25 YEARS OF
SHAPING ATTITUDES
CHALLENGING INJUSTICE
CHANGING LIVES

TRANSFORMING
THE UK'S
RESPONSE
TO HIV

NAT

HIV
– a strategy for success

October 2012

TRANSFORMING THE UK'S RESPONSE TO HIV

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Contents

In 2012 there are many things to celebrate about the progress made in tackling the HIV epidemic both globally and in the UK. Over thirty years since the first cases of HIV were diagnosed, there have been enormous steps forward both in terms of treatment and care for people living with HIV and in testing technology to enable us to diagnose early. However, there is still much to be done and after an initially robust response to HIV in the UK, there is now growing concern that progress is stalling.

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INTRODUCTION

THE NEED FOR AN HIV STRATEGY

HIV in the UK

By the end of 2012 it is estimated that there will be 100,000 people living with HIV in the UK. We have not reduced rates of new infection. Annual HIV diagnoses remain stubbornly high. The two communities most affected are gay and bisexual men and African men and women. Approximately one in twenty gay and bisexual men and one in twenty African men and women in the UK are living with HIV. In 2010, 3,000 gay and bisexual men were newly diagnosed with HIV; this is the highest number of gay and bisexual men newly diagnosed with HIV ever reported in a single year.[1]

In the same year, half of all people diagnosed were diagnosed late; people diagnosed late have a ten-fold increased risk of death within one year of HIV diagnosis compared to those diagnosed promptly. And still nearly a quarter of people living with HIV in the UK are unaware of their status. This is of real concern given that the majority of transmissions come from people who are themselves unaware that they have HIV.

Advances in treatment have seen enormous improvements in quality of life and life expectancy for people living with HIV. In 2010, 85% of people on treatment had an undetectable viral load within a year of starting medication, a marker of successful treatment. However, this success in treatment has not been matched by improvements in social support for people living with HIV. Many still experience stigma and discrimination, live in poverty and cannot access the psychological support they need.

Although HIV remains one of the most serious infectious diseases affecting the UK, public understanding and knowledge of HIV is poor and getting worse. Recent Ipsos MORI research commissioned by NAT revealed that only one in three adults were able to correctly identify all the ways HIV is and is not transmitted from a list of options, with almost a fifth mentioning one incorrect method such as spitting or sharing a glass. One in five were unaware that HIV is transmitted through sex without a condom between a man and woman.[2] The research also showed a link between poor knowledge about HIV and negative and judgemental attitudes towards people living with HIV. There is clearly still a need to improve awareness among the public, both to prevent the spread of HIV - each new infection costs the UK over a quarter of a million pounds in direct lifetime medical costs alone - and to prevent misconceptions which fuel stigma and discrimination.

Despite this situation, there is no strategy for HIV in England - the last national strategy for sexual health and HIV came to an end in 2010. Over 90% of people living with HIV in the UK live in England, and yet England is the only country within the UK not to have a strategy.

INTRODUCTION

THE NEED FOR AN HIV STRATEGY

> **Through my long involvement with NAT, I've seen first-hand what a difference strong Government leadership can make in delivering an effective and evidence-based response to HIV. In this, our 25th birthday year, we call on the Government to provide this leadership and work with people living with HIV to develop a new strategy for HIV in England**

Dame Denise Platt, Founder Trustee and Current Chair of NAT

Why is a strategy so important?

Experience shows that a strategic approach makes the difference between progress and failure.

We saw at the beginning of the epidemic what a difference a planned approach to HIV prevention can have. In the UK we introduced systematic harm reduction measures to prevent infection amongst people who inject drugs - the result is we have one of the lowest rates of HIV in this group compared to many other European countries where such measures were only introduced later. This will have generated significant cost savings to the NHS. A strategic approach also had an important impact on testing; the last strategy introduced targets to reduce undiagnosed HIV, which had a dramatic impact on the number of people offered an HIV test in a sexual health clinic (now 69% of people who go to a sexual health clinic have an HIV test).

The need for a national strategy is even more important now than before because of the move towards localism. HIV is an infectious disease that does not respect local government boundaries and so national leadership to complement local knowledge and expertise is essential; as a national epidemic HIV needs to be addressed nationally.

The Government announced some time ago that they were developing a 'sexual health policy document' but this has been significantly delayed and is unlikely to address all the necessary dimensions of HIV. HIV is often considered to be solely a sexual health issue. Whilst this is an important aspect of the epidemic - the vast majority of cases in the UK are sexually transmitted - there are many other aspects to HIV. HIV is a long-term condition, with health, social care and psychological implications. Many people living with HIV are experiencing poverty or other social pressures such as poor housing, immigration difficulties or detention. It remains a stigmatised condition bringing specific challenges to ensuring people living with HIV can fully access their rights and are treated with respect.

