

21 YEARS OF
SPEAKING OUT
CHANGING LIVES



HIV

...all grown up?



Responding to the UK HIV epidemic in 2008

HIV ...all grown up?

Foreword

NAT's twenty-first birthday provides an ideal opportunity to take stock of the HIV epidemic in the UK.

The challenges today are very different from those we faced in 1987 when NAT was established. HIV was often treated with fear, and even hysteria, back in the 1980s when little was understood about the virus.

Much of that early ignorance may have dissipated, but do we as a society really know what HIV in the UK looks like in 2008? Have we kept pace with the rapid changes in who are affected, with treatment options and effectiveness, with the emerging daily life issues for those with HIV?

“A twenty-first birthday is the right time to ask – are we all ‘grown up’ in our response to HIV in the UK, knowledgeable, thoughtful, determined?”

This important report sets out a very clear and comprehensive picture of HIV in the UK after two decades of significant change and development in the epidemic. It highlights where real progress has been made – and identifies some of the continuing and new challenges we face in our response.

It also sets out a clear agenda for action.

Deborah Jack, Chief Executive, NAT October 2008

The number of people living with HIV in the UK continues to rise...

- More than 80,000 people are now living with HIV in the UK.
- New HIV diagnoses continue to be well over 7,000 a year – significantly higher than the number ten years ago (in 1998 there were 2,864 diagnoses).
- The number of people being infected with HIV in the UK is rising.
- People with HIV are now living much longer and healthier lives as a result of improved treatments (known as anti-retroviral therapy, or ‘ART’).

... we estimate that there will be more than 100,000 people living with HIV in the UK by the end of 2010.

The profile of people diagnosed with HIV is changing.

- More heterosexuals are now diagnosed each year with HIV than gay and bisexual men - a significant proportion of these are infected in other countries but are only diagnosed when they are in the UK.
- The age profile of people living with HIV is changing – over 1 in 13 people with HIV are now over the age of 55 and in 2007 more than 1 in 10 new diagnoses were in young people under 24.
- In 2007 20,600 HIV positive Black Africans were receiving care in the UK, compared to just 2,960 in 1998.
- The prevalence of HIV amongst Black Caribbean communities in the UK is three times higher than that of the general population.
- There has been an increase in HIV outside London. Although London is still home to about half of all people living with HIV in the UK, the number of people living with HIV is increasing in every region of the UK.
- In the last five years we have seen increases in the number of injecting drug users diagnosed with HIV, and raised levels of HIV transmission.

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TRANSFORMING
THE UK'S
RESPONSE
TO HIV

Over 90% of HIV positive people in the UK live in England.

PREVENTION

In the early days of the HIV epidemic, the UK was at the forefront of HIV prevention.

We led the way in introducing targeted prevention activities (e.g. condom distribution) aimed at the communities most affected by HIV.

We were one of the first countries to introduce needle exchanges for injecting drug users.

...but HIV prevention is no longer treated as a priority in the UK

NAT research shows that despite the growing numbers of people living with HIV in the UK over the last ten years, investment in HIV prevention has declined in real terms.

Although there are well-established national HIV prevention programmes, most funding has now been devolved to the local level, where there are no 'must-do' targets or incentives linked to HIV prevention.

There is clear evidence of HIV prevention budgets being diverted locally to support acute care and address more general budgetary deficits.

Current drug policy and practice is extremely variable across the four nations and frequently does not give adequate emphasis to protecting injecting drug users from HIV infection.

“ ‘The end of centrally ring-fenced funding in 2002 placed the responsibility to identify and prioritise HIV prevention needs and allocate funding at a local level - six years on, we still have a lot to do to get consistent investment across the country in the long-term benefits of HIV prevention.’

Peter Nieuwets, Commissioning Manager, South East Coast Specialised Commissioning Group

UK prisons do not offer clean needles to allow prisoners who are injecting drugs to protect themselves from HIV infection, and access to condoms in prison is variable and often poor.

There has been no sustained investment to support people living with HIV in the UK in reducing risks of onward HIV transmission to their sexual partners.

Government commitment to new prevention technologies is focused on developing countries, ignoring the benefits they could bring to people in the UK.

➔ **Condoms are not available at all in prisons in Northern Ireland.**

Four things we want to see in four years' time:

- **A significant rise in HIV prevention expenditure across the UK to meet the increased prevention needs of all communities affected by HIV.**
- **An increase in the proportion of gay and bisexual men, and of African-born men and women, who consistently use condoms for penetrative sex.**
- **Injecting drug users having full access to needle exchange, condoms, HIV and hepatitis testing, methadone maintenance therapy and harm reduction advice, both in the community and in prisons.**
- **Specific budgets allocated to support people living with HIV in maintaining good sexual health and preventing onward transmission.**

Priorities for action:

- The establishment of a prison needle exchange pilot in the UK.
- Effective local needs assessments to be conducted in relation to HIV prevention for all affected communities.
- Creation of an economic model which identifies the lifetime cost of a new HIV infection to illustrate the benefit of investment in effective prevention programmes.
- Greater involvement of a wider range of local and national stakeholders in the national HIV prevention programmes to ensure integrated and effective prevention work.
- Integration of prevention into broader care and support for people living with HIV.
- Early clarity over national regulatory and licensing arrangements for new prevention options that, when developed, can also be used in the UK.

