



## HIV PREVENTION IN ENGLAND: A VISION FOR THE FUTURE

### 1. Why should HIV prevention be a national priority?

Every year between 6,000 and 7,000 people are diagnosed in England with HIV, a preventable infectious disease. This is three times the number of a decade ago. HIV is a serious condition which if untreated leads to the destruction of the immune system and death. Treatment, however, now means that those diagnosed in time can lead full lives and enjoy a near-normal lifespan. This should not, however, weaken our prevention efforts, for a number of reasons.

#### 1.1 *The Economic Argument*

One reason is simply the economic one. The Health Protection Agency has estimated that one new infection means between £280,000 and £360,000 in direct lifetime health costs for the public purse. And this does not include possible related costs should there be time off work, or a need for benefits or social care, nor the costs of other illness which may arise as a result of HIV infection, nor the substantial additional costs from any further person or people who get HIV from that individual. The HPA estimate that had we prevented all the UK-acquired infections diagnosed in 2008 we would have reduced future HIV-related direct costs by £1.1 billion.<sup>1</sup>

#### 1.2 *The Health Argument*

Whilst treatment is now very effective, HIV is still a very serious health condition. It is incurable, and treatment once begun cannot be interrupted or stopped without serious health implications. It results in higher levels of mental health problems, and increased prevalence of cardiovascular disease, renal problems, osteoporosis, lung and anal cancers, as well as accelerating the ageing process. Whilst some people do well on treatment, others do less well. For many people with HIV their health fluctuates, and there are side-effects of treatment such as severe fatigue, diarrhoea and depression. There is an obligation to our fellow-citizens to minimise the numbers who have to cope with this long-term condition.

#### 1.3 *The Health Inequalities Argument*

There are of course other health conditions much more widely prevalent in society which also need to be addressed. But when considering where we focus attention and place resources we must do more than look at gross national data. There has been for a number of years a welcome policy concern to address health inequalities, and look at particular sections of society disproportionately affected by ill-health.

About one in 800 people overall have HIV. But amongst gay men it is one in twenty (and amongst gay men in London one in ten, in Brighton one in eight). Similarly, one in twenty have HIV in African communities in the UK. So for these minorities - who also experience health inequalities in other areas - HIV is a public health crisis. A concern for health equality recognises the ethical case to invest in prevention to protect the well-being of these groups and reduce the excessive burden of HIV-related ill-health.

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<sup>1</sup> HPA 2009 'HIV in the United Kingdom: 2009 Report'

## **2. How are we doing at HIV prevention?**

The key outcome in terms of success in HIV prevention must be a decline in HIV incidence (the rate of new HIV infections in a population). This is, however, hard to estimate since people are diagnosed with HIV often many years after infection occurred, making it hard to get a 'real time' sense of what is happening. It is hoped that newly developed 'RITA' testing might enable us to get a better sense of incidence in the UK. An important proxy for prevention success, however, is rates of unprotected sex. In the last decade we have seen significant increases and then a plateau at a high level in rates of unprotected sex amongst gay and bisexual men. Furthermore 10% of Africans surveyed by Sigma Research reported unprotected sex with a partner of a different HIV status in the last year. If annual HIV diagnoses of UK-acquired infections are looked at there has been an inexorable increase over the last ten years.

More broadly there has been a significant decline in public knowledge of how HIV is transmitted when compared with ten years ago, with 20% of people in 2010 not knowing HIV is transmitted by sex without a condom between a man and a woman, and the same percentage not knowing it can be transmitted by sex without a condom between two men. 18% of people between 18 and 24 do not feel they know enough about HIV to protect themselves from transmission and 52% of this age group would be interested to know more about HIV today (as do 44% of the public overall).<sup>2</sup> This stark evidence of need is matched by data showing that about 25% of UK-acquired infections now diagnosed in any year are amongst non-African heterosexuals, whose prevention needs are currently not met by any national prevention programme.

All these statistics suggest there is substantial unmet prevention need which we should be addressing. It could well have been worse had it not been for the prevention that has been done over recent years. But given the rates of unprotected sex being reported and the continuing high number of new HIV diagnoses, it is not enough simply to ask for 'more of the same'. It is necessary also to ask ourselves whether there are things to do which we have not as yet done, and things which we should do differently.