For these reasons, a multi-faceted approach is essential to ensure that there is a cross-government response to HIV - it is not just an issue for the Department of Health.

In 2001 the UK signed the United Nations Declaration of Commitment on HIV and AIDS, pledging to take action to tackle HIV both in the UK and internationally (a pledge renewed in 2011). This included a commitment to developing a comprehensive strategy to address all the different aspects of HIV. As other countries take the lead on this issue, with the US, South Africa and France recently launching HIV strategies, we remain behind and in breach of our international commitments.

What do we want to see?

NAT is calling on the Government to work with people living with HIV and the organisations that support them to develop an HIV strategy for England. A strategy that looks at all aspects of HIV:

- HIV as a sexual health condition and the prevention and testing needs associated with this;
- HIV as a long-term condition and the health, social care and welfare needs this brings;
- and HIV as an equality and human rights issue including the steps needed to end stigma and discrimination.

To support each of these strands the strategy must also improve the current low levels of public awareness and understanding about HIV that fuel stigma and discrimination and undermine prevention and testing campaigns.

The Government should appoint a 'champion' to oversee the implementation of this strategy in England to make sure it becomes a reality.

Here we set out what we believe an HIV strategy covering these central areas should include.

1: Health Protection Agency (2011) ***HIV in the United Kingdom: 2011 report***
All data cited elsewhere in this report, unless otherwise stated, is taken from the HPA www. hpa.org.uk.

2: NAT (2011), ***HIV: Public knowledge and attitudes, 2010***, www.nat.org.uk

SEXUAL HEALTH, PREVENTION AND TESTING

A national strategy should deliver effective HIV prevention to halt the spread of HIV and allow early diagnosis through ethical, accessible and appropriate testing.

Prevention

Experts agree that we have not yet succeeded in reducing rates of HIV transmission in the UK, with every year approximately 7,000 people newly diagnosed. At the same time there is evidence that local funding for HIV prevention has been neglected or cut.

The current reforms of the public health service in England present a unique opportunity to change this. Under the new system, Public Health England will have national oversight of HIV prevention, with for the first time the delivery and funding of HIV prevention the responsibility of local authorities. With this opportunity, also comes threat, as there is no requirement for local authorities to invest in HIV prevention, despite the clear cost effectiveness of doing so - every case prevented saves over a quarter of a million pounds in medical costs alone.

So we need a strategy to ensure that there is leadership on HIV prevention in this new landscape, with Public Health England supporting local authorities in delivering effective HIV prevention and local authorities assessing local need and properly resourcing these activities.

The advances in HIV treatment offer prevention as well as health benefits. With recent recognition of the role of HIV drugs in preventing the onward transmission of the virus, it is important that national funding is available to provide treatment for everyone with HIV who wishes to prevent transmission to their sexual partners, even if it is before it is recommended they start treatment for their own health needs.

The US has licensed the use of anti-retroviral drugs as a pre-exposure prophylaxis (PrEP) to help prevent HIV infection amongst those at very high risk. Research is underway in the UK to look at how PrEP might work amongst gay and bisexual men here. Again, funding must be available to implement any recommendations arising from this, as well as leadership to make sure we make the most of new prevention tools in the future, integrating these with existing methods.

The Government's continued funding of a national HIV prevention programme targeting the groups most at risk of HIV infection (gay and bisexual men and African communities) is welcome; more now needs to be done to evaluate the effectiveness of this programme. There needs to be an increase in the proportion of gay and bisexual men and African men and women choosing safer sex options such as consistent condom use and a reduction in multiple or concurrent partners with clear strategies to make this happen.

In addition, Caribbean communities have about three times the HIV prevalence of the wider population, as well as poorer outcomes for other aspects of sexual health.[3] A strategic approach to addressing HIV in these communities is vital and must be developed as a priority in local authorities with significant Caribbean populations, linked to wider sexual health work.

> **“Putting money in place for HIV prevention is great, but the absence of a national strategic approach to HIV by government is worrying, particularly given the high levels of new diagnoses and the number of people diagnosed late.**
> Robert, living with HIV

With a growing number of people living with HIV not from these high risk groups - nearly 25% of newly infected people are neither gay or bisexual men nor African men and women - steps must be taken to ensure that the prevention needs of the rest of the population are met, particularly in the context of declining public awareness and knowledge.[4]

Although 95% of HIV cases in the UK are the result of sexual transmission, HIV can also be spread through sharing drug injecting equipment. In the past the UK has successfully implemented harm reduction measures - in particular, provision of clean injecting equipment and opioid substitution treatment (OST), such as methadone. As a result, the UK has a very low rate of HIV amongst injecting drug users. However, there is now growing concern that a new emphasis on 'full recovery' and abstinence may undermine this, deterring people from OST, and increasing the number of people injecting and sharing needles.

