Independent Advisory Group
on Sexual Health and HIV

Building on progress

Enhancing the response to HIV in England

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Independent Advisory Group on Sexual Health and HIV
Working Group Report

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Foreword

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November 2009

The Independent Advisory Group on Sexual Health and HIV (IAG) was established in 2003 to provide advice to the Government on its Sexual Health and HIV Strategy for England[1]. In the last three years, the Advisory Group has published 'Public health policy HIV and AIDS'[2] (2007). It has also conducted a major mid-term review of the National Strategy for Sexual Health and HIV, 'Progress and priorities – Working together for high-quality sexual health'[3], which was produced by MedFASH (2008) and to which the Government has recently responded (July 2009)[4].

Both these publications – and other work undertaken by the IAG – point to the need for more to be done in the following areas: an increase in prevention activity especially at local level, planning for the future provision of clinical and social care services to meet changing needs and demands for those with HIV, along with increased efforts to identify people with HIV earlier so they can access appropriate support and treatment. The recommendations in this report are designed, in the main, to dovetail with current programmes already underway and contribute positively to England's ever evolving HIV services.

The human immunodeficiency virus (HIV) was first identified in 1983 – 20 years before IAG's inception. It is hard to remember the profound impact HIV had on society then. The discovery of HIV and the condition that became known as AIDS was on the front pages of newspapers and in the public eye day after day as the news of this virus which attacked the human immune system reverberated around the world.

At a time before effective treatments existed, the response to HIV was innovative and pioneering. New voluntary organisations mushroomed nationally. Many were set up by people with HIV, their friends and families, often in order to meet the needs arising from the impact HIV was having on their lives in the absence of appropriate services. Early interventions, open access to confidential services, and community-based responses, along with initiatives such as 'buddying' schemes, living wills, needle exchange and condom distribution, became part of a range of recognised provision across the UK and around the world.

These new organisations and innovative approaches are now the bedrock of HIV prevention and care in our society and undoubtedly a reason the UK hasn't experienced the same levels of HIV as many other European countries.[5]

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[1] Better prevention, better services, better sexual health - The National Strategy for sexual health and HIV http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003133

[2] Public Health Policy, HIV and AIDS, IAG published date etc.

[3] Progress and priorities review of the National Strategy for sexual health and HIV, http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/@dh/documents/digitalasset/dh_086741.pdf

[4] Moving forward: progress and priorities - working together for high quality sexual health: Government response to the Independent Advisory Group's review of the Sexual Health and HIV Strategy http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103090 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103090

[5] UNAIDS – unaids.org

In 1983, faced with an unprecedented situation, the Government response was rapid – comprehensive, pragmatic and sustained. The strategy was supported with an unparalleled allocation of resources to alert the general public to the risks of HIV.

Now, HIV has for many people evolved into a long-term condition. As a result, the sense of urgency so obvious in the 1980s has ebbed. In fact, it can be argued that the profile of HIV in this country is too low and that newer generations are not as well-versed in HIV as they should be, both from a personal protection point of view and in terms of increasing understanding about the disease and creating an HIV-literate society.

HIV-related stigma and discrimination is still a reality for many people, especially as groups who are most affected – gay men and Africans living in the UK – remain marginalised in many spheres. HIV is an ever changing field and, as we continue to learn more about the disease and its impact, the need to regularly review and update the provision of HIV services to keep up with these advances is vital.

When writing this report, the following facts were key to the development of our recommendations:

1. HPA data suggest sustained high levels of new diagnoses in the UK with a slight fall in diagnoses among black Africans which are probably related to migration patterns. New diagnoses among Men who have Sex with Men (MSM) remain high in 2008.

   There is also evidence of a slow but steady increase in new diagnoses acquired heterosexually within the UK. These data highlight the need for more and sustained prevention programmes.
2. Over a quarter of people with HIV do not know they have the virus.
3. There are 8,000 people with HIV who are over 50 which accounts for ten percent of the total number of people diagnosed. With an ageing HIV population, and one that includes many African families affected by HIV, the social needs of people with HIV are changing and growing.
4. Support and funding for social care are at risk.

As we reach the ninth year of the National Strategy for Sexual Health and HIV, the IAG has worked alongside the Department of Health to consider the priorities for HIV and HIV services.