## **3. What needs to change in HIV prevention?**

NAT believes there is much we can do to improve the quality and effectiveness of HIV prevention in England. This involves altering the structures and processes for our prevention activity, and also its content. We acknowledge we are currently in a period of transition to different NHS and public health structures. We trust the DH sexual health document will look towards arrangements post-April 2013 and identify appropriate actions which can be implemented in the intervening period to improve our response to the HIV epidemic.

### **Structures and Processes**

#### *3.1 Re-organise HIV prevention work at the national level*

There are currently two national HIV prevention programmes - CHAPS, which serves men who have sex with men (MSM); and NAHIP, which serves African communities - and their contracts come to an end in March 2012. It is vitally important that HIV prevention work continues to be funded by the DH at the national level. The national HIV prevention programmes have provided research, resources, and guidance on how to deliver effective HIV prevention work, which are invaluable for those working at the local level on targeted HIV prevention work. They represent a central fund of knowledge and expertise which it is essential to maintain. For such marginalised communities, always a minority at the local level, it is only at the national level that

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<sup>2</sup> For more information see 'HIV - Public Knowledge and Attitudes, 2010' NAT January 2011

there can be the 'economy of scale' to develop resources, commission research, gather evidence of best practice and strategise interventions.

Going forward, however, we believe there are some fundamental changes which should be made to our national HIV prevention work. Responsibility for this work will be handed over formally to Public Health England (PHE) in April 2013. We trust that the DH sexual health document will in the intervening period introduce some of the key changes to ensure PHE inherits an appropriately funded and effective national contribution to reducing HIV incidence.

- National HIV prevention work should not solely focus on the two most affected populations, MSM and African communities, but additionally embrace within its strategy and functions the HIV prevention needs of the wider public and other specific communities (for example black Caribbean communities).
- An HIV prevention programme board should be established with responsibility to
  - develop a strategic approach nationally to HIV prevention,
  - shape a common evaluation framework,
  - propose prevention activities which could usefully be funded at the national level,
  - advise on the approval of applications for national HIV prevention funding,
  - provide guidance to local authorities on the planning and commissioning of local HIV prevention work,
  - receive and comment on progress reports, and
  - oversee the independent evaluation of activities funded by national HIV prevention monies.

The Board should include not just a range of voluntary sector representatives but also epidemiologists, clinical and behavioural scientists, clinicians and local authority representatives

- There must be much greater transparency for nationally funded HIV prevention work, including on the funds provided and how they are disbursed, more details of best practice around the country, and evidence of success. At the moment it is extremely difficult to find any of this out. The result is confusion as to the role and purpose of the programmes and a loss of confidence in their work. Furthermore, such transparency is necessary given that taxpayers' money is involved.
- Funding for national HIV prevention work should be increased. The recent House of Lords select committee report made a compelling case that funding is currently inadequate to meet need.

### *3.2 Prioritise and incentivise investment in prevention at the local level*

There has at the local level over the last ten years been disinvestment in targeted HIV prevention activities by Primary Care Trusts, even though annual HIV diagnoses have increased significantly, with much higher rates of unprotected sex in at-risk groups compared with the late 1990s. There are high-prevalence areas which have no dedicated HIV prevention funding and more generally there is widespread confusion even within PCTs as to what funding is going into HIV prevention work. There seems in some places to be a mistaken belief that prevention is 'taken care of' by the national HIV prevention programmes and nothing more is necessary, when in fact the programmes are designed simply to catalyse action at the local level.

The establishment of Public Health England (PHE), a ring-fenced public health budget and the responsibility for health improvement being moved to local authorities, all should mean an opportunity to re-focus on the need to plan and resource HIV prevention at the local level. Whilst local authorities should of course have considerable discretion as to how to meet local prevention need, there needs also for a sensitive and stigmatised condition such as HIV to be greater details in the local authority mandate from PHE than would otherwise be the case:

