No plan, no progress: the case for a UK strategy on HIV

It is thirty years since the first cases of HIV were diagnosed. The UK's initial response was robust and strategic, and much was achieved. But progress has now stalled.

We have not reduced rates of new HIV infection and annual HIV diagnoses remain stubbornly high. We have not reduced the proportion of people with HIV who are undiagnosed. Most people with HIV are still diagnosed late, after the point when they should have started treatment. People with HIV still experience stigma and discrimination and are more likely to struggle and live in poverty.

This situation is unacceptable in the UK in 2011. A national strategy for HIV is vital if we are to address these problems and once more make progress in responding to the HIV epidemic.

There have of course been great achievements - some of the best HIV treatment and care in the world, a strong legal framework against discrimination, real impacts on mother-to-child transmission and on infections amongst injecting drug users, to name just a few. But much more needs to be done. At a time when an increasing proportion of decisions are to be taken at a local level, there is a real danger that some of our progress, particularly in relation to prevention and testing, will be lost. This is not the time to abandon a strategic approach to HIV. It is the time to renew, refresh and extend it to meet the challenges of the next decade.

HIV is a serious health issue for the UK

HIV remains one of the most serious infectious diseases affecting the UK. There are over 90,000 people with HIV in the UK and the figure will soon reach 100,000. In London one in every 200 people has been diagnosed HIV positive. All areas of the country have seen increases in HIV over the last decade. Approaching 7,000 people are diagnosed with HIV every year.

Public understand and knowledge of HIV is poor and is getting worse. A recent Ipsos MORI poll commissioned by NAT revealed only three in ten adults were able to correctly identify the ways HIV is and is not transmitted. This lack of knowledge means that people are unable to protect themselves and others from HIV infection. And each new infection costs the UK up to £360,000 in direct lifetime medical costs alone.

Over a quarter of people with HIV do not know they are infected. The majority of transmissions come from people who are themselves unaware that they have HIV. More must be done to diagnose people and prevent further transmission.

Over half of people are diagnosed late (on average eight years after infection occurred), and some are already very ill when diagnosed. This leads to far higher annual treatment costs and is potentially fatal; of those who died of an HIV-related cause last year, over three-quarters were diagnosed late.

HIV stigma and discrimination still affect many people. This harms people with HIV and can deny them opportunities to contribute to and participate in society. So society is also the loser. Such stigma also seriously undermines our ability to respond to HIV effectively - it makes people afraid to test for HIV, and unwilling to think or talk about HIV-related risk.

HIV disproportionately affects some already vulnerable and socially excluded groups in our society. More needs to be done to meet the prevention needs of black African communities and gay and bisexual men - in both communities one in twenty have HIV. This is a health inequalities issue. However, there are also a rising number of UK-acquired infections amongst people not in high risk groups - they now account for about 25% of newly diagnosed UK infections every year.

Why do we need a UK HIV Strategy? …

Because strategic action makes the difference between progress and failure in the fight against HIV

How we respond to HIV makes an enormous difference to whether the epidemic increases or decreases in a population. It also makes a massive difference to whether people with HIV live long healthy lives or experience serious ill-health and earlier death. For example, the UK at the very beginning of the HIV epidemic introduced harm reduction measures to prevent infection amongst people who inject drugs - the result is we have one of the lowest rates of HIV amongst injecting drug users, compared for example with many other European countries where such measures were only introduced later, or Russia where harm reduction is still opposed and which has the fastest growing epidemic in the world. In relation to sexual transmission also, in Africa different countries have seen success or setbacks, depending on how strategically and effectively they have responded to the epidemic.

Because it ensures a joined-up and comprehensive response – the only approach which will work

There are a lot of different elements to tackling HIV effectively. We need treatment for HIV itself but also for the illnesses resulting from HIV infection and for mental health needs. We need prevention in a wide range of settings and for many different groups of people to support safer sex. We need laws and policies to stop stigma and discrimination against people with HIV and those groups most affected by HIV. We need good social care, better employment practice and increased efforts to tackle the poverty that so disproportionately affects people with HIV and undermines efforts to provide care. We need to look at policies such as those in our immigration system which are resulting in interruptions to treatment or which are deterring people from testing. We need to change an NHS which still allows the majority of people with HIV to remain undiagnosed for an average of eight years.

So a national strategy ensures that HIV is addressed by all necessary bodies in a consistent and mutually supportive way - Department for Education, Department for

Work and Pensions, UK Border Agency, for example, and not just Department of Health; GP practices, cancer specialties, and not just sexual health clinics; local government and not just the NHS; schools, media, employers, and not just HIV charities.