A great deal is already being done to address new developments and ideas in our response to HIV but this is not always part of an overall plan that is shared and embedded at the local level. HIV may be seen to be significant when looked at from a regional perspective but not at the individual Primary Care Trust (PCT) or local authority level.

What we have mainly identified is the need to respond more quickly to new advances and ensure that guidance can be applied broadly. We hope this report is a useful aid in informing future decisions. I would like to thank everyone who has contributed to its development and to recognise that there are many groups around the country doing excellent work who are not mentioned specifically.

Methodology

Much of the information in this report derives from qualitative work. The IAG Working Group on HIV ran a programme of three workshops addressing:

- Prevention;
- Services; and
- Stigma and discrimination.

The working group was chaired by Derek Bodell, Deputy Chair of the IAG on Sexual Health and HIV.

Membership of the IAG Working Group on HIV comprised an extensive network covering medical, social and personal knowledge of HIV, as well as skills in prevention, treatment, care, research and service provision. This facilitated access to some of the most up-to-date, best-informed advice available, both from the IAG and a broader expert constituency. A list of members of the working group is given on page 18.

As well as the findings of the workshops, the activity for this report coincided with the Department of Health's review and proposed revision of its national HIV prevention contracts. These are CHAPS (Community HIV and AIDS Prevention Strategy) for gay and bisexual men, the National African HIV Prevention Programme (NAHIP), and the African AIDS Helpline.

The Department of Health asked the IAG to augment the working group's activity with a programme of four regional meetings that looked at these contracts. The feedback from those meetings, documented separately, has informed this report and contributed to the Department of Health review.

The IAG Working Group on HIV also commissioned two reports:

'Investment in behavioural and biomedical research for an improved UK response to HIV' by Professor Graham Hart[6] from University College London, which addresses the gaps in respect of research and development.

'The potential impact of Anti-Retrovirals and new prevention technologies on HIV transmission in the UK' by Keith Alcorn[7] from NAM, which assesses the likely impact of Anti-Retrovirals (ARVs) and new prevention technologies on future prevention and support services in the UK.

In addition, the IAG received a paper by Elisabeth Crafer on a gendered approach to HIV which formed a further part of our source material.[8]

The National AIDS Trust (NAT) produced a policy analysis from which important points have been drawn in formulating our recommendations and this can be found on the NAT website at **www.nat.org.uk**.

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[6] Investment in behavioural and biomedical research for an improved UK response to HIV, see appendices page 28

[7] The potential impact of Anti-Retrovirals and new prevention technologies on HIV transmission in the UK, see appendices page 20

[8] Gendered approach to HIV, see appendices page 31

Executive Summary

'Building on progress - Enhancing the response to HIV in England' reviews the changing landscape of HIV and HIV services in England and considers what needs to be addressed when planning services for the future.

This report addresses concerns relating to policy, prevention, research and service planning. It also reviews issues around stigma and discrimination.

HIV, once seen as a death sentence, has become a long-term condition for most people diagnosed early and receiving good treatment and on-going monitoring. This is due to progress in Highly Active Anti-Retroviral Therapy (HAART).

At the end of 2007, there were 52,000 people accessing HIV services in the UK[9]. Fifteen percent of those accessing services are now over 50 and this percentage will continue to increase[10]. The greater longevity of people with HIV means future services will need to contend with complex issues associated with an ageing population and all the related issues of pensions, the effect of HIV treatment on medication that may be needed to deal ageing, long-term care and the continuing challenges of HIV-related stigma.

Because of the increased longevity of those with HIV, both social services and the NHS face new challenges that will involve significant co-ordination within their services and across government departments and regions. It is important that the development of policies to effect change and their implementation are made consciously and strategically. As well as gay men, other groups that may be affected by HIV – such as black Africans and their families – will continue to require service provision, all of which needs to be planned for. For this reason, our first recommendation is that the Department of Health build on the Cross-Governmental Forum already established by the Department for International Development (DFID). This forum should comprise a top-level membership – both politically and within the health and social care services – and its role should be to review policies that impact on HIV in England and, where appropriate, the UK (page 7).

Our recommendations addressing the needs of people living with HIV focus on ensuring that engagement through statutory Patient and Public Engagement (PPE) is as effective as possible and identifying new and innovative ways to ensure participation and consultation (page 8).

