Report: Updated August 2009

HIV Testing Action Plan

To increase uptake of HIV testing and reduce late diagnosis in the UK

Transforming HIV testing in the UK

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A strategic action plan to increase uptake of HIV testing and reduce late diagnosis in the UK

Introduction

NAT (National AIDS Trust) is the UK's leading charity dedicated to transforming society's response to HIV. We develop policy and campaign for change to stop the spread of HIV and improve the lives of people living with HIV. We provide fresh thinking, expert advice and practical resources.

One of NAT's four strategic goals is focused on HIV testing: early diagnosis of HIV through ethical, accessible and appropriate testing. We call for increased political will, commitment and resources from a wide range of stakeholders for needs-based HIV testing. We also help encourage and facilitate innovative and evidence-based interventions.

NAT has held a series of expert seminars and developed a number of policy documents on HIV testing in recent years. Each of these included a variety of recommendations and areas for further action. NAT reviewed these recommendations so as to develop a suggested plan of activities for taking them forward.

This resulting action plan provides an overview of NAT's thinking on current HIV testing strategies in the UK. It then identifies priority activities to increase political will, commitment and resources from a wide range of stakeholders for further HIV testing efforts. These are aimed to increase the numbers of people tested and reduce the proportion of those diagnosed late in the UK.

Transforming HIV testing in the UK

In the UK, 2007 figures revealed record levels of HIV diagnosis, particularly among certain groups including gay and bisexual men and African communities. Yet it is estimated that more than a quarter (28 per cent) of people with HIV in the UK are unaware of their infection. Those unaware of their infection are putting both their own health and that of their sexual partners at risk. It is estimated that more than 50 per cent of new infections occur through transmission from undiagnosed individuals.

This comes at a time when local spending on HIV prevention in the UK has decreased in real terms. Without intensified testing efforts, including sustained long-term funding, the numbers of people with HIV will continue to increase. If rates continue, NAT estimates that by 2010 nearly 100,000 people could be living with HIV in the UK.

Historic 'opt-in' approach

The primary model for providing HIV testing in the UK has been client-initiated voluntary counselling and testing (VCT). These programmes are 'opt-in', meaning individuals must actively seek an HIV test at a healthcare facility. Historically these have been mainly restricted to sexual health and community clinics. However, uptake of 'opt-in' HIV testing has been limited. The only setting that has used a different model has been antenatal settings, where the approach has been on an 'opt-out' basis. This model is discussed in further detail below.

Current testing services are not meeting the continued high level of undiagnosed need. According to one study only 62 per cent of gay and bisexual men in the UK have ever tested for HIV.[1] This compares to over 85 per cent in Australia. In addition, many opportunities to diagnose HIV in clinical settings are being missed by healthcare professionals, even in communities with high prevalence. Of those who were newly diagnosed with HIV in 2007, 42 per cent of black Africans were diagnosed late.[2] Late diagnosis fuels morbidity and mortality, seriously increasing the likelihood of a poor response to treatment and of ill health and early death.

'Opt-out' approach

While expanded access to client-initiated HIV testing and counselling is needed, other approaches are also required if uptake of testing is to increase and the proportion of those diagnosed late is to be reduced. From a public health perspective, knowledge of HIV status can be a powerful motivator for behaviour change. People with positive test results change towards safer sexual behaviour, thereby reducing onward transmission.[3]

New guidance was prepared in 2006 by both the US Centres for Disease Control and Prevention and World Health Organisation/UNAIDS in light of increasing evidence that provider-initiated testing and counselling could increase uptake of HIV testing and improve access to health services for people living with HIV. Initial data from the US suggest that this model is feasible and has been helpful in increasing the number of new HIV diagnoses, despite slow progress in widely rolling out this new approach.[4, 5]

Provider-initiated HIV testing and counselling involves a healthcare provider recommending when appropriate an HIV test to patients attending a healthcare facility. This model is often called 'opt-out'. In these cases, once specific pre-test information has been provided, the HIV test would ordinarily be performed unless the patient declines, so informed consent remains. This model has been used in the UK since 2000 in antenatal settings, where 'opt-out' testing has been found to be acceptable and to have a higher uptake than other methods.[6]