Despite the known benefits of providing clean injecting equipment in the community, UK prisons do not offer clean needles to allow prisoners who inject drugs to protect themselves from HIV. Needle exchanges have been successfully introduced in prisons in a number of other countries in Europe, but the Government is unwilling to introduce them here without UK-specific evidence.

We want to see a national strategy commit to a prison needle exchange pilot to establish the benefits of providing clean needles where they are needed.

A national HIV strategy should ensure that:

- Local authorities carry out effective HIV prevention needs assessments and properly resource prevention activities
- Public Health England provides leadership on HIV prevention, taking steps to ensure local authorities invest in appropriate prevention
- National funding is provided to ensure treatment as a prevention method is available for everyone living with HIV who wishes to access it
- Integrated prevention strategies are developed including the range of prevention methods available (including condom use, partner reduction, treatment as prevention and PrEP)
- There is continued investment in a national HIV prevention programme targeting gay and bisexual men and Africans with a focus on evaluating and improving campaigns
- Steps are taken to meet the prevention needs of the wider population
- There is commitment to a drugs policy that protects people who are injecting drugs from HIV infection through continued access to opioid substitution treatment, clean injecting equipment and, for the use in custody, the establishment of a prison needle exchange pilot.

SEXUAL HEALTH, PREVENTION AND TESTING

Testing

Improving the availability and uptake of HIV testing must be a central part of a future HIV strategy. Approximately a quarter of people living with HIV do not know they have the virus and there is clear evidence that the majority of new transmissions come from people who are themselves unaware of their HIV status.

Diagnosing people in good time not only has health benefits for the individual, but also has enormous preventative benefits. Once people have been diagnosed they can access behavioural support to practise safer sex. In addition, due to the impact of treatment on infectiousness, those diagnosed and on treatment are far less likely to pass on the virus.

As well as the prevention benefits of testing, there are definite health benefits to early diagnosis. Overall, 90% of people who died within a year of HIV diagnosis between 2000 and 2009 were diagnosed late. In contrast, if diagnosed and treated on time, most people living with HIV can expect to have a near normal life expectancy.

It is therefore crucial that under the new public health arrangements, Public Health England works with local authorities to prioritise HIV testing and develop local testing strategies in line with national guidelines.

The last national strategy delivered some good results with a significant increase in the uptake of HIV testing in antenatal services, and an increase in HIV tests being offered and accepted in sexual health clinics. There have also been improvements in HIV testing technology which make it much easier and quicker to test.

Yet despite this, the testing rates amongst gay and bisexual men and Africans are still far too low - the numbers of gay and bisexual men who reported 'ever testing' for HIV in a 2008 survey was only 75%, with a far lower number testing in the last twelve months (as recommended in NICE guidelines).[5] Amongst Africans, a 2008/09 survey found that 40% of Africans had never tested for HIV.[6]

Diagnosing people in good time not only has health benefits for the individual, but also has enormous preventative benefits.

Awareness of symptoms of HIV is poor amongst health professionals and at risk communities. There are repeated failures to diagnose people, with symptoms and indicators of HIV being ignored or missed - over half of people diagnosed in 2010 were diagnosed late, after the stage that treatment should have begun. For this reason more needs to be done to ensure health professionals and communities at risk recognise symptoms of HIV infection, including early symptoms, so they know when to test.

A national HIV strategy should ensure that:

- Local authorities develop integrated testing strategies and ensure testing is commissioned across a wide variety of settings in line with national guidelines to reduce late HIV diagnosis
- Healthcare workers (especially those in primary care and emergency medicine) are trained to recognise symptoms of HIV infection, including signs of early infection
- Gay and African communities are educated about the symptoms of HIV infection and the benefits of testing for HIV at least once a year
- GPs are financially incentivised to diagnose HIV to prevent late diagnosis
- Best practice around partner notification is defined and routinely adopted by clinics to reduce undiagnosed HIV
- Home testing is legalised and effectively regulated with appropriate safeguards in place.

Partner notification, the process of contacting the sexual partners of someone diagnosed with HIV, is a highly effective way of getting people tested and diagnosed. Audits show up to 37% of partners traced and tested through this process were diagnosed HIV positive as a result.[7] Despite this, the role of partner notification in prevention and testing is neglected and under resourced; this should be addressed in a future strategy.