We also provide a series of recommendations for a possible cross-governmental response to stigma and discrimination which includes the Department of Health, the Home Office, the Department for Work and Pensions, the Ministry of Justice and the Department for Children Schools and Families (page 14).

We strive for an 'HIV-literate' medical and social care workforce. There are still considerable gaps in knowledge about HIV among this group. A wider range of secondary care - and necessary competences in the workforce – is now needed. At the moment, no national standards for social care exist despite a commitment to that effect in the National Strategy. Although the idea of standards was not raised specifically in our discussions, it may be useful for this to be explored further by the Department of Health in collaboration with Communities and Local Government. Encouragingly, the Department of Health is investing in e-learning programmes for GPs and Practice

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[9] Sophid data Health Protection Agency http://www.hpa.org.uk/webw/HPAweb&HPAwebStandard/HPAweb_C/1195733790666?p=1201094588844.

[10] Health Protection Agency www.hpa.org.uk

Nurses on sexual health as a means of improving dissemination of relevant research findings[11],and information about HIV and HIV testing should form part of this investment. However, more still needs to be done. Our report section on services includes the recommendation that HIV service provision overall should be consolidated and updated (page 16).

The drive from Government to improve access and move healthcare from acute care to primary and community settings, with an ensuing emphasis on self-care, is important for those living with HIV. The increased availability of improved diagnostic testing outside of clinical settings has, and will continue to have, profound and positive implications for people with HIV. Traditionally they been diagnosed and treated in acute settings but they may now be able to use an increased range of community-based services and support that are interlinked, with appropriate access to specialist clinically-led services.

We review how prevention, testing and health improvement might be enhanced with the aim of bringing down late diagnosis rates. This will require a government-backed programme to implement the UK national guidelines for HIV testing. We also consider how to ensure that all PCTs and SHAs are engaged in this activity (page 9).

An essential provision is the ring-fenced AIDS Support Grant (ASG) for local authorities to meet the social care needs of people with HIV. In 2007, the Government announced an increase in funding for the ASG of an additional £17.6 million over three years – this has only one year left to run. Our findings indicate that the ASG is a key part of good community and social care provision. The principles that supported its introduction are as pertinent now as they ever were and the ASG should be continued. The NAT's assessment of the impact of the ASG is relevant here[12]. We recommend the retention of the ASG (page 16).

An important aspect to emerge from the work of the IAG is the lack of a clear overview of the interventions and provision for HIV that exist at a local level across England. Changes in the NHS and a shift in the Government's role to primarily setting the policy agenda, with implementation now determined at a local level, has resulted in reduced investment and co-ordination by PCTs.

This in turn has led to an increased reliance in some areas on nationally funded initiatives such as CHAPS and NAHIP. These were designed to support and enhance local activity, never to be a substitute for it.

It would be helpful if key information on research findings, new developments in guidance on the care and treatment of people with HIV, and any details on local prevention initiatives and other HIV activity could be held nationally and made readily available. The Department of Health is considering a web-based portal or gateway to relevant research and evidence[13]. We welcome this as a good beginning but also make recommendations around evidence and dissemination which will provide a research and development strategy designed to capture the best national and local interventions there are (page13).

There is a vibrancy and creativity among the individuals and organisations working on HIV. 'Building on progress - Enhancing the response to HIV in England' aims to provide workable suggestions to harness and build on their commitment and energy to ensure that the future challenges posed by HIV in our society are met effectively and with grace.

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[11] Response to Progress and priorities http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103090

[12] AIDS Support Grant – making the difference? http://www.nat.org.uk/Media percent20library/Files/Policy/Poverty percent20and percent20Social percent20Disadvantage/AIDS percent20Support percent20Grant percent20NAT percent20review percent2011 percent20August percent202009-1.pdf

[13] ibid

Key recommendations

This section of the report outlines six main areas for which we make our recommendations. These are:

1. **National cross-governmental overview of HIV**
2. **Needs of people living with HIV**
3. **Prevention, testing and health improvement**
4. **Evidence and dissemination**
5. **Stigma and discrimination**
6. **Services**

Each area has key recommendations, drawn from the issues raised in the working groups. These are a selection of what we believe will most improve the HIV response and the lives of people living with and affected by HIV in England.

The key recommendations are listed below:

1 National cross-governmental overview of HIV

The IAG recommends:

- The Department of Health should build on the Cross-Government Forum established to support the DFID's HIV work, to broaden its remit and use it as a means of reviewing policies that impact on HIV in England and, where appropriate, the UK.