“ ‘Ongoing, brief prevention counselling is a cost-effective measure that can be incorporated into routine care for HIV-positive individuals. The HIV outpatient clinic is an ideal setting for the delivery of this intervention to large numbers of individuals with HIV in the years following their HIV diagnosis.’

Centre for Disease Prevention and Control, US

TESTING

We have seen real advances in HIV testing.....

HIV tests can now diagnose HIV as early as 12 days after infection.

There are also tests available where the initial result can be obtained within 20 minutes of the test being performed.

There has been a significant increase in the uptake of HIV testing in ante-natal services.

Waiting times for appointments in sexual health clinics have dropped significantly and many more tests are now being offered and accepted in these clinics, encouraged by the national strategy for sexual health and HIV.

“In the 2006 Gay Men’s Sex Survey 62% of UK gay men said that they had ever had an HIV test. That compares with over 85% in Australia. We need as a priority more widespread and more regular HIV testing amongst gay men in the UK.”

Dr Valerie Delpech, Health Protection Agency

...but too many people remain undiagnosed

One in three people living with HIV in the UK don’t know that they are infected, putting both their own health and that of their sexual partners at risk.

Undiagnosed HIV is estimated to be responsible for around half of all new infections.

HIV home sampling tests are currently only available privately in the UK.

There is only very limited access to HIV testing outside sexual health services and ante-natal care.

HIV testing rates amongst gay and bisexual men, and amongst African men and women, are still far too low, with only just over half ever having had an HIV test.

Symptoms of HIV infection are frequently misdiagnosed by healthcare professionals who are not HIV specialists.

One in three people are currently diagnosed ‘late’ - after the point at which they should have begun ART - which seriously increases the likelihood of a poor response to treatment and of early death.

Four things we want to see in four years’ time:

- **A change in testing culture – with annual testing becoming the norm for gay and bisexual men and over 80% of African men and women having had an HIV test.**
- **A reduction in the proportion of people diagnosed ‘late’ from 34% (the current figure) to at most 20%, and as a result a reduction in deaths amongst HIV positive people.**
- **Consistent testing offered across all medical specialties when people present with relevant conditions or symptoms.**
- **A significant increase in the number of tests carried out outside sexual health and ante-natal clinics – specifically in GP surgeries, community settings and from home sampling kits.**

Over 40% of Black African men in the UK are diagnosed late.

Priorities for action:

- Sustained funding over the next four years for initiatives to reduce undiagnosed HIV.
- GP contracts and financial incentives revised to make sure primary care plays its part in improving the nation’s sexual health, including in HIV testing and diagnosis.
- Training for relevant health professionals so that they recognise the symptoms of HIV infection.
- Piloting of home-sampling kits fully integrated within an NHS sexual health service.
- A review of existing testing messages to ensure that they reflect current practice and there is an appropriate emphasis on the benefits of early testing.
- New HIV testing campaigns that emphasise 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.

“It’s so disheartening that after more than 20 years of HIV, doctors are still missing the diagnosis in a substantial number of cases. Whether by ignorance, embarrassment or judgementalism this is unacceptable.”

Dr William Ford-Young, General Practitioner

TREATMENT

HIV treatment has improved enormously....

Combination anti-retroviral therapy (ART) was first introduced in the UK in 1996 – and from a single drug option then, we have now moved to twenty-four different approved treatment options today.

Whilst treatment options increase, the annual cost of treatment for most people is decreasing.

Side-effects of treatment are far better understood and managed.

ART also has a preventative benefit. Effective treatments reduce the level of HIV in body fluids (viral load) and therefore reduce the risk of someone on treatment passing HIV on.

HIV is the only serious communicable disease that is not treated free of charge in the UK irrespective of a person's residency status. And the people who are denied free treatment are often those who can least afford it.

“Over the past 21 years, we have seen HIV treatment improve from complex and, often, toxic anti-HIV drug regimens – where someone living with HIV needed to take up to two dozen pills three times a day, often with food restrictions – to much easier-to-take and -tolerate combinations often consisting of one or two drugs, taken either once or twice a day with or without food.

Edwin J Bernard, Editor HIV Treatment Update, NAM

..... but not everyone in the UK benefits from the treatment available

Not everyone with HIV in the UK is entitled to free HIV treatment due to recent changes in charging regulations relating to non-UK residents.

Despite the benefits of ART, a significant number of people make the decision not to start treatment when recommended by their doctor.

Many people are still being diagnosed too late to fully benefit from treatment.

If ART is not taken as directed, this can result in drug-resistance – yet people often don't get the ongoing support they need to help them adhere to treatment.