Increasing testing options is vital. Home testing kits are currently unlawful in the UK but we know some people are already buying them online from overseas. A national strategy needs to legalise home testing and set out how to integrate this new technology effectively and safely into existing testing strategies.

Awareness of symptoms of HIV is poor amongst health professionals and at risk communities.

3: NAT (2010), *HIV and black Caribbean communities in the UK*, www.nat.org.uk
4: NAT (2011), *HIV prevention and the wider UK population*, www.nat.org.uk
5: Sigma Research (2008), *Gay Men's Sex Survey*, www.sigmaresearch.org.uk
6: Sigma Research (2009), *Bass Line 2008-09: Assessing the sexual health HIV prevention needs of African people in England*, www.sigmaresearch.org.uk
7: NAT (2012), *HIV partner notification: a missed opportunity?*, www.nat.org.uk

HIV AS A LONG-TERM CONDITION

A national strategy should recognise HIV as a long-term condition with actions to ensure equitable access to treatment, care and support for people living with HIV to enable them to manage their own health. With many HIV positive people now living into older age, a national strategy must now consider how to meet the needs of older people. Too many people living with HIV also experience extreme hardship; tackling poverty must be a central aim of the strategy, bringing both individual and public health benefits.

Health and social care

One of the good news stories of the last thirty years is the progress made in HIV treatment; HIV is no longer a death sentence and most people diagnosed today can expect to have long and healthy lives. It is therefore important, that at a time of major change to the NHS in England, the quality of HIV treatment services are maintained.

It will be essential that there is integrated commissioning in the new system to ensure the range of treatment and care needs of people living with HIV are met. People living with HIV must also have a voice and input into their care. New services must particularly consider the needs of gay and bisexual men and Africans, the two communities most affected by HIV in the UK. In addition, care pathways must consider the needs of young people as they move from child to adult services.

Changes to how services are commissioned also present an opportunity to improve the care received by prisoners and people in immigration removal centres. Taking HIV medication regularly is vital to its success. In the past, despite the best efforts of individual healthcare professionals, access to drugs has often been interrupted, with serious health consequences.

Effective care and support includes support to have a fulfilled sex life and equal access to sexual and reproductive health services, with measures in place to ensure people living with HIV can access conception and maternity services in line with national guidelines.

There has been concern that increasing budget restraints will lead to treatment decisions based on cost rather than on what is best for the patient. A national strategy should make clear that treatment decisions must be based primarily on the health needs of the individual, in line with the national treatment guidelines, with cost only relevant when comparing drugs with equivalent clinical outcomes.

> **“It just makes sense for the Government to recognise, and provide leadership on, HIV as a long-term condition not only to make sure people living with HIV have the support they need to stay well – including emotional support – but also because it saves money for everyone in the long run.**
>
> Rebecca, living with HIV

Effective treatment does not mean that people living with HIV automatically have a high quality of life.

Effective treatment does not mean that people living with HIV automatically have a high quality of life. People living with HIV are at a higher risk of mental health problems - a 2008 survey found that 70% of respondents had experienced anxiety or depression in the past year - and many require social care support.[8] An HIV strategy must look not just at medical care, but take a wider view, ensuring people living with HIV have access to the services they require to live well and manage HIV as a long-term condition.

Social care and psychological support have a crucial role in maintaining the health and wellbeing of people living with HIV. The value of peer support and counselling services is widely recognised. For example, at the point of diagnosis, these services help people understand what this means for them and how to think about disclosure. Such support can reduce the impact of emotional and psychological problems that make adherence to treatment difficult. And adherence to treatment is crucial if it is to be effective. Without strict adherence there is a risk of developing drug resistance, and, in addition, the chances of passing the virus on are increased.

Encouragingly there is specific funding allocated to help local authorities provide social care for people living with HIV. However, this is no longer ring fenced and in a time of budget cutbacks there is evidence that it is being spent on other areas.

HIV AS A LONG-TERM CONDITION

This leaves many people living with HIV without the services they require to manage their long-term condition. Many of these are voluntary sector open access services - services open to anyone living with HIV who needs help - which are now facing a funding gap. Without these services social care can become a form of crisis management, rather than a preventative cost effective system that promotes independence and self-care.

HIV is a lifelong condition and more research is needed on the changing needs and experiences of people with HIV in the UK over their lifetime. Research looking at areas such as social need, ageing, sexual behaviour and experiences of treatment should be planned and funded, ideally as a cohort study. This would improve our understanding of what it is like to live with HIV today.

People living with HIV must have a voice and input into their care.