National testing guidelines

In the UK, the Department of Health's Chief Medical Officer (CMO), Professor Sir Liam Donaldson, wrote to the NHS in September 2007 highlighting best practice about offering and recommending where appropriate, HIV testing in all healthcare settings not just those traditionally offering this service.[7] The BHIVA, BASSH and BIS new national testing guidelines published in 2008 are intended to facilitate an increase in HIV testing in all healthcare settings as recommended by the CMO and others in order to reduce the proportion of individuals with undiagnosed HIV infection.[8]

1: Sigma Research (2008) *Multiple Chances: Findings from the United Kingdom gay men's sex survey 2006*, www.sigmaresearch.org.uk.

2: Defined as either a CD4 count of <200 cells/mm^3 (current threshold is now <350 cells/mm^3) or an AIDS-defining illness at HIV diagnosis. HPA (2008) *Sexually transmitted infections in black African and black Caribbean communities in the UK: 2008 report*, www.hpa.org.uk.

3: Shinsana et al (2004) *Does knowing one's HIV status matter in HIV prevention?* International AIDS Conference, Bangkok, abstract ThOrC1414.

4: Branson (2007) *Implementing US HIV Testing Policy: CDC's experience and lessons learned*, IAS2007 presentation, www.ias2007.org.

5: US Centres for Disease Control and Prevention (2007) 'Rapid HIV Testing in Emergency Departments', *Morbidity and Mortality Weekly Report*, 56: 597-601, www.cdc.gov.

6: Simpson et al (1998) 'Uptake and Acceptability of Antenatal HIV Testing: Randomised controlled trial of different methods of offering the test', *British Medical Journal*, 316: 262-7, www.bmj.com.

7: Donaldson (2007) Improving the detection and diagnosis of HIV in non-HIV specialities including primary care, www.dh.gov.uk.

8: British HIV Association, British Association for Sexual Health and HIV and British Infection Society (2008) *UK National Guidelines for HIV Testing 2008*, www.bhiva.org.

The guidelines recommend that HIV testing should be routine and 'opt-out' in certain healthcare settings such as sexual health clinics, antenatal services (as is already the case), termination of pregnancy services, drug dependency programmes and healthcare services for those diagnosed with other conditions including tuberculosis and hepatitis. Testing should also be offered to key at-risk groups and in communities with high prevalence, with repeat testing offered to those most at risk, such as gay and bisexual men. All healthcare professionals including doctors, midwifes and nurses should be able to offer and perform an HIV test.

Overall, these recommendations offer real opportunities to increase testing uptake and to reduce the proportion of people who are diagnosed late. They also give rise to a number of policy challenges including:

- Getting needed support from relevant clinical bodies to implement the new testing guidelines including non-HIV specialties
- Revising GP contracts and financial incentives to ensure primary care plays its part in HIV testing and diagnosis
- Training for healthcare professionals, particularly non-HIV specialists, to identify risk, early symptoms of HIV infection and how to offer a test sensitively
- Agreeing audits in line with relevant standards
- Ensuring access to appropriate follow-up treatment and integrated care pathways for everyone in the UK diagnosed with HIV, irrespective of setting of diagnosis or residency status.

The NHS has national screening programmes which target people who are at increased risk of specific conditions, such as Chlamydia in young people under 25 years old. National screening programmes ensure resources are targeted at those most likely to benefit, and can save the NHS money that would otherwise be spent in treating advanced conditions and the complications caused by late diagnosis. A National Screening Programme for HIV, based on the new national testing guidelines, would be immensely effective in ensuring NHS bodies implement the relevant recommendations.

New testing technologies

New testing technologies that enable rapid and accurate HIV testing are increasingly becoming available in the UK. There are now tests where the initial result can be obtained within 20 minutes of their being performed. Other tests such as fourth generation assay tests – which are common in the UK – can detect HIV 12 days after infection by testing for both HIV antibodies and p24 antigens simultaneously and can provide a reliable result within one month of infection. This means there is no longer a need to wait for a three month 'window period' before getting tested. National testing guidelines state that it is reasonable to expect universal provision of these assays, although they are currently not offered by all primary screening laboratories.