Four things we want to see in four years' time:

- Everyone living with HIV in the UK, irrespective of residency status, should be accessing, as clinically recommended, free HIV treatment from the NHS.
- Treatment decisions continuing to be based on clinical appropriateness, not cost.
- Relevant government policies (for example on immigration and on housing) which fully support adherence to treatment by people living with HIV.
- Continued investment in research and development of new treatment options for people living with HIV.

Adherence is the single most important factor for successfully treating HIV, and yet the optimal adherence required for anti-HIV therapy (95%) is much higher than levels that might be adequate for treating other types of long-term conditions.

Priorities for action:

- HIV must be exempted by the Government from NHS charges.

“Anti-retroviral therapy (ART) is one of the most cost-effective medical interventions there is.

If we deny [people] that cost-effective intervention they will simply present in Accident & Emergency and then in intensive care with greater and greater frequency and in a matter of .. days cost the NHS as much as a year's ART.'

Yusef Azad, Director of Policy and Campaigns, NAT, giving evidence to Parliament's Joint Committee on Human Rights

LIVING LONGER

HIV is now a long-term condition for most infected people in the UK

There has been a significant increase in life expectancy for people diagnosed with HIV.

Many people with HIV are stable in their condition and only need to see their clinician three times a year for routine checks.

“It is gradually dawning on people who never thought they would get to retirement that they now have to start thinking about it.”

Paul Ward, Terrence Higgins Trust

...but this raises new challenges and questions

A generation of young people born with HIV are growing up.

We have an ageing population of people living with HIV but older people's services have a limited understanding of HIV and there is much more to learn about the interaction between HIV and the ageing process.

People with HIV are more susceptible to certain cancers, to liver and kidney disease and to cardiovascular disease – either because of the side-effects of treatments or as a result of the impact of HIV itself on the immune system.

There is an increased need to consider the reproductive rights of people living with HIV. There is significant variation across the country in affordable and accessible options for safe conception.

The transition from children to adult services and from adult to older people's services is not well managed for people living with HIV.

Financial services still do not treat HIV appropriately as a long-term condition. Nobody living with HIV in the UK can currently buy life insurance despite immense improvements in life expectancy.

“Growing from a teenager into an adult can be a difficult time for anyone, but if you are living with HIV there is even more to deal with. We hear from many young people that we work with that they find the system bewildering and they often do not have enough opportunities to ask questions and ensure they are fully informed about HIV, particularly around their treatment regimes.”

Nimisha Tanna, Body & Soul

Four things we want to see in four years' time:

- **Care services for older people delivered that meet the needs of those living with HIV, without stigma or discrimination, and with respect and understanding.**
- **All people living with HIV having informed and free choices in relation to conception.**
- **Fair and accessible financial services, including insurance, provided for people living with HIV that reflect the advances in treatment/condition management.**
- **A clear strategy for meeting the needs of young people living with HIV as they grow up.**

“Sperm-washing is recommended to protect the uninfected female partner of an HIV-positive male, but is expensive, currently only provided by a few centres and patient-funded in over 50% of cases.”

‘Management of HIV infection in pregnant women’
BHIVA 2008

Priorities for action:

- Appropriate best practice and resources developed and agreed for the care of older people living with HIV in all settings, including those receiving domiciliary care and those in residential accommodation.
- Commitments in the NHS Next Stage Review to improve personalised care for long-term conditions must explicitly include people living with HIV.
- Increased collaboration between HIV clinicians and those from other relevant specialties (for example, oncology, cardiovascular disease) and involvement of other secondary care specialists in clinical networks.
- A review undertaken by the Association of British Insurers in collaboration with the HIV sector to ensure that the UK is at the forefront of best practice in provision of financial services to people living with HIV.

➡ **A recently published study in The Lancet¹ found that the average life expectancy of a 20-year old diagnosed with HIV between 2003 and 2005 had increased 13 years compared with those who began therapy in the late 1990s.**

WIDER CARE

Non HIV-specialist health and social care frequently fails to meet the needs of people living with HIV

People with HIV have a range of wider health needs, just like anyone else, but HIV, and its implications for other health conditions, are poorly understood by most health and social care providers not working directly on HIV.

Increasingly, HIV clinics provide only immediate HIV-related care and HIV positive people must go to their GP or other hospital departments for healthcare.

People living with HIV are at higher risk of mental health problems but there are few mental health services with expertise in HIV-related issues.

“**‘HIV social care, support and information services are often seen as secondary to treatment and care budgets. They are constantly under threat and their survival often depends on the negotiating power of commissioners.’**

The growing challenge - A strategic review of HIV social care, support and information services across the UK²

▶ **Little information is held on how the AIDS Support Grant is being spent and there have been reports of this funding being diverted at a local level for other purposes.**

There is no guidance or agreed best practice for the social care of people living with HIV and, despite increases in the AIDS Support Grant, social care and support for many people living with HIV is too often inadequate.

In much of the UK, healthcare and social care for people living with HIV are not effectively integrated, either in commissioning or in delivery of services.