A national HIV strategy should ensure that:

- HIV is recognised as a long-term condition and appropriate support is in place for people living with HIV to maintain good physical and mental health
- New NHS commissioning bodies work with local authorities to develop integrated care pathways to meet the health and social care needs of people living with HIV (including young people and those in prisons or immigration removal centres)
- People living with HIV are consulted and actively involved in the commissioning of health and social care services so that they genuinely meet their needs
- People living with HIV have access to the full range of sexual and reproductive health services
- Treatment decisions are based primarily on clinical appropriateness and national guidelines, not cost
- Local authorities fund social care support and open access services for people living with HIV, to assist them in maintaining health and wellbeing
- Further research is carried out into HIV as a long-term condition to understand the on-going and changing needs of people living with HIV.

Ageing

It is something to celebrate that more and more people diagnosed with HIV are living into old age. In 2010 one in five people diagnosed with HIV were over fifty, with this proportion expected to grow significantly over the next five years. However, with this success come challenges.

Many of those diagnosed before the discovery of anti-retroviral drugs face significant health problems. Loneliness, isolation, financial insecurity and related mental health problems have been highlighted as a concern, particularly for older gay and bisexual men who are less likely to have family or children to care for them in old age.

Support services for older people are not always prepared for or sensitive to the needs of people living with HIV. There is currently no guidance for residential and domiciliary care providers on providing appropriate services for people living with HIV, and unfortunately people sometimes experience stigma and discrimination when they try to access mainstream services.

There are also many unanswered medical questions both about the impact of the virus itself on the ageing process and the impact of many years of anti-retroviral treatment. Further research into these areas is essential if we are to continue to meet the care needs of people living with HIV as they grow old.

A national HIV strategy should ensure that:

- Services for older people are designed to consider and meet the needs of people living with HIV
- Guidance for residential, domiciliary and palliative care providers on providing appropriate support for HIV positive service users is developed and implemented
- There are integrated care pathways for older people living with HIV and staff in all relevant services receive training on HIV and treat people living with HIV with dignity and respect
- Further research is carried out into the impact of HIV on ageing and the long-term effects of treatment on both women and men, and the findings inform the treatment and care provided.

The impact of HIV on other health conditions associated with ageing and the treatment of these conditions is still unknown and increased collaboration between HIV clinicians and those from other relevant specialties will be important.

HIV AS A LONG-TERM CONDITION

Poverty

An effective HIV strategy needs to be about far more than prevention and testing and effective health and social care. HIV can affect every aspect of a person's life and between 2006 and 2009, one in six people accessing HIV treatment in the UK was living in poverty and had to access hardship support.[9]

The impact of poverty on someone living with HIV is particularly detrimental. Poverty can worsen an HIV positive person's health, as they are unable to afford the nutritional food, appropriate housing or heating they need to remain well when living with a compromised immune system. It can also make adherence to treatment more difficult - when people struggle to provide the basics in life for their families, looking after themselves and taking their treatment become a lower priority.

Poverty can be caused by a variety of factors. Some people living with HIV face significant barriers to employment. One study of people living with HIV in London found that less than 50% of people were in employment, with black African respondents facing particular disadvantage in employment, income and housing.[10]

For many people living with HIV the benefits system is a vital source of support. The recent reform of Incapacity Benefit (now Employment and Support Allowance) is therefore a source of stress. The new assessment often fails to recognise the complexity of HIV as a fluctuating condition, leading to costly and unnecessary appeals.[11]

Others are unable to work because of their immigration status. They are reliant on minimal benefits set at a level significantly lower than income support, which leave them and their families living in poverty and unable to pay for the food and healthy living environment needed to stay well.

> **“It is great news that the Government has made HIV treatment free, but if people can't afford the basics in life – a bus fare, nutritious food and decent housing – it is hard for them to stay well. For so many people these are real issues we need to address now through a comprehensive strategy.**
>
> Pamela Nash, MP, Chair of the All-Party Parliamentary Group on HIV and AIDS

A national HIV strategy should ensure that:

- Changes are made to the benefit system to ensure that people living with HIV who need it have access to appropriate financial support and housing
- Asylum seekers are given the right to work after six months and asylum support is equivalent to income support
- There is access to free infant formula for HIV positive mothers who need it
- There is universal access to primary care as a key access point for HIV testing and wider identification of sexual health needs
- Recent immigration rules that mean that NHS debt can restrict entry or stay in the UK are reversed.

In some instances this forces HIV positive mothers to breast feed their babies, even though this carries a risk of HIV transmission, because they cannot afford to buy infant formula.

Restrictions on access to healthcare add to the problems some migrants face. Although HIV treatment is now available free of charge to everyone in England, many people experience significant distress because of debts relating to other healthcare they are unable to pay for. These debts now have serious implications with new immigration rules restricting entry or stay in the UK for those with a debt of £1,000 or more. Maintaining free primary care in England is vital and access should be improved, not least because this provides an opportunity for HIV testing, with wider public health benefits.