- All local authorities should be required in their future joint strategic needs assessments to include assessment of HIV prevention and testing needs, and to reflect those needs appropriately in joint health and wellbeing strategies.
- All local authorities should consider how best to use resources made available via the national HIV prevention programmes.
- All local authorities should consider what HIV prevention activities might be more useful and effectively undertaken at a wider geographical level through local authority cooperation.
- All local authorities should dedicate funds from their ring-fenced public health budgets for community-based sexual health interventions which include targeted HIV prevention work for most-at-risk communities.
- All local authorities consider opportunities to integrate HIV prevention messages into broader sexual health campaigns and information.
- There should be clarity and consistency as to how HIV prevention activities and funding are defined and recorded so as to monitor activity across local authorities accurately.
- The Department of Health/Public Health England should determine, and provide advice on, a meaningful national HIV prevention outcome to enable local authorities to assess the progress and success of their interventions. Draft outcomes currently published relate to HIV testing but do not directly address HIV prevention need. There may also be scope for developing advice on further prevention indicators which can be adopted at the local level.

### 3.3 *Begin to evaluate our prevention work properly*

There is currently a lack of consensus on how to evaluate our HIV prevention work - the result being in some quarters a loss of confidence in investing in these vital interventions. The government-funded national HIV prevention programmes tend simply to assess in small samples how many people recognise particular campaigns. There needs to be a new emphasis on outcomes, in particular in behaviour change.

To that end, we need:

- A national consensus developed on how to evaluate effectively HIV prevention in terms of reduced risk-taking behaviours
- Prevention work commissioned with evaluation as an integrated aspect of the activity
- Investment in the research capacity necessary to undertake evidence-based evaluation work, for example in cohort studies
- The development of outcome indicators for prevention at local and national levels with appropriate data collection to enable us to monitor progress
- Independent evaluation undertaken of nationally funded prevention work, overseen by the proposed HIV prevention programme board.

### 3.4 *Involve HIV/GU clinics in HIV prevention strategies and interventions*

Much of the high-profile and funded HIV prevention work has been undertaken by community organisations. Increasingly it is apparent that HIV/GU clinics have a key role to play in reducing HIV incidence. HIV prevention strategies at national and local levels need to involve HIV clinical staff at the stage of strategy development and integrate and resource clinic-based activity to complement community-based work.

Key activities for clinics will involve:

- provision and promotion of HIV testing,
- support of people living with HIV on treatment to maximise the proportion with an undetectable viral load,
- support of people with HIV in the management of sexual risk, STI diagnosis, disclosure and safer sex
- behavioural one-to-one interventions with those at elevated risk of HIV infection (these can also be provided by community organisations but the clinic is an important opportunity for such interventions).

### 3.5 *Create health partnerships with businesses to reduce risk-taking behaviours amongst most affected groups*

There are many businesses which specifically serve particular communities. For those businesses in gay, African and Caribbean communities there are numerous opportunities to engage customers with accessible information relating to safer sex, HIV risk and HIV testing, as well as signposting to further advice and support. Their brand support for HIV awareness can itself recommend the issue to customers as something for serious consideration. Prevention efforts should increase partnership working with relevant community businesses.

There are also current examples, in other areas of public health, such as alcohol-use and obesity, of engaging relevant businesses who affect behaviour patterns and consumption (for example through the Public Health Responsibility Deal). The same approach is needed for HIV prevention. A good start would be working with gay businesses and in particular those of the 'gay scene'. This is not only about gay businesses promoting HIV prevention messages and encouraging testing, though this is necessary. It is also about such businesses looking self-critically at their own activities to ensure they do not promote high-risk sexual behaviours.

## **Content**

### 3.6 *Re-formulate our prevention messages*

HIV prevention messages and campaigns have often been of high quality but there are elements which have been missing. In particular:

- Campaigns need to motivate people, in an era of effective treatment, to avoid HIV infection. This does not mean basing campaigns on fear or exaggerating the negative consequences of infection or treatment. It does mean explaining clearly how difficult it can be to live with such an incurable long-term condition.
- There needs to be clarity that in any single act of anal or vaginal intercourse the best way to prevent HIV transmission is the correct use of a condom and lubricant. Some information on other 'harm reduction' approaches (for example, on avoiding poppers during anal intercourse), whilst useful, has omitted this vital point and inadvertently undermined condom advocacy.

