

TRANSFORMING
THE UK'S
RESPONSE
TO HIV



October 2010

HIV: an Agenda for Action



Foreword

HIV is a global health challenge, with over 33 million people infected and around 2 million deaths a year from AIDS. There needs, of course, to be an international, well-resourced response and the UK has been at the forefront of such efforts. What must not be forgotten, however, is that the UK itself has an HIV epidemic, concentrated in specific communities, such as gay men and black African communities, but also beginning to be felt more widely. By the end of 2011 there will be 100,000 people living with HIV in the UK.

NAT (National AIDS Trust) is publishing this 'Agenda for Action' for the UK because, whilst we have much to be proud of in our national response to date, more can and should be done to address HIV. All of us have a part to play – individuals, businesses, trade unions, civil society, faith organisations, healthcare professionals, to name a few. But with a new Parliament and Government we particularly wish to bring HIV to the attention of our politicians and decision-makers as a health condition which demands political action.

This document sets out both what our key aims should be if we are to address HIV effectively in the UK, and also the practical actions to be taken to achieve those aims. We are asking you to pledge to 'act' on this Agenda, and make a real difference.



Deborah Jack, Chief Executive, NAT

HIV in the UK today

By 2011 over 100,000 people in the UK will be living with HIV. Over a quarter of people with HIV do not know they have it.

The two communities most affected are gay and bisexual men, and black African men and women – together they account for approximately three quarters of all people in the UK with HIV. There are, in addition, elevated rates of HIV amongst

injecting drug users. Each year also sees increasing numbers of white heterosexual men and women diagnosed with HIV.

Just as who is affected by HIV changes over time, so does the age range. Diagnosis in the over 50s has increased 234% in the last decade, and over 50s now account for approximately 20% of people accessing HIV care in the UK.

Our services and policies must adjust to meet the HIV-related needs of many older people.

London accounts for half of all people with HIV but there are concentrations in places such as Manchester and Brighton, and a growing prevalence across the country.

Treatment for HIV is now very successful and people diagnosed in time can have a life

expectancy approaching normal. They can work, form relationships, have families, play sport; in short, live a full and active life. But HIV remains a serious, incurable condition resulting in increased illness for many, and requiring, once begun, lifelong treatment with sometimes debilitating side effects.

Aim: To ensure that there is a national strategic approach across the UK to tackling HIV

In 2001 all countries, including the UK, made a commitment at the United Nations to have a national strategic approach to combating HIV. According to the UN the national strategy must confront stigma and discrimination, promote human rights, be genuinely multisectoral, and address prevention, treatment, care and support, respecting the right to the highest attainable standard of physical and mental health.

In England these obligations are discharged through the National Strategy for Sexual Health and HIV. However, the strategy ends in 2010. It has provided the strong, national leadership which is essential for an effective response to HIV, and this must be continued.

The HIV epidemic in England is significantly different from that of ten years ago when the existing strategy was launched. There have been considerable developments in HIV testing and prevention, in treatment, in who is affected by HIV, in the organisation of the NHS and social care, and in the rights of people living with HIV. Additionally, following the recent changes to the political landscape and the increased devolution of decision making powers to a local level, a new national approach is now essential.

Scotland, Wales and Northern Ireland have all recently agreed strategic approaches for the next few years to address HIV in devolved policy areas.

ACTION

- ▶ **Develop a strategic approach to HIV across the UK, and a national strategy for England, which complements those in place for Scotland, Wales and Northern Ireland**
- ▶ **Provide in the national strategies for strong and accountable leadership and make certain there is cross-departmental commitment to implementation**

Aim: To reduce rates of HIV transmission through effective prevention

Every year approximately 7,000 people are diagnosed with HIV in the UK, three times more than ten years ago. Experts agree that we have not yet succeeded in reducing rates of HIV transmission.

The last decade has seen increasing numbers of people infected with HIV in the UK at the same time that funds for HIV prevention at a local level have been neglected or cut. This is because HIV prevention has not been a clear national public health priority, nor effectively incentivised locally.

The proportion of people able to identify the main ways in which HIV is transmitted has significantly declined since 2000. Education about HIV in schools is patchy

at best, with too many young gay men being denied essential information to enable them to avoid HIV transmission. Risk-taking behaviours amongst the groups most affected by HIV remain high.

Effective prevention will save considerable amounts of money. For each HIV infection prevented, between £280,000 and £360,000 is saved in lifetime healthcare costs. So, if we had prevented the HIV infections acquired in the UK and diagnosed in 2008, we would, over time, have saved £1.1 billion to the public purse. On top of this we must add the costs of social care, benefits payments, the impact on the economy of lost working hours, and of further onward HIV transmission.

ACTION

- **Recognise HIV as a key issue for public health and prioritise it within the new Public Health Service**
- **Develop local and national HIV prevention programmes that influence behaviour change**
- **Ensure Sex and Relationships Education is taught to all children and specifically includes teaching about HIV and appropriate acknowledgement of same-sex relationships**

Aim: To significantly reduce the number of people with HIV who are diagnosed late

55% of people with HIV are currently diagnosed after the point when they should have started their treatment, and 32% at a point when their immune system is seriously impaired.