8: Sigma Research (2009), *What do you need? 2007-2008*, www.sigmaresearch.org.uk
9: NAT and THT (2010), *Poverty and HIV 2006-2009*, www.nat.org.uk
10: Ibrahim F., Anderson J., Bukutu C., Elford J., (2008) Social and economic hardship among people living with HIV in London, *HIV Medicine 9* (8): 616-624
11: NAT (2011), *Fluctuating symptoms of HIV*, www.nat.org.uk

EQUALITY AND DISCRIMINATION

A national strategy should seek to eradicate HIV-related stigma and discrimination and ensure that people living with HIV are aware of and access their rights.

Stigma and discrimination

Advances in treatment mean that most people diagnosed with HIV today will have long and healthy lives. But public understanding and attitudes to HIV have not kept up with these developments. As a consequence, people living with HIV often experience stigma and discrimination based on fear and ignorance. Many people living with HIV also face prejudice related to their sexuality and/or race. And stigma within affected communities - for example, discrimination against HIV positive people from within gay and African communities - can be very damaging. Specific action to tackle this is urgently needed.

Public services should provide an environment of care and support. However, of the one in three people living with HIV who have experienced discrimination, half of these occurred within a healthcare setting.[12] There is also evidence of discrimination in schools, both against pupils and also staff who are living with HIV. When people living with HIV come in contact with the criminal justice system, often as victims of crime, they are not always treated with the respect and understanding they deserve. It is not only in life that people face discrimination - some pathologists are refusing to undertake post-mortems on HIV positive individuals. This sort of discrimination by public services must be addressed.

Since 2001 people living with HIV can be prosecuted for passing on HIV to their sexual partners. Police, lawyers and judges often demonstrate a poor understanding of HIV during these cases. Such prosecutions have led to stigmatising media coverage and the unhelpful messages that only people with diagnosed HIV are responsible for safer sex.

In the UK, a quarter of women experience intimate partner violence in their lifetime, but a recent study found that amongst women living with HIV this percentage rises to over half, with one in seven experiencing violence in the last year.[13]

A national HIV strategy should ensure that:

- There is Government leadership across all relevant departments to tackle HIV related stigma and discrimination
- Public Health England provides support to local authorities to address stigma and discrimination including identifying measures of success
- Training and education is provided for frontline staff in key public services, such as health, social care, police and education, so that people living with HIV no longer experience stigma and discrimination when accessing such services
- Criminal prosecutions for reckless transmission of HIV are ended
- HIV positive women are appropriately recognised in government strategies and initiatives to reduce intimate partner violence and support is available to those who experience it
- Policies are based on evidence not stigma and misconception - for example, an end to occupational exclusions for HIV positive healthcare workers and a review of financial services to ensure policies reflect advances in treatment.

Despite this, HIV is not currently mentioned in England's Action Plan to end violence against women and girls (apart from in an international context) or in the Department of Health's Action Plan to improve services for women who are victims of violence.

Stigma can be a barrier to people accessing or remaining in work. In addition, occupational restrictions for healthcare workers do not take into account advances in treatment and our knowledge about the impact this has on someone's ability to pass on the virus. These restrictions are now out-of-date and discriminatory, needlessly preventing highly skilled HIV positive dentists and surgeons from working in the UK.

Occupational restrictions are not the only policies based on out-dated evidence. A thorough review of financial services is needed to ensure people living with HIV have fair access to a full range of insurance and mortgage policies at premiums which take into account the latest evidence on health and life expectancy.

> **“It is not right that people living with HIV still experience discrimination; the Government must act now to make sure people are treated fairly and can access their rights.**
>
> Paul, living with HIV

EQUALITY AND DISCRIMINATION

Equality

Since the last national sexual health and HIV strategy, the Equality Act 2010 has been passed, introducing many important new protections for people living with HIV.

This was a great step forward but more needs to be done to realise the full potential of this legislation. The 'dual discrimination' provisions that protect people who face prejudice as a result of two 'protected characteristics' - for example race and disability - have yet to be implemented. There are also proposals to repeal certain aspects of the Act which offer important protection to people living with HIV.

The Public Sector Equality Duty ensures that public authorities consider the needs of people living with HIV amongst others. This must be retained and strengthened as an important tool to assist public bodies in thinking through how their services and actions affect those who face disadvantage.