- Changes in partner numbers and patterns need also to be advocated as an effective approach to reducing risk of HIV transmission. Internationally, it has been a combination of increased condom use and reduced partner numbers which has shown most impact in reducing HIV infection rates but in the UK there has been to date a lack of information on partner numbers and HIV risk, particularly for gay and bisexual men

### 3.7 *Reduce late diagnosis and increase early diagnosis*

Over half of HIV diagnoses in any year are 'late', that is after the time when HIV treatment should have begun. This is the rough equivalent of five or more years living with HIV undiagnosed during which time there is of course a much greater risk of unknowingly passing HIV on to sexual partners. With an HIV positive diagnosis people tend to become more aware of HIV transmission risk and the need for safer sex to protect others, and HIV treatment significantly reduces infectiousness (see below). Increasing HIV testing and reducing late diagnosis is therefore a key preventive intervention as well as being immensely important for the health of those concerned.

It is estimated that between 50 and 70% of HIV transmissions are from those who have themselves only recently been infected and who are in the highly infectious early stage of 'primary HIV infection'. Therefore to have a significant preventive impact in addition to reducing late diagnosis we need to increase early diagnosis.

England therefore needs an HIV testing strategy developed in light of these preventive benefits. In particular:

- Improved HIV testing needs to be incentivised at national and local levels by an agreed Public Health Outcome Indicator around late HIV diagnosis and by provider payment mechanisms.
- Annual HIV testing, and more frequently according to risk, needs to be strongly promoted amongst sexually active gay and bisexual men.
- A consensus needs to be developed on recommended frequency of HIV testing for those from African communities.
- Both gay and African communities should be educated about the symptoms of primary HIV infection.
- Healthcare workers (especially those in primary care and emergency medicine) should be trained to recognise possible symptoms of primary HIV infection and recommend HIV testing
- Best practice around partner notification should be determined and disseminated, and outcomes evaluated, to drive up HIV diagnoses.
- HIV testing across a wide range of healthcare settings should be rolled out in accordance with the BHIVA/BASHH/BIS UK National HIV Testing Guidelines and NICE Public Health Guidance.
- HIV home testing should be legalised and effectively regulated..
- Disincentives to HIV testing need to be addressed - for African men and women there are particular concerns, some justified, around confidentiality, entitlement to treatment and immigration processes where much more can be done to allay fears and incentivise testing. There must also be concerted and strategic work to address HIV stigma and discrimination which are a deterrent to people finding out their HIV status.

### 3.8 *Maximise the proportion of diagnosed HIV positive people who have a suppressed viral load*

It has in recent years become apparent that people with HIV on treatment whose viral load is suppressed to an undetectable level have their infectiousness so reduced that it is extremely unlikely they will pass on HIV. In London there have been agreed indicators for the quality of HIV treatment and care, one of which is an undetectable viral load one year after starting anti-retrovirals (achieved last year for 90% of London patients).

- Outcome indicators around the proportion of HIV positive patients with a suppressed viral load should be rolled out nationally
- HPA statistics suggest a significant proportion of people diagnosed with HIV are not on anti-retrovirals even though their CD4 count indicates they should be. This appears to be particularly the case amongst younger people. There are also some concerns about the numbers of people diagnosed but then lost to care. Further work must be done to maximise the entry of those diagnosed with HIV into treatment and care, and commencement of ARVs when clinically recommended.
- More generally, it should be recognised that wider social care and psychological support are essential components in keeping many people adhering to their medication and so virally suppressed. Appropriate services (including peer support) should be provided to support individuals who need it.
- Clear guidance should be developed on the early initiation of HIV treatment for those who are at ongoing risk of transmitting HIV to sexual partners.

### 3.9 *Develop HIV prevention strategies to meet the needs of the wider population*

The HIV epidemic in England has changed over time. It began as a predominantly homosexual epidemic and then changed as it also affected Africans who had migrated to the UK. There has for the last few years also been an increasing number of new HIV diagnoses of heterosexuals who have acquired HIV in the UK and who are not from African communities. In 2008 this group accounted for about a quarter of new UK-acquired HIV diagnoses but they are not served by either of the two national HIV prevention programmes, CHAPS and NAHIP.