Primary HIV infection

New testing technologies mean there is even less reason for people to wait to be tested. Although some people do not experience any symptoms of HIV infection until after many years of living with the virus, the majority of people with HIV do show some symptoms soon after infection. Symptoms usually develop about 10 days after infection. These symptoms occur in between 70 and 90 per cent of people during this time. This is often called primary HIV infection.[9] Such symptoms disappear after two to three weeks and then a person can seem healthy for a number of years. The most common symptoms of primary HIV infection are fever, rash and severe sore throat all occurring together. This triad of symptoms is very unusual and should indicate the need for an HIV test.

Benefits of testing early

New testing messages are needed that reflect current knowledge, technology and services, and that emphasise the health benefits of early diagnosis. Knowing early means that people can be evaluated for treatment even before other symptoms appear. Generally, the earlier treatment is started the more effective it will be. Current treatment guidelines in the UK, Europe and US now recommend starting antiretrovirals at a CD4 cell count of 350 (cells/mm^3). This reflects evidence that patients who begin treatment earlier have a reduced risk of serious illness and death compared to those starting treatment later.[10, 11] This means most people who start treatment early can live long, healthy and active lives.

9: For further information see NAT's report *Primary HIV Infection* at www.nat.org.uk.

10: Robbins et al (2009) 'Incomplete Reconstitution of T Cell Subsets on Combination Antiretroviral Therapy in the AIDS Clinical Trials Group Protocol 384', *Clinical Infectious Diseases*, 48: 350-361.

11: aidsmap (2008) *Benefit of starting HIV treatment early outweighs the risk of toxicities, SMART study shows*, www.aidsmap.com.

There are also wider public health benefits. People living with HIV who are diagnosed and on treatment are less infectious and therefore less likely to pass the virus on to others. Research findings also show that knowledge of HIV status is a powerful motivator for behaviour change. People with positive test results change towards safer sexual behaviour.[12, 13] One observational study also found people who are aware of their positive HIV status are not only more likely to practice safer sex, but seek medical care and plan for the future.[14]

Home testing

Innovative testing strategies for HIV are also needed for those who are unwilling or unable to access clinic-based services. Common barriers to testing in healthcare settings include privacy concerns, stigma, transportation costs, long waiting times and restricted clinic opening hours. Reliable and accurate home sampling and self-testing kits for HIV could be an important part of testing strategies in the UK. These types of tests could offer greater privacy and convenience for individuals. While home sampling for HIV is legal in the UK, kits are currently only available privately. Pilots of home sampling kits fully integrated within NHS sexual health services could increase uptake of testing and yield important information about the feasibility and effectiveness, including cost-effectiveness of offering home sampling kits through the NHS.

12: US Centres for Disease Control and Prevention (2004) 'High-risk sexual behaviour by HIV-positive men who have sex with men 2000-2002', *Morbidity and Mortality Weekly Report*, 53:891-894, www.cdc.gov.

13: Shisana et al (2004) *Does knowing one's HIV status matter in HIV prevention?* International AIDS Conference, Bangkok, abstract ThOrC1414.

14: US Centres for Disease Control and Prevention (2000) 'Adoption of protective behaviours among persons with recent HIV infection and diagnosis – Alabama, New Jersey and Tennessee', *Morbidity and Mortality Weekly Report*, 49:512-515, www.cdc.gov.