Legislation is vital in protecting people living with HIV from discrimination but cannot alone bring about cultural change. More needs to be done to make sure employers are aware of their legal obligation to people living with HIV; and people living with HIV need to be aware of their rights, and what to do when these are breached. Continued access to legal advice will be particularly important given the recent reforms to legal aid.

A national HIV strategy should ensure that:

- Current protections within the Equality Act 2010 are retained and the dual discrimination provisions implemented
- The Public Sector Equality Duty is retained and strengthened
- Employers and recruitment agencies are aware of rights and responsibilities within the Equality Act
- People living with HIV understand their rights and have access to advice and redress when they experience discrimination
- Guidance is developed so public services, employers and other relevant bodies understand their obligations to safeguard the confidentiality of people living with HIV.

Confidentiality is very important to people living with HIV. Legal protections are in place, but often service providers and employers do not understand the restrictions on sharing health information. Ignorance about HIV means people have a misplaced sense of obligation to share information about someone's HIV status, when instead they should be safeguarding people's confidentiality.

12: J Elford et al. 2007, *HIV-related discrimination reported by people living with HIV in London, UK*. AIDS and Behaviour

13: Dhairyawan R et al. *Intimate partner violence in women living with HIV attending an inner city clinic in the United Kingdom: prevalence and associated factors*. 18th Annual Conference of the British HIV Association, Birmingham, abstract O5, 2012.

PUBLIC EDUCATION AND AWARENESS

A national strategy should improve public understanding of HIV. This is fundamental to achieving success in other areas; knowledge is essential to prevention and testing, to planning and delivering health, social care and support services and to ending the stigma and discrimination that people living with HIV still face.

The number of people living with HIV in the UK has trebled in the last ten years but over the same period there has been a significant decline in public knowledge of how HIV is transmitted. Public attitudes have not kept pace with improvements in treatment, and a significant minority of the public still hold stigmatising and discriminatory views about people living with the virus.

Perhaps this is not surprising as there has been no real investment in educating the public about HIV. Recent sexual health campaigns - especially those aimed at young people - have made no mention of it at all. Young people rarely learn about HIV in schools, where sex education is still not compulsory and remains, in some areas, extremely limited. This is particularly a concern for young gay and bisexual men who often leave school without the information they need to protect themselves from HIV infection.

The media very rarely write about HIV. When they do they often perpetuate myths and misunderstanding through sensationalist language or misreporting of the facts. In this environment many people living with HIV find it difficult to be open about their HIV status, so there is an absence of public figures who feel able to speak freely about the reality of living with HIV today.

> **“Without ending ignorance about HIV, things won’t improve; but with good education we can transform people’s attitudes. If the Government took the lead on this it would make a real difference.**
> Alastair, living with HIV

A national HIV strategy should ensure that:

- HIV is included in wider public education campaigns about sexual health so that people understand how the virus is and is not passed on, how to protect themselves and when to test
- All young people have a good understanding of HIV by the time they leave secondary school
- There is positive and accurate coverage about HIV in the media, with improved mechanisms for challenging poor reporting
- There is support and encouragement to secure greater visibility for people living with HIV in public life
- Accurate and accessible information about HIV is available to everyone.

WHAT'S NEEDED

An HIV Strategy

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 and others from HIV infection. We see a national HIV strategy as fundamental to making this vision a reality.

A comprehensive national HIV strategy for England should ensure that:

- Local authorities carry out effective HIV prevention needs assessments and properly resource prevention activities
- Public Health England provides leadership on HIV prevention, taking steps to ensure local authorities invest in appropriate prevention
- National funding is provided to ensure treatment as a prevention method is available for everyone living with HIV who wishes to access it
- Integrated prevention strategies are developed including the range of prevention methods available (including condom use, partner reduction, treatment as prevention and PrEP)
- There is continued investment in a national HIV prevention programme targeting gay and bisexual men and Africans with a focus on evaluating and improving campaigns
- Steps are taken to meet the prevention needs of the wider population
- There is commitment to a drugs policy that protects people who are injecting drugs from HIV infection through continued access to opioid substitution treatment, clean injecting equipment and, for the use in custody, the establishment of a prison needle exchange pilot
- Local authorities develop integrated testing strategies and ensure testing is commissioned across a wide variety of settings in line with national guidelines to reduce late HIV diagnosis