Whilst HIV prevalence in the wider UK population may be low, such new diagnoses will continue to increase in terms of absolute numbers with all the related serious implications for the individuals concerned and for healthcare provision. The Government must commit itself to appropriate HIV prevention and testing interventions to meet the needs of the wider public.<sup>3</sup> These could include

- integrating HIV information into wider sexual health campaigns,
- general HIV prevention and testing campaigns in high prevalence areas (for example, in parts of London),
- improved and consistent HIV information required to be taught in all schools.

In addition, Caribbean communities have about three times the HIV prevalence of the wider British population, as well as poorer outcomes for other aspects of sexual health. A strategic approach to addressing HIV in Caribbean populations should be developed as a priority, in the first instance by those local authorities in regions with significant need - in London and the Midlands - and linked to wider sexual health work.

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<sup>3</sup> For detailed consideration of this issue see NAT 'HIV Prevention and the Wider UK Population' 2011

### *3.10 Ensure all young people received high quality sex and relationships education and are taught about HIV in secondary school*

Young people do not recall the AIDS awareness campaigns of the 1980s and 1990s. There have been no public information campaigns around HIV for well over a decade nor are we aware of any plans for one. Sex and relationships education (SRE) in schools is thus the one opportunity for population-based information around sexual health, safer sex, the risks of HIV transmission and different kinds of sexual relationship, including same-sex relationships. Progress has been made in developing the SRE curriculum to address these issues. But problems remain, including the poor training of teachers and the fact that schools are free to decline to teach SRE. Further work on the SRE curriculum and on teacher training must be undertaken with the explicit aim of ensuring high levels of HIV awareness amongst the general public, and support for safer sex for young gay men. SRE (as part of Personal, Social, Health and Economic (PSHE) Education) should become a compulsory part of the National Curriculum.

It is also necessary to maintain HIV as a compulsory part of the school curriculum and improve the quality of the content taught.<sup>4</sup>

### *3.11 Maintain and enhance further those high quality prevention efforts which have been shown to work*

There are some targeted prevention efforts of which we should be proud and which have been extremely effective. One is routine opt-out ante-natal screening and the treatment of those pregnant women who are HIV positive to ensure the baby is born without HIV. This has resulted in the near eradication of mother-to-child transmission in the UK.

Similarly, the early and robust adoption of harm reduction measures for injecting drug users at the outset of the HIV epidemic - for example, provision of clean injecting equipment and of opioid substitution therapy (OST, e.g methadone) - has meant HIV prevalence amongst IDUs is relatively low compared with other countries and only a small percentage of people with HIV being seen for care were infected by injecting drug use (only 2%, of whom a significant number would have been infected abroad).

A third area where the UK has modelled an effective response to the HIV epidemic is in the quality of its surveillance data collected by the Health Protection Agency, and in relation to mother-to-child transmission by the National Study of HIV in Pregnancy and Childhood (NSHPC) and the Collaborative HIV Paediatric Study (CHIPS). The work of these organisations is essential in determining how well we are doing in HIV prevention and where to focus greater prevention efforts.

Successes tend to be lost if taken for granted, and it is important consciously to aim to maintain and even improve on these achievements. Whilst overall uptake of HIV testing is very high in ante-natal units, this masks significant variation between regions. With respect to IDUs there has been a worrying increase in HIV prevalence in London. Current concerns not to maintain people indefinitely on methadone may if misapplied propel drug-dependent individuals back into risk-taking behaviours. Reorganisation of public bodies may, if mishandled, threaten the quality and scope of essential HIV surveillance work. There are, in other words, present threats to our past success and plenty of evidence that there is still more to do.

## **NAT October 2011**

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<sup>4</sup> In England HIV is taught within biology as a compulsory part of the national curriculum. The content of the national curriculum is currently under review. It is essential that any changes do not result in the loss of the limited compulsory education young people receive on HIV.

**Further NAT references:**

**HIV Prevention and the Wider UK Population 2011**

**And also:**

**HIV - Public Knowledge and Attitudes 2010**

**HIV Testing Action Plan 2009**

**Home Testing for HIV 2008**

**Primary HIV Infection 2008**

**Primary HIV Infection: knowledge amongst gay men 2011**

**Partnership Patterns and HIV Prevention amongst MSM 2010**

**HIV Treatment as Prevention 2011**

**HIV and black Caribbean communities in the UK 2010**

**Injecting drug users and HIV 2010**

**Tackling Blood-Borne Viruses in Prisons 2011**