  The group should have senior level membership and be chaired by someone with an acknowledged standing on HIV. This person should be given the corresponding responsibility and resources to support an overview of the Government's strategic and policy priorities, along with the authority to monitor and review the impact of their implementation.

  There should be a regular national meeting on HIV as part of improved efforts to disseminate new guidance and advice; showcase good practice and research findings, and provide an opportunity to debate future priorities. The meeting should be open to participation by statutory agencies, voluntary organisations and groups of people living with and affected by HIV.

Rationale:

The evidence provided to the working group indicated that policies emanating from other government departments have an impact on the national HIV response. The most obvious has been criminal prosecutions of HIV transmission. But others arise in the provision of information and education in schools and the challenges arising from stigma and discrimination in many settings. This is specifically highlighted later in the document.

Whilst the Department of Health has supported efforts to address some of these concerns, this can be undermined if there is not broader involvement, or the impact of interventions is not monitored and evaluated to determine effectiveness.

We believe that at a minimum an annual cross-departmental meeting focused on domestic needs will assist the process of building HIV awareness across the spectrum of government. A group currently exists led by DFID, with the aim of supporting the Government's development agenda on HIV.

We propose that the remit of this group is broadened, along with the frequency of meetings, and that dedicated meetings are held on domestic issues with participation from appropriate voluntary and statutory agencies and professional groups to help inform and assist discussion and policy development.

This move could have implications for groups like the Department of Health Expert Advisory Group on AIDS (EAGA). It may be useful to examine how these can work together and certainly for EAGA to have full membership.

During the operation of the working group, it became clear that members' awareness of the advice, guidance and research that the Department of Health, among others, has supported, was lower than expected. From comments at the workshop, it also appears that existing national meetings do not provide the right forums for people working in HIV to debate, discuss and share information that may be useful to their own work or policies on prevention and care provision.

An appropriate forum would give an opportunity to highlight progress and be a focal point for media interest, other than World AIDS Day, which has rightly developed an increasingly international focus. It no longer provides the platform it once did to highlight the effect and needs of HIV in England and the rest of the UK.

The proposed collaboration between the George House Trust's Conference and the British HIV Association (BHIVA)/British Association for Sexual Health and HIV (BASHH) Conference for Spring 2010 in Manchester may provide a good opportunity to assess the value and potential of these types of events.

2 Needs of people living with HIV

The IAG recommends:

- The Department of Health produces and disseminates guidance that can be used by PCTs and local authorities as part of their ongoing responsibilities under Patient and Public Engagement (PPE). PPE involvement is a statutory requirement of all NHS organisations (See Section 11 Health & Social Care Act). The law places a duty on NHS Trusts, PCTs and Strategic Health Authorities (SHAs) to make arrangements to involve and consult patients and the public in service planning and operations and the development of proposals for change.

The proposed guidance should be based on the experiences of research groups and Non-Governmental Organisations (NGOs) who have established proven models to access and involve people with HIV in policy development and the planning of services. This guidance should include the use and value of web-based tools in consultations with people with HIV. As the lead, the Department of Health should work in collaboration with those with direct knowledge and experience, which includes NAM, Sigma Research, Terrence Higgins Trust (THT), NAT, the African HIV Policy Network (AHPN), and organised groups of people living with HIV. This work should be in consultation with the NHS Centre for Involvement.

Rationale:

With the impact of effective treatments on life expectancy, as well as HIV, increasingly recognised as a long-term condition, there is a growing need for the systematic involvement of people living with HIV in policy and planning at the local, regional and national level. Developments in the evolution of the condition are happening at a time when organisations exist that represent specific groups with HIV – such as PozFem, the National Network of Women with HIV – but there are no national organisations to represent the voices of all people with HIV. This is also occurring as the impact of an HIV diagnosis is changing, with the inevitable effect on current and longer term services.

The indications are that many people with HIV are less directly involved with HIV groups and increasingly look to other methods of contributing to consultations or surveys. Among these, web-based communication has proved most popular. Building on and disseminating the experiences of NAM and Sigma Research for local application is a valuable way of obtaining direct responses from people with HIV, particularly MSM, who are not otherwise easily accessed or identifiable.