- Healthcare workers (especially those in primary care and emergency medicine) are trained to recognise symptoms of HIV infection, including signs of early infection
- Gay and African communities are educated about the symptoms of HIV infection and the benefits of testing for HIV at least once a year
- GPs are financially incentivised to diagnose HIV to prevent late diagnosis
- Best practice around partner notification is defined and routinely adopted by clinics to reduce undiagnosed HIV
- Home testing is legalised and effectively regulated with appropriate safeguards in place
- HIV is recognised as a long-term condition and appropriate support is in place for people living with HIV to maintain good physical and mental health
- New NHS commissioning bodies work with local authorities to develop integrated care pathways to meet the health and social care needs of people living with HIV (including young people and those in prisons or immigration removal centres)
- People living with HIV are consulted and actively involved in the commissioning of health and social care services so that they genuinely meet their needs
- People living with HIV have access to the full range of sexual and reproductive health services
- Treatment decisions are based primarily on clinical appropriateness and national guidelines, not cost
- Local authorities fund social care support and open access services for people living with HIV, to assist them in maintaining health and wellbeing
- Further research is carried out into HIV as a long-term condition to understand the on-going and changing needs of people living with HIV
- Services for older people are designed to consider and meet the needs of people living with HIV
- Guidance for residential, domiciliary and palliative care providers on providing appropriate support for HIV positive service users is developed and implemented
- There are integrated care pathways for older people living with HIV and staff in all relevant services receive training on HIV and treat people living with HIV with dignity and respect
- Further research is carried out into the impact of HIV on ageing and the long-term effects of treatment on both women and men, and the findings inform the treatment and care provided
- Changes are made to the benefit system to ensure that people living with HIV who need it have access to appropriate financial support and housing
- Asylum seekers are given the right to work after six months and asylum support is equivalent to income support
- There is access to free infant formula for HIV positive mothers who need it
- There is universal access to primary care as a key access point for HIV testing and wider identification of sexual health needs

WHAT'S NEEDED

- Recent immigration rules that mean that NHS debt can restrict entry or stay in the UK are reversed
- There is Government leadership across all relevant departments to tackle HIV related stigma and discrimination
- Public Health England provides support to local authorities to address stigma and discrimination including identifying measures of success
- Training and education is provided for frontline staff in key public services, such as health, social care, police and education, so that people living with HIV no longer experience stigma and discrimination when accessing such services
- Criminal prosecutions for reckless transmission of HIV are ended
- HIV positive women are appropriately recognised in government strategies and initiatives to reduce intimate partner violence and support is available to those who experience it
- Policies are based on evidence not stigma and misconception - for example, an end to occupational exclusions for HIV positive healthcare workers and a review of financial services to ensure policies reflect advances in treatment
- Current protections within the Equality Act 2010 are retained and the dual discrimination provisions implemented
- The Public Sector Equality Duty is retained and strengthened
- Employers and recruitment agencies are aware of rights and responsibilities within the Equality Act
- People living with HIV understand their rights and have access to advice and redress when they experience discrimination
- Guidance is developed so public services, employers and other relevant bodies understand their obligations to safeguard the confidentiality of people living with HIV
- HIV is included in wider public education campaigns about sexual health so that people understand how the virus is and is not passed on, how to protect themselves and when to test
- All young people have a good understanding of HIV by the time they leave secondary school
- There is positive and accurate coverage about HIV in the media, with improved mechanisms for challenging poor reporting
- There is support and encouragement to secure greater visibility for people living with HIV in public life
- Accurate and accessible information about HIV is available to everyone.

> It is not right that people living with HIV still experience discrimination; the Government must act now to make sure people are treated fairly and can access their rights.

Paul, living with HIV

> Putting money in place for HIV prevention is great, but the absence of a national strategic approach to HIV by government is worrying, particularly given the high levels of new diagnoses and the number of people diagnosed late.

Robert, living with HIV

> Without ending ignorance about HIV, things won't improve; but with good education we can transform people's attitudes. If the Government took the lead on this it would make a real difference.

Alastair, living with HIV

> It just makes sense for the Government to recognise, and provide leadership on, HIV as a long-term condition not only to make sure people living with HIV have the support they need to stay well – including emotional support – but also because it saves money for everyone in the long run.

Rebecca, living with HIV

This report drew on evidence from a range of sources, most significantly:
The Health Protection Agency - www.hpa.org.uk
City University London - www.city.ac.uk
Sigma Research - www.sigmaresearch.org.uk
British HIV Association - www.bhiva.org
NAT - www.nat.org.uk

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GILEAD

NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expertise and practical resources. We champion the rights of people living with HIV and campaign for change.

TRANSFORMING
THE UK'S
RESPONSE
TO HIV

NAT

25 YEARS OF

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 and others from HIV infection.

Our strategic goals:

All our work is focused on achieving five 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
- enhanced understanding of the facts about HIV and living with HIV in the UK
- eradication of HIV-related stigma and discrimination.

www.NAT.org.uk

www.lifewithHIV.org.uk – a resource for HIV positive people

www.HIVaware.org.uk – what everyone should know about HIV

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