Because it provides leadership and expertise at a national level

HIV is an infectious disease and does not respect local government boundaries. A national epidemic needs to be addressed nationally. Inaction in one locality has an impact more widely as people move around the country.

HIV is a complex condition and expertise is needed to respond effectively to the variety of its medical and social challenges. Low prevalence areas will not have the numbers with HIV, the experience nor the resources to develop such expertise, for example on effective prevention or testing approaches. A national strategy ensures best practice is consistently adopted across the country and that no one 'reinvents the wheel'.

Because HIV is more than just a sexual health issue

Of course HIV in the UK is mainly transmitted sexually and so HIV has to be an essential consideration in our national approach to sexual health. But this is not sufficient for an effective response to HIV. In addition to addressing issues around sexual transmission, an HIV strategy has to look at HIV as a long-term condition with all the implications for lifetime healthcare, social care, psychological support, and self-management. The strategy must also focus on the very specific challenges around equality and human rights for people with HIV, aiming to eradicate the stigma and discrimination which so undermine HIV prevention and the well-being of people with HIV.

Because it ensures HIV is not neglected or side-lined

HIV is a stigmatised condition which affects often socially unpopular groups – such as gay men, people who inject drugs, migrants from certain countries – and which may be linked to behaviours which some people dislike or disapprove of. An effective response will have to involve a wide variety of organisations and individuals at national and local level working together to a shared and consistent vision. There is an ongoing risk of at best neglect or at worst harmful and discriminatory policies and practice arising from such stigma, unless there is clear and principled leadership from the centre on the importance of addressing HIV, and on the need for our response to be based on evidence and human rights.

Because this is internationally agreed best practice – and an international commitment

In 2001 the UK, along with countries from around the world, signed the United Nations Declaration of Commitment on HIV and AIDS, and pledged to take action to tackle HIV both within the UK and globally.

The Declaration acknowledges the importance of strong leadership in tackling HIV nationally. The UK committed to developing and implementing a multi-sectoral strategy for combating HIV which confronts stigma, eliminates discrimination, promotes human rights including the right to the highest attainable standard of physical and mental health, addresses risk, prevention, care, treatment and support.

This is seen as important for all countries, not just low-income countries or those with a generalised epidemic. Without a UK HIV strategy, we are currently in breach of our international commitments and failing to meet best practice in addressing the epidemic.

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Q&As

Q: Hasn't the Government announced they are developing a sexual health policy document? Won't that give us a strategy for HIV?

A: The Government's planned document is not described as a strategy and in any event will not be sufficient to tackle HIV. Sexual health policy will only address HIV as a sexually transmitted infection. But it is also transmitted through sharing injecting equipment. Furthermore, it is not curable and so any strategy must consider HIV as a serious long-term condition. It is also highly stigmatised so a third core element in any strategy is how to deal with stigma and discrimination and ensure equality for people living with HIV.

Q: Don't' Scotland and Wales already have HIV strategies?

A: Yes they do and they are very important – but England has 95% of all people in the UK with HIV and there is no strategy for them. Furthermore, although health policy is a devolved mater, there are other very relevant policies such as those on immigration, benefits and equality which remain UK-wide and where we need a UK-wide approach. So a UK strategy is needed which meets need in England, which is coordinated with those in the other three nations and which also addresses key UK-wide policy issues.

Q: Why should HIV be treated differently to other health conditions? Why is it special?

A: We don't think HIV should be treated differently. All we want is for it to be treated equally. In the UK currently we have strategies tackling a variety of medical conditions, including a mental health strategy, a cancer strategy, and an autism strategy. HIV is an infectious, preventable, long-term and complex condition which also requires a comprehensive, strategic approach.

Q: Why can't it all just be done locally?

A: HIV still only affects small numbers of people compared with many other health conditions, though those with HIV are disproportionately concentrated in particular communities and groups. Low numbers mean many local authorities may ignore HIV issues. HIV is also a complex condition both medically and socially - how to prevent HIV transmission, improve testing and provide good treatment and care for people living with HIV requires expertise which is simply not available in every local area. It is sensible and cost-effective to provide such expertise from the centre in a national strategy. Finally, HIV can attract prejudice and moralising judgements which harm an effective response - at a local level the voice of people with HIV and affected communities may not be strong enough to counteract such a tendency. At a national level a strategy is far more likely to be free of such prejudice and be based on rights and evidence, with the voices of people with HIV heard and respected.

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