3 Prevention, testing and health improvement

The IAG recommends:

- The active promotion of prevention activity and reducing late diagnosis activity at individual and joint PCT level, as appropriate, through the inclusion of HIV within the remit of the National Support Team (NST) - Sexual Health.
- The development of a prevention framework as recommended in the strategy review 'Progress and priorities – Working together for high-quality sexual health'.
- The development of a government-backed programme to implement the UK national guidelines for HIV testing.
- The development of specific plans for a programme to reduce late diagnosis that can be applied nationally, regionally and locally, as appropriate. This should be based on available national and international evidence and informed by the experience of Department of Health funded pilot projects and NHS London. This should take into account the growing debate that the target should be people with CD4 counts of less than 350 and not 200.
- The Department of Health, with the active involvement of the Regional Directors of Public Health (RDPH)'s sexual health leads in the SHA, and relevant staff from government offices, stages an England-wide "roadshow" to share the outcomes of the above recommendations with PCTs and SHAs, and promote their adoption and use.

- The Department of Health should initiate a review of the potential benefits of providing information on HIV to the general population, to sit alongside targeted prevention work.

Rationale:

The review of the National Strategy for Sexual Health and HIV, 'Progress and priorities – Working together for high-quality sexual health', found that sexual health, including HIV, was not seen as a priority by the majority of PCTs and it was a struggle in many areas to get funding.

An exception to this was around the 48-hour access target for Genito-Urinary Medicine (GUM) sexual health clinics, against which PCTs were monitored. However overall, the picture that emerged was of a fractured process where sexual health was not corporately owned by PCTs, and public health and commissioning often failed to establish clear collaboration.

In recent years, HIV has developed stronger links with the broader sex and reproductive health agenda. HIV can be seen within the overall work to promote a healthy and enjoyable sex life that also reduces the risk of unintended pregnancies and exposure to sexually transmitted infections.

However, the Workshop on HIV Prevention conclusions resonated with the MedFASH review findings that not enough HIV prevention work is being supported, particularly at the local and regional level, and there are still major challenges to make sure HIV education and prevention are properly integrated in broader sex education.

It is also clear from the workshop that there is an over-reliance on national HIV prevention programmes to meet all needs, when these were only intended to supplement work at the local level – itself very limited as previously mentioned. This is a further example of where effective interventions involve other government departments, in this case not just health, but education and local government.

In 'Progress and priorities', Priority for Action Four highlighted the need to invest in prevention across sexual health and at the national level to develop a prevention framework. This was intended to guide health promotion and prevention activity and also address the need for better coordination between national and local activity, as well as collaboration across departments. Our experience can only endorse this recommendation.

In relation to HIV treatment and care costs, figures can vary from £10,000 - 16,000 on average per patient per annum. This will depend on clinical need. But a clear consensus statement on the costs and what they include, particularly for commissioners and planners, would be useful, as would the economic benefits of early diagnosis and reducing levels of onward transmission.

Health Protection Agency (HPA) data suggests that a significant number of people with a CD4 count of 200 or below are not accessing HAART. This will inevitably be much greater for those with a CD4 of 350 or less. The reasons are varied (and include for example those only very recently diagnosed), but it is clear that a concerted and strategic effort must now be put into maximising the uptake of HAART, as is clinically recommended. It is possible, for example, that more can be done to communicate the effectiveness and greater tolerability of current HAART regimens.

Developments such as the Recent Infection Testing Algorithm (RITA, formally known as STARHS) testing are welcomed. RITA is now a routine component of the public health surveillance of HIV. These tests enable the identification of individuals who have been diagnosed within six months of infection, highlighting those groups at greatest risk of infection in the UK. Currently around half of all newly diagnosed HIV infections are being RITA tested, with national coverage planned by the end of 2010.

In 2007, the Chief Medical Officer (CMO) and Chief Nursing Officer sent a "Dear colleague" letter to all doctors and nurses in all healthcare settings to offer more HIV testing.

In September 2008, national guidelines on testing were produced by BHIVA, BASHH and British Infection Society (BIS)[14], recently reinforced by the CMO in a letter to the Presidents of Medical Royal Colleges and Chair of the Academy of Medical Royal Colleges. As stated in the guidelines, the aim has been to reduce late diagnosis of HIV infection, associated with increased mortality and morbidity[15]; impaired response to HAART[16], and increased cost to healthcare services[17].