Priorities for action

Priorities for action

It is clear that we have seen real advances in HIV testing in the UK. However, far too many people remain undiagnosed, which has serious implications for both individual and public health. To transform society's response to HIV testing, changes we would like to see in the next four years include:

- **A transformation in testing culture with annual testing becoming the norm for sexually active gay and bisexual men and a significant increase in the numbers of African men and women having had an HIV test.**

Priorities for action include:	With leadership from:
A review of existing testing messages to ensure they reflect current knowledge, technology and services and that there is an appropriate emphasis on the benefits of early and repeat testing	HIV sector
New HIV testing campaigns integrated into *Making It Count* and *The Knowledge the Will and the Power* that emphasise to gay and bisexual men and black Africans the health benefits of early diagnosis, the value of regular testing for those with multiple partners, possible symptoms of early HIV infection and how much easier it is becoming to access HIV tests and receive reliable results	Government, CHAPS/NAHIP partners
Information on the importance of at least annual testing for sexually active gay and bisexual men	HIV sector, gay media
Information on the importance of early testing for sexually active black African men and women	HIV sector, black African media

- **A significant reduction in the proportion of people diagnosed 'late' and as a result a reduction in early deaths amongst HIV positive people.**

Priorities for action include:	With leadership from:
A review of existing testing messages to ensure they reflect current practice and that there is an appropriate emphasis on the benefits of early testing	HIV sector
Increased and sustained funding for testing initiatives to reduce undiagnosed HIV	Government
Improved data collection to support HIV testing particularly around incidence (e.g, STARHS to establish recency of infection)	Public health authorities
A survey of commissioning for HIV testing activities	HIV sector
Development of guidelines for commissioners in assessing local HIV testing need	Commissioners
Adoption at regional and local level of targets to reduce late diagnosis, with strategies and resources to meet those targets	Strategic Health Authorities
Information on primary HIV infection available to those at risk and taken into account by 'gatekeeper services' such as NHS Direct, out-of-hours GP services and sexual health advice lines	HIV sector, gatekeeper services

Consistent HIV testing that uses the latest technologies across all medical specialties when people present with relevant risks, conditions or symptoms.

Priorities for action include:	With leadership from:
Training for relevant health professionals so they recognise the symptoms of HIV infection, including early stage symptoms	Professional health bodies, healthcare training bodies
An audit of labs conducted to assess consistent use of latest testing technologies including the fourth generation assay test	Government, public health authorities, HIV sector
Include an HIV testing requirement in Provider Service Specifications for relevant secondary care specialties such as TB	Commissioners

A significant increase in the number of HIV tests performed outside sexual health and antenatal clinics, particularly in GP surgeries, community settings and from home sampling kits.

Priorities for action include:	With leadership from:
Consider what aspects of the new national HIV testing guidelines could be adopted as a National Screening Programme for HIV	National Screening Committee
GP contracts and financial incentives revised to make sure primary care plays its part in improving the nation's sexual health, including HIV testing and diagnosis	Government
Increase levels of HIV testing in primary care with GPs confident in taking a sexual health history and offering and performing an HIV test	Government, Royal College of GPs, PCTs
Agree targets and audits in relation to roll-out of HIV testing and diagnosis in primary care	Professional health bodies
Piloting of home sampling kits fully integrated within an NHS sexual health service	PCTs, local HIV services
Introduction of blood-based home sampling for HIV in the UK to increase even further the reliability of home sampling test results	Private sector
Amend the *HIV Testing Kits and Services 1999 Regulations* to permit and regulate self-testing kits which would allow the Government to ensure proper quality control and management of self-testing	Government
Ensure that manufacturers of any self-tests for HIV provide access to post-test counselling and links to local sexual health networks as an integral part of their testing service	Government, regulatory agencies

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

www.nat.org.uk

About NAT

NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expert advice and practical resources. We campaign for change.

SHAPING ATTITUDES.
CHALLENGING INJUSTICE.
CHANGING LIVES.

All NAT's work is focused on achieving four strategic goals:

- Effective HIV prevention
- Early diagnosis of HIV through ethical, accessible and appropriate testing
- Equitable access to treatment, care and support for people living with HIV
- Eradication of HIV-related stigma and discrimination

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The printing of this document was made possible as a result of the generous support of Gilead Sciences.

National AIDS Trust is a registered Charity No. 297977 and a Company Limited by Guarantee (registered in England and Wales) No.2175938. Registered office: Target Winters Ltd, 29 Ludgate Hill, London, EC4M 7JE

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