Public bodies are meant to promote the equality and social inclusion of people with HIV through disability equality schemes, and should involve people with HIV in their development but an NAT review revealed that this rarely happens in practice.

“**‘All young people are to have access to age appropriate services which are responsive to their specific needs as they grow into adulthood.’**

National Service Framework ‘Key Issues for Primary Care’ 2004

Four things we want to see in four years’ time:

- ▶ **All HIV clinics providing comprehensive psycho-social care for service-users to support management of HIV and wider sexual health, adherence to medication and the broader well-being of people with HIV.**
- ▶ **Transparent and accountable use of the AIDS Support Grant in England and effective arrangements in place to meet the social care needs of people living with HIV in all four nations.**
- ▶ **Joint strategic needs assessments undertaken by local authorities and primary care trusts which are based on current and comprehensive information so as to deliver co-ordinated and appropriate health and social care services for people living with HIV.**
- ▶ **People with HIV always meaningfully involved in the planning of their care and support, and in development of services which affect them.**

Priorities for action:

- ▶ Commissioners and providers of care services for older people to engage on the issue of HIV.
- ▶ Best practice in provision of psycho-social care and support for people living with HIV identified and agreed for the UK.
- ▶ Production of clear guidance for public bodies on involvement of people living with HIV in development of future equality schemes, with monitoring arrangements to ensure involvement takes place, is appropriate and makes a difference.

“**‘On the two occasions I have met my GP, he has never asked me about my HIV. Although he is aware of my HIV status, he fails to understand the significance that HIV has on my life and has made decisions about my health with no reference to my HIV or its effect. How is this giving me a better health service?’**

Tim – HIV positive man

POVERTY

Too many people with HIV are living in poverty, and experiencing health inequalities

Data from the Crusaïd Hardship Fund suggests that one in three people diagnosed with HIV in the UK have experienced poverty at some time.

HIV positive people face significant barriers to employment, in particular stigma and discrimination. Less than half of people diagnosed with HIV are in paid employment.

Poverty affects significant numbers of people living with HIV across all groups, but there is particular disadvantage in employment, income and housing for Black African heterosexuals living with HIV.

In one survey of people with HIV 21% had experienced housing-related problems in the previous 12 months.³

“Increasing numbers of people living with HIV are applying to Crusaïd’s Hardship Fund because they do not have enough money to meet even their most basic needs. Employment offers a really important route out of poverty but too often HIV positive people face enormous barriers to finding work.”

Robin Brady, Crusaïd

Evidence shows that homelessness and poor housing significantly increase the likelihood of poor health and early death for people living with HIV.

Many people who were diagnosed with HIV before the advent of ART are finding themselves in a difficult economic position as a result of financial decisions they made when they expected to die in the near future.

A substantial number of people living with HIV rely on one or more benefit and there is a high level of anxiety about the impact of current benefit reform on HIV positive people.

Four things we want to see in four years’ time:

- ▶ **People living with HIV treated as a priority for access to social housing.**
- ▶ **A higher proportion of people with HIV in employment, and with an adequate income to meet, at the very least, their basic and health-related needs.**
- ▶ **For those people living with HIV unable to work, a benefits system which supports an appropriate standard of living to ensure they live healthily and with dignity.**
- ▶ **Incentives to work and to return to work which also recognise the barriers faced by people with HIV in entering the workforce, and the complex physical and psychological factors in managing such a long-term condition.**

“The stress of homelessness or inadequate housing makes things even more difficult for people living with HIV and compromises good medical care.”

Dr Jane Anderson, Homerton University Hospital

Priorities for action:

- ▶ Public health and equalities impact assessments conducted for planned and proposed benefits reform as it affects people with HIV.
- ▶ Funding for further qualitative and quantitative research into the employment experiences of people with HIV, identifying those factors which can encourage and sustain people with HIV in fulfilling paid employment.
- ▶ Continuation of funding for dedicated services to meet the housing needs of people living with HIV and introduction of training and guidance for housing professionals at all levels.

RIGHTS

There have been welcome improvements in legal protection for people living with HIV

Since December 2005 people living with HIV have had legal protection against discrimination from the point of diagnosis under the Disability Discrimination Act (DDA).

The DDA also places a duty on statutory bodies to promote disability equality.

...but other legal developments fail to respect the human rights of people living with HIV and people's rights are frequently ignored or undermined.

Since 2001 people have been prosecuted for transmitting HIV to their sexual partners. This development was a decision of the courts and contradicted stated government policy.

Police, prosecuting lawyers and judges have often demonstrated poor understanding of HIV when dealing with people living with HIV.

Prosecutions for 'reckless transmission' have resulted in stigmatising media coverage, and in a dangerous perception that responsibility for safer sexual behaviour lies only with people diagnosed with HIV.

“ ‘It is time to remove HIV stigma and fear from British policing. Myths and fears persist in the botched and heavy-handed police investigations of HIV transmission. The police can do far better.’

