 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 (DoH) 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 Department has also funded three projects in London and Sheffield working with community-based organisations for men who have sex with men, and African communities – the groups most at risk of HIV in the UK, working in partnership with NHS services. The Health Protection Agency is completing an overview of all eight pilots and will publish 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 DoH-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 and 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 Service: an opportunity to Halve It

The White Paper 'Equity and Excellence: Liberating the NHS' looks to move public health services to local authorities.¹⁴

Public health is likely to become a joint responsibility of local public health bodies and local authorities, while funding for public health will go to local authorities. There will need to be coordination of the NHS Commissioning Board and local GP consortia on public health. 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 Accident and Emergency hospital departments have also had good results.

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.

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

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.

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Good guidelines already exist from the leading professional bodies to increase testing, and guidance from NICE is forthcoming. 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 Service evolve, all the relevant players – local communities, GP 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) within 5 years.
- Halve the proportion of people living with undiagnosed HIV within 5 years.

We call upon all levels of government to:

- Make HIV a public health priority both locally and nationally.
 - Include HIV as a specific area of priority in the new public health White Paper and include levels of HIV in the calculation of the public health premium.
- Ensure the Health Service (whether the NHS or the Public Health Service) gives HIV the appropriate priority on the ground by requiring that it is systematically considered in local health needs assessments and health planning processes.
 - Implement the forthcoming NICE public health guidance on HIV testing by encouraging 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:
 - Men who have sex with men, and
 - Black-Africans.
 - Ensure that people diagnosed with HIV have access to antiretroviral therapies known to reduce viral loads and potential onward transmission of HIV.
- Offer healthcare practices 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 and levels of new infection.

REFERENCES

- 1 Health Protection Agency. HIV in the UK: 2009 Report. <http://www.hpa.org.uk/Publications/InfectiousDiseases/HIVAndSTIs/0911HIVUK2009Report>. Publication date November 2009. Accessed 27 October 2010.
- 2 Health Protection Agency. Health Protection Report. Diagnosed HIV infection in the UK: 2009 update. Volume 4 No 32; 13 August 2010. <http://www.hpa.org.uk/hpr/archives/2010/news3210.htm#hiv>. Updated 13 August 2010. Accessed 27 October 2010.
- 3 Smith R et al. HIV transmission and high rates of late diagnoses among adults aged 50 years and over. *AIDS* 2010;24:2109–2115.
- 4 Gazzard BG et al. British HIV Association Guidelines for the treatment of HIV-1-infected adults with antiretroviral therapy 2008. *HIV Med* 2008;9:563–608.
- 5 Antiretroviral Therapy Cohort Collaboration. Life expectancy of individuals on combination antiretroviral therapy in high-income countries: a collaborative analysis of 14 cohort studies. *Lancet* 2008;372:293–299.
- 6 Pinkerton SD et al. Infections prevented by increasing HIV serostatus awareness in the United States, 2001 to 2004. *J Acquir Immune Defic Syndr* 2008;47:354–357.
- 7 Fox J et al. Reductions in HIV transmission risk behaviour following diagnosis of primary HIV infection: a cohort of high-risk men who have sex with men. *HIV Med* 2009;10:432–438.
- 8 Krentz HB and Gill J. Despite CD4 cell count rebound the higher initial costs of medical care for HIV-infected patients persist 5 years after presentation with CD4 counts less than 350 μ l. *AIDS* 2010, advance online publication, September 16 2010. DOI: 10.1097/QAD.0b013e32833f9e1d.
- 9 Department of Health – Chief Medical Officer Letter. Improving the detection and diagnosis of HIV in non-HIV specialties including primary care. <https://www.cas.dh.gov.uk/ViewandAcknowledgment/ViewAlert.aspx?AlertID=100818>. Updated 13 September 2007. Accessed 28 October 2010.
- 10 British HIV Association, British Association of Sexual Health and HIV, British Infection Society. UK National Guidelines for HIV Testing 2008. <http://www.bhiva.org/documents/Guidelines/Testing/GlinesHIVTest08.pdf>. Updated 1 September 2008. Accessed 28 October 2010.
- 11 National Institute for Health and Clinical Excellence. Increasing the uptake of HIV testing among men who have sex with men: draft guidance consultation. <http://guidance.nice.org.uk/PHG/Wave19/4>. Updated 27 September 2010. Accessed 28 October 2010.
- 12 National Institute for Health and Clinical Excellence. Increasing the uptake of HIV testing among black Africans in England: draft guidance consultation. <http://guidance.nice.org.uk/PHG/Wave19/3>. Updated 27 September 2010. Accessed 28 October 2010.
- 13 Burns FM et al. Missed opportunities for earlier HIV diagnosis within primary and secondary healthcare settings in the UK. *AIDS* 2008;22:115–122.
- 14 Department of Health. Equity and excellence: Liberating the NHS. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353. Updated 12 July 2010. Accessed 28 October 2010.

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**Royal College of
General Practitioners –**
Sex, Drugs and HIV Group