Being diagnosed late significantly increases the likelihood of serious illness and early death. 73% of people with HIV who died in the UK in 2008 had been diagnosed after the point when

their treatment should have begun. By contrast, if diagnosed and treated in time, people with HIV can now look forward, on average, to near normal life expectancy.

Late diagnosis also has serious public health implications. Undiagnosed and untreated, the likelihood of someone with HIV infecting others rises significantly. Earlier diagnosis enables people to protect themselves and others, and effective treatment reduces infectiousness.

Despite the unarguable benefits of early diagnosis, and improvements in testing technology which make it much easier

and quicker to test for HIV, there are repeated failures to diagnose HIV across the NHS, with symptoms and indications of HIV being ignored or missed. The UK National Guidelines for HIV Testing set out recommendations for HIV tests to be far more widely offered across a range of healthcare and other settings – these recommendations must be implemented if we are to reduce late diagnosis.

ACTION

- ▶ **Commission HIV testing across the NHS in line with the UK National Guidelines for HIV Testing**
- ▶ **Train relevant healthcare workers across the NHS to test for HIV as recommended in the UK National Guidelines for HIV Testing**

Aim: To address the current failings in treatment, care and support for people living with HIV

HIV is no longer a death sentence. HIV treatment is now more effective than ever and people with HIV can live long and active lives, managing their HIV as a long term condition.

However, the reality for far too many people with HIV is one of constant struggle. Severe poverty, an increased likelihood of mental health problems, high rates of unemployment, and uncertain immigration status are just some of the difficulties faced by many people with HIV.

People living with HIV require care and

65,320 people with diagnosed HIV accessed care in the UK in 2009.

This is a 7% increase from 2008 and 250% from 2001.

support to help them come to terms with their diagnosis, to live with stigma, to deal with disclosure, to adhere to treatment, and remain in or return to work. Good social care and psychological support are essential, but they are not consistently

provided across the country to agreed, high quality standards.

Those within the immigration system often face problems such as charging for treatment, destitution, treatment interruption or delay. This not only puts their health at risk but also poses a threat

to wider public health.

Prisoners and other detainees with HIV also need special attention to ensure their treatment and care is maintained to appropriate clinical standards. Too often instead their needs are neglected.

ACTION

- ▶ **Provide HIV treatment to anyone in the UK who needs it without any interruption, delay or deterrence**
- ▶ **Meet the psychological support needs of people living with HIV through the provision of high quality, accessible services consistent with agreed national standards**
- ▶ **Ensure all people living with HIV have access to social care services capable of meeting their needs**
- ▶ **Put in place fair and efficiently administered benefits processes which are well informed about HIV, and appropriately support those people with HIV who are able to work, and those who are not**

Aim: To make rights, equality and respect a reality for people with HIV in the UK

Over the years great strides have been made towards promoting equality in the UK, including for people with HIV. However, HIV-related stigma and discrimination remain a serious challenge today.

One in three people with HIV say they have experienced discrimination because of their HIV status. Discrimination occurs in many settings and can have a devastating impact on people's lives. Faced with stigma and discrimination people can become marginalised and socially isolated, and may have greater difficulty managing their health condition and safer sex.

The Government must take the lead in combating HIV stigma and discrimination by eliminating them from public services, which, at present, are where people with HIV are most likely to encounter stigma and discrimination.

**If you would like to sign up to
HIV: An Agenda for Action
please email:
action@nat.org.uk**

ACTION

- ▶ **Train and educate frontline staff in key public services, such as health, social care, police and education, so that people with HIV no longer experience HIV stigma and discrimination when accessing such services**
- ▶ **Put the Equality Act specific duties into effect as soon as possible, with those for the Department of Health, Home Office, Department of Education and Department of Work and Pensions coordinated to explicitly address HIV equality issues**
- ▶ **Review and appropriately revise outdated occupational exclusions for people living with HIV**
- ▶ **Raise public awareness of HIV, so as to end misconceptions and create a well-informed, supportive society**

Aim: To deliver effective commissioning of HIV that addresses local need

It is vital that services are able to meet both the needs of people living with HIV, the needs of those groups most affected by HIV, in particular gay and bisexual men, and black African communities, and the wider public health needs of the local population. In order to achieve this, these services must be commissioned effectively, using good quality, accurate data and expert knowledge.

At a time of major change in how healthcare,

social care and public health interventions are delivered, it is important to maintain the quality and equity of current services, and indeed use opportunities to improve them. This will require agreed, high quality standards and patient pathways. As important will be training on HIV for the new Commissioners and clinicians involved in planning HIV services, and effective collaboration in the interests of patients and the public.

ACTION

- ▶ **Maintain comprehensive and independent HIV surveillance data to ensure Commissioners are able to clearly identify need and allocate resources accordingly**
- ▶ **Develop, at the national level, agreed health outcomes for HIV against which local performance can be consistently measured**
- ▶ **Ensure HIV services are commissioned at an appropriate level and with the required expertise to ensure equitable access to high-quality services**
- ▶ **Integrate effectively the work of the commissioning bodies, i.e. local authorities, GP consortia and the NHS Commissioning Board**



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 in order to halt the spread of HIV
- ▶ 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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