Chris Morley, George House Trust

Some people experience hate crime on the basis of their HIV positive status – for example, vandalism, threatening behaviour, harassment or assault – but the hate crime protections available in the Criminal Justice Act 2003 do not apply to people with HIV in the same way that they do to all other disabled people.

Increasingly people with HIV are faced with unreasonable demands to share information about their HIV status with others or have their status disclosed without their permission.

“ ‘HIV-related hate crime is still a feature of far too many lives, and we're not doing enough to deter it or to pass appropriate sentences. That is why my Member's Bill on offences aggravated by prejudice proposes full protection for all people living with HIV from the day that they are diagnosed.’

Patrick Harvie, Green MSP

Four things we want to see in four years' time:

- **An end to criminal prosecution for reckless transmission of HIV.**
- **Hate crime against people living with HIV treated as seriously by police, by prosecuting authorities and by the courts when sentencing as other hate crime against disabled people.**
- **The police, and professionals in the legal system and courts, effectively trained in HIV issues, both the basic biological and medical information, and also relevant social issues, including stigma and discrimination.**
- **Respect in society for the rights to privacy and confidentiality of all people living with HIV.**

“ ‘Prosecuting people for transmitting HIV is far more complex than a few demonising media headlines would suggest. Prejudice, fear and misconceptions all play a part in the cases and in turn are increased by them. We need to break that cycle of stigma.’

Lisa Power, Terrence Higgins Trust

Priorities for action:

- Executive action, in legislation if necessary, to ensure disability hate crime provisions on monitoring, reporting and sentencing are applied to HIV hate crime.
- Police forces across the UK to undertake equalities and occupational health training which covers HIV from both a biological and social perspective.
- Best practice guidelines agreed by the Association of Chief Police Officers (ACPO) to improve criminal investigations of HIV transmission.
- The equalities bench book for judges updated to ensure accurate and up-to-date information about HIV in a UK context.
- Development of guidance on the importance of confidentiality of HIV status for everyone working in health and social care, for employers and for those working within the legal system.

“ ‘44% of people in a survey of public attitudes to HIV said they would expect to be told if one of their colleagues was HIV positive.’

NAT 'Public Attitudes towards HIV 2007'

ASYLUM

Asylum seekers living with HIV have some of the greatest unmet needs

Migration to the UK has significantly changed the nature of the HIV epidemic since many people have come from countries with high HIV prevalence.

The immigration process is complex and raises a number of problems for those with HIV.

Asylum seekers are not allowed to work to support themselves or their families, but instead have to rely on benefits which are significantly lower than basic income support. This can have harmful impacts on self-respect and mental health and push people into near destitution and inappropriate economic dependence.

“Every ring of the doorbell, they’ve come to deport me, that’s what it feels like, the sight of a police car, are they looking for me, you know; that’s the life you have to live and definitely with the virus you don’t need that.”

HIV positive Ugandan woman, ‘My heart is loaded’⁴

“The average length of time between a migrant entering the UK and being diagnosed with HIV and accessing care is nearly five years. This refutes claims that people are arriving in the UK with the intention of accessing free NHS care.’

‘The myth of HIV-health tourism’,
NAT September 2008

Removal at short notice - either within the UK or out of the country - has repeatedly resulted in missed medication with serious consequences for the person’s health.

Despite the best efforts of many individual professionals, conditions in Immigration Removal Centres still fail to ensure consistent high quality treatment and care for those living with HIV.

There has been little attention paid to people living with HIV who are successful in their immigration application, supporting them as they become integrated as UK residents.

People with HIV are being deported to countries without accessible HIV treatment – the result will be their early deaths.

Four things we want to see in four years’ time:

- ▶ All asylum seekers who have been in the country for six months or more having the right to work and to study.
- ▶ All people who actually live in the UK, irrespective of their residency status, accessing all NHS primary and secondary care free of charge.
- ▶ An immigration system which maximises opportunities to link individuals into high quality and appropriate healthcare, including information on HIV risk and prevention, sexual and reproductive health, and HIV testing.
- ▶ No one deported with HIV to a country where they will not be able to easily access HIV treatment to maintain their health.

Priorities for action:

- ▶ The UK Border Agency must audit all its policies and processes to identify necessary improvements and ensure the immigration system supports the HIV-related needs of migrants to the UK.
- ▶ There should be an urgent review of current guidelines on employment rights of asylum seekers.

“Government policy unfairly restricts asylum seekers’ access to employment and training, as well as a range of other services. What asylum seekers want is to be able to work and pay their own way in the UK. The Government should allow asylum seekers to support themselves and their families, and contribute to the communities in which they are rebuilding their lives.’

Gemma Juma, Refugee Council

“I don’t want to be fed by the state, I want to feed myself and the money the state gives is not enough.’

HIV positive African man, ‘I want to survive, I want to win, I want tomorrow’⁵

4: Doyal, Anderson; Homerton University Hospital, Queen Mary London, Positively Women, THT

5: Doyal, Anderson, Apeteng; Homerton University Hospital, Queen Mary London, AHPN, THT

GAY MEN

Gay and bisexual men continue to be the community most affected by HIV in the UK.

There is high prevalence of HIV amongst gay men. Nationally it is estimated that one in twenty gay men have HIV but it is significantly higher in some areas.

There has been a worrying increase in diagnoses amongst young gay men but we still do not have sex and relationships education in schools which meets their needs.

“ ‘Gay men start smoking younger and smoke longer compared with straight men. Smoking is most common among men with HIV.’

Who's doing what? Drug and alcohol findings from the National Gay Men's Sex Survey 2008

Gay men have elevated health needs in other areas, for example around smoking, drugs and alcohol use, and mental health. These both undermine the health of HIV positive gay men, and their ability to manage their condition well. And for drugs and alcohol use, and poor mental health, there can be added risks of HIV infection.

There has been an increase in risk-taking behaviour amongst gay men.

In a recent study, a quarter of gay men with long-term health issues reported a mental or emotional health problem. Amongst gay men with HIV this proportion rises to three-quarters.

“ ‘Sometimes I got really angry about the fact that the teacher never mentioned gay people, but mostly I just felt as though it was my own fault for being this way.’

Blake S 2003 ‘Young gay men talking’

Four things we want to see in four years' time:

- **Compulsory sex and relationships education in all schools which includes appropriate reference to same-sex relationships and all schools implementing effective policies to address homophobic bullying.**
- **National gay men's health strategies developed and resourced in all four nations of the UK, with full involvement of gay men themselves - linking HIV and sexual health service provision with a wider range of services meeting gay men's needs (for example on smoking, mental health and drug use).**
- **A statutory duty on all public bodies to promote equality of lesbian, gay, bisexual and transgendered people.**
- **Increased engagement of the gay community on HIV-related issues.**

➤ **Approximately one in 10 gay men in London are infected with HIV, and in Brighton one in eight.**

Priorities for action:

- Ensuring the new Equality Bill delivers on the Government's commitment to a single equality duty which will include promotion of equality of lesbian, gay, bisexual and transgendered people.
- The departments of health in all four nations must begin a process to develop gay men's health strategies to guide policy, planning and investment and service delivery.

“ ‘Well my generation, we weren't there when HIV first came out, so we didn't see the full brunt of it. I know a lot of my friends have unprotected sex. HIV might be something at the back of your mind or a slight panic the next morning but really you think HIV is something that happens to someone else.’

Rob, 21, gay man, London

VISIBILITY

HIV is less visible than it used to be and public awareness is poor

There has been a significant decline in public knowledge of how HIV is transmitted over the last decade.

Some of the lowest levels of HIV knowledge are in London, where half of all people with HIV live.

Sex and relationships education is not a compulsory part of the national curriculum and there is only very limited, and biologically focused, information on HIV in many schools.

There is no consistent and structured school education on social aspects of HIV, for example the unacceptability of HIV stigma and discrimination.

Although media reporting of HIV is improving, inaccurate and sensational stories still appear - feeding myths and misconceptions about HIV and how it is transmitted.

There are very few public figures who are open about their HIV status, and currently no established characters living with HIV in mainstream soaps or television dramas.

“HIV is rarely covered in the media except in the context of Africa.... and when there is a story about the HIV in the UK it usually contains inaccuracies or demonises someone living with HIV. I want to see my life reflected in the media.”

Richard - HIV positive man

Recent newspaper headlines:

Women handed HIV death sentence from lover (Metro)

Hols Fiend Gives 6 Girls HIV. Asylum seekers Aids timebomb at caravan park (The Sun)

Mum's secret life as HIV siren (South London Press)

Thousands living in fear after health worker tests HIV positive (Daily Mail)

Four things we want to see in four years' time:

- **Significantly increased levels of public knowledge of how HIV is transmitted.**
- **An education system which teaches a new generation of young people about HIV within the context of compulsory sex and relationships education, but also addresses social issues such as stigma and discrimination.**
- **An end to inaccurate and sensational reporting of HIV in the media.**
- **Greater, and supportive, visibility for people living with HIV both in media and cultural representation, and in public life.**

Priorities for action:

- HIV should be more visible in sexual health information for the general public.
- Government action to make sex and relationships education compulsory in all schools.
- Effective training for all teachers delivering sex and relationships education which encompasses information on both HIV and same-sex relationships.
- Proactive initiatives to portray realistic HIV stories in the media, with the BBC and Channel 4 taking the lead as part of their statutory duty to promote disability equality.

In a recent NAT survey conducted by Ipsos MORI only 79% of respondents knew HIV was transmitted through unprotected sex between a man and a woman, compared to 91% in 2000.

STIGMA & DISCRIMINATION

Stigma and discrimination persist against people living with HIV

Whilst scientific understanding of HIV, and of how to treat it, has developed rapidly over the last two decades, social attitudes are changing much more slowly.

Many people living with HIV experience 'multiple discrimination' because, in addition to being HIV positive, they are gay or from a minority ethnic group or are an asylum seeker.

A recent NAT survey revealed that 69% of people feel there is still a great deal of stigma in the UK around HIV.

One in three people with HIV report having experienced discrimination.

Healthcare settings were the place where people living with HIV most frequently experienced discrimination.

There is evidence of discrimination in schools – with children as young as four being excluded because they are HIV positive.

'Of those who reported experiencing HIV-related discrimination, almost a half said this involved a healthcare worker including their dentist (25.3%) or primary care physician (17.4%).'

Elford J et al 'HIV-related discrimination reported by people living with HIV in London, UK'⁷



'Gay and bisexual men in our groups talked of an erosion of their benefits and their rights as people with HIV, allied with a sense that they were losing the support and understanding of the broader gay population.'

'Outsider status: Stigma and discrimination experienced by Gay men and African people with HIV'⁶

UK discrimination law fails to protect those who are perceived to be HIV positive even if, in fact, they are not, and those discriminated against because of association with HIV (for example relatives, carers, people who work on HIV issues).

People living with HIV are often nervous of accessing legal redress in discrimination cases, particularly fearing wider disclosure of their HIV status.

Stigma often occurs within the communities most affected by HIV – gay and bisexual men, and African men and women.

In England, despite the commitment of the national strategy for sexual health and HIV to address HIV stigma and discrimination, there is no cross-departmental action plan to address HIV stigma and no sustained allocated budget to support proven programmes.

Four things we want to see in four years' time:

- **An NHS free from HIV stigma and discrimination, treating people with HIV in every setting, including primary care, with professionalism, dignity and respect.**
- **An increase in successful legal challenges to HIV discrimination in courts and tribunals.**
- **Effective legal protections against HIV discrimination by perception or association and which also addresses multiple discrimination.**
- **Evidence of increased support for people with HIV amongst the communities most affected - gay and bisexual men and African communities.**

Priorities for action:

- The new Equality Bill should include provisions on discrimination by perception and association, and on multiple discrimination, as well as resolving current legal confusion over the nature of protections available for disabled people.
- The UK's departments of health must plan, resource and coordinate sustained education and training for all NHS staff to eradicate HIV stigma and discrimination from the NHS.
- Development of cross-departmental plans for each nation to combat HIV-related stigma and discrimination which include health, employment, education, immigration and community development.



'Discrimination also occurs at a national policy level. HIV is the only communicable disease not exempted from NHS charges for overseas visitors in England. Disability hate crime provisions exclude people living with HIV from their benefits. It was only with the advent of HIV that the courts decided that disease transmission could be prosecuted by the criminal law.'

Deborah Jack, Chief Executive, NAT

6: NAT/Sigma Research 2004

7: AIDS and Behaviour December 2007

KNOWLEDGE GAPS

There are still serious gaps in our knowledge and understanding of the HIV epidemic in the UK

The UK has one of the best HIV surveillance systems in the world, with further improvements being continually made. But our knowledge of rates of HIV infection occurring in the UK ('HIV incidence') remains limited.

There is very limited information on the extent to which HIV prevention activities in the UK are having an impact in reducing rates of HIV infection.

The last survey of rates of HIV and hepatitis in UK prisons was over ten years ago and we do not have data on HIV diagnosis and treatment or on HIV/hepatitis C co-infection in prisons.

We have only limited research on the health and wider life experiences (e.g. in employment, relationships) of people living with HIV in the UK.

There are significant gaps in social and behavioural research into the communities most at risk of HIV infection - gay men, African communities, injecting drug users.

“ ‘Poor, excluded, and often homeless and addicted, most prisoners have significant health needs and are particularly vulnerable to HIV and hepatitis. The last survey of HIV and hepatitis C in UK prisons was over 10 years ago. A new survey is needed to ensure prompt action on blood borne viruses.’

Juliet Lyon, Prison Reform Trust

“ ‘In Amsterdam since 1984 a cohort study of gay men has continually provided robust and significant data on sexual risk behaviour, epidemiology, psycho-social aspects, and statistical modelling revolving around HIV transmission and other HIV-related outcomes. Similarly, a cohort among injecting and non-injecting drug users has been active since 1985.’

See: www.amsterdamcohortstudies.org

Four things we want to see in four years' time:

- **Robust estimates for HIV incidence in the UK and development of agreed prevention indicators which allow us to track progress.**
- **Up-to-date knowledge both of HIV prevalence in UK prisons and of new infections occurring in prisons.**
- **Ongoing funding for social research into health-related behaviours and wider relevant issues amongst affected communities and people living with HIV.**
- **Structured evaluations consistently undertaken of UK prevention programmes and sharing of findings at a national, regional and local level.**

Priorities for action:

- STARHS (Serological Testing Algorithms for Recent HIV Seroconversion) testing rolled out for all HIV test samples to assess recency of infections.
- Disaggregated sexual health data collected for all UK prisons.
- Resources allocated to evaluation of UK prevention interventions, focussing on outcomes, as an integral part of service planning in order to create a strong evidence base.
- A national survey of rates of blood borne viruses (including HIV) in UK prisons to take place as soon as possible.
- A comprehensive review of recent and current HIV research in the UK, to identify key gaps in our current knowledge and research priorities to be addressed.

“ ‘Social and behavioural research into HIV must be given priority alongside the development of new drug treatments for the infection.’

Professor Jonathan Elford, City University, London

POLITICAL COMMITMENT

There is a lack of political commitment to HIV in the UK, and no clear strategic vision as to how to address HIV into the next decade

HIV remains one of the great challenges to the UK's public health and is profoundly linked to health inequalities.

Public health investment currently focuses on obesity, smoking and alcohol and drugs use, and far less on sexual health. And when sexual health is mentioned, HIV is too often sidelined or ignored.

As a stigmatised condition affecting often marginalised communities, there is a special and additional responsibility on the Government to maintain political attention on HIV in the UK.

There have recently been some signs of renewed political engagement on HIV – such as Gordon Brown's World AIDS Day message in 2007 and an increase in funds for the AIDS Support Grant – but there is little ongoing political attention to HIV in the UK.

There is no senior official charged with the national response to HIV who has access across all departments of state, and can champion HIV issues across Whitehall and to Ministers.

There is no consensus on how we measure 'success' in responding to HIV in the UK.

England's national strategy for sexual health and HIV comes to the end of its current timeline in 2011. As we move into the second decade of the twenty-first century we need comprehensive cross-departmental strategies on HIV in all four nations, and those strategies need to be effectively coordinated.

There is no strategy for sexual health and HIV agreed for Northern Ireland.



'The recent 'Review of the National Strategy for Sexual Health & HIV' highlighted the lack of progress on preventing new cases for HIV. There is an urgent need for a specific HIV prevention strategy and clear leadership to ensure an appropriate focus on this important area of public health.'

Dr Helen Ward, Imperial College, London

Two things we want to see in four years' time:

- ▶ **A clear statement from the Government as to how they intend to bring HIV in the UK up the political agenda and keep it there – and a five-year HIV strategy agreed in all four nations of the UK.**
- ▶ **An NHS which incentivises local engagement on HIV through appropriate and effective HIV-related targets, inspection and regulatory processes.**

Priorities for action:

- ▶ Agreeing a sexual health strategy for Northern Ireland which adequately addresses HIV.
- ▶ Processes initiated to agree by 2010 a clear HIV strategy in all four nations with effective co-ordination.
- ▶ A senior official appointed who is charged with championing the HIV strategy across Whitehall.
- ▶ Additional resources provided to the Department of Health sexual health team to increase HIV policy capacity within England.

In the Government's Public Health White Paper 'Choosing Health' 2004, the word HIV appears only seven times in all of its 203 pages, and only one of those references substantively considers HIV.



AFTERWORD

During the twenty-one years of NAT's existence the HIV epidemic in the UK has changed in some fundamental ways – in terms of scientific knowledge, availability of effective treatment, the communities affected, the legal implications, to give just a few examples. What has not changed, or not changed enough, is the continuing stigma and discrimination linked to HIV. There is still a drift towards at best neglect and at worst injustice on HIV issues.

Unless those with responsibilities - and above all politicians, both nationally and locally - explicitly and actively make HIV a matter they care about and prioritise, we are not going to keep up with the changing face of the epidemic in the UK.

“People with HIV are entering old age, or growing up, applying for jobs, trying to conceive, forming relationships, coming to terms with a wonderfully extended life expectancy, managing a complex long-term condition, working out when, and how, to share their HIV status with others.”

This is what HIV looks like in the UK in the twenty-first century, much more a part of ordinary life, and for many more people. We need a society which supports those of us living with HIV across the wide range of needs identified in this report. We need a renewed determination to reduce rates of new HIV infection. We need an end to stigma and discrimination in all their forms.

We have in this report identified priorities for action, across many areas of public life – but that is to be expected. HIV affects very different people in many different situations. NAT is prepared to meet the challenge of transforming the UK's response to HIV. We invite our government, nationally and locally, our MPs, our NHS, our leaders and decision-makers, employers ... we invite you, reader, to join us.

Dame Denise Platt DBE, NAT Chair

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

Our vision:

Our vision is a world in which people living with HIV are treated as equal citizens with respect, dignity and justice, are diagnosed early and receive the highest standards of care, and in which everyone knows how, and is able, to protect themselves from HIV infection.

Our strategic goals:

All our 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.

Our thanks

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How we work:

- We believe we make the most lasting and positive impact on the greatest number of lives by changing attitudes, behaviour, decisions and policies - and we seek to influence those whose actions have the biggest impact on the lives of people affected by HIV in the UK.
- We listen to people living with, and affected by, HIV and those who support them and we put the needs and rights of HIV positive people at the heart of everything we do.
- We pride ourselves on being independent and evidence-based. We are committed to partnership working and we work in a collaborative and productive manner with a range of partner organisations to share experience and knowledge and make the greatest collective difference.



SHAPING ATTITUDES CHALLENGING INJUSTICE CHANGING LIVES

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