Furthermore, from a public health perspective, knowledge of HIV status is associated with a reduction in risk behaviour[18]. It is therefore anticipated that earlier diagnosis will result in reduced onward transmission[19]. Modeling suggests that over half of new infections in the US occur through transmission from individuals in whom HIV has not been diagnosed. Furthermore, modeling in the US has suggested that routine screening for HIV infection is both cost-effective and comparable to the costs of other routinely offered screening where the prevalence of HIV exceeds 0.05 percent[20].

All published literature suggests that uptake of testing increases where universal routine ('opt-out') strategies have been adopted[21-23]. This is recommended in the new guidelines. Universal HIV ('opt-out') testing means all individuals attending specified settings are offered and recommended an HIV test as part of routine care, but with the option to refuse a test. NAT gives a rationale and recommendations for testing in primary care settings in their report, 'Primary HIV Prevention'.

The main message is that there is strong evidence that early diagnosis of HIV infection is being missed as healthcare workers do not recognise symptoms resulting from HIV infection that are presented to them. This also appears to be true when people present with indicator conditions such as tuberculosis (TB). In that instance, people presenting with TB symptoms are not routinely tested for HIV, even though the potential for co-infection is recognised around the world. The effect is a lost opportunity to the individual to know their diagnosis.

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14 BHIVA/BASHH/BIS UK National Testing Guidelines http://www.bhiva.org/files/file1031097.pdf

15 Health Protection Agency (HPA), Centre for Infections. The UK Collaborative Group for HIV and STI Surveillance.*Testing Times. HIV and other sexually transmitted infections in the United Kingdom: 2007*. http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1203084355941

16 Stöhr W, Dunn DT, Porter K et al. on behalf of the UK CHIC Study. CD4 cell count and initiation of antiretroviral therapy: trends in seven UK centres, 1997–2003. *HIV Medicine*, 2007, **8**, 135–41.

17 Krentz HB, Auld MC, Gill MJ. The high cost of medical care for patients who present late (CD4<200 cells/ L) with HIV infection. *HIV Medicine*, 2004, **5**, 93–8.

18 Marks G, Crepaz N, Janssen RS. Estimating sexual transmission of HIV from persons aware and unaware that they are infected with the virus in the USA. AIDS, 2006, **20**, 1447–50. http://www.aidsonline.com/pt/re/aids/pdfhandler.00002030-200606260-00012.pdf;jsessionid=LHGYMBT176T4KKms5qv9ynYGtQp7QnkvWryzQbJFB9jfm7v7Zz3v!1629792715!181195629!8091!-1

19 Vernazza P, Hirschel B, Bernasconi E *et al*. Les personnes séropositives ne souffrant d'aucune autre MST et suivant

20 Sanders GD, Bayoumi AM, Sundaram V et al. Cost-Effectiveness of Screening for HIV in the Era of Highly Active Antiretroviral Therapy. *New Engl J Med*, 2005, **352**, 570–85.

21 Simpson WM, Johnstone FD, Boyd FM *et al*. Uptake and acceptability of antenatal HIV testing: randomised controlled trial of different methods of offering the test. *BMJ*, 1998, **316**, 262–7.

22 Haukoos J, Hopkins E, Byyny R *et al*. and The Denver Emergency Department HIV Testing Study Group (2008). Opt-out Rapid HIV Screening in the Emergency Department: Preliminary Results from a Prospective Clinical Trial. CROI 2008, Abstr 544b. http://www.retroconference.org/2008/PDFs/544b.pdf

23 Cohan D, Gomez E, Charlebois E. Patient Perspectives and Testing Uptake with Abbreviated versus Standard Pretest HIV Counseling in the Prenatal Setting: A Randomized-Controlled, Non-inferiority Trial. CROI 2008; Abstr 535a. http://www.retroconference.org/2008/PDFs/535a.pdf un traitment antirétroviral efficace ne transmettent pas le VIH par voie sexuelle (An HIV-infected person on antiretroviral therapy with completely suppressed viraemia ("effective ART") is not sexually infectious). *Bulletin des Médecins Suisses*, 2008, **89**(5), 165–9. http://www.saez.ch/pdf_f/2008/2008-05/2008-05-089.PDF

Strong evidence also suggests primary HIV infection contributes significantly to onward HIV transmission. The individual is particularly infectious at this stage (one recent study estimated that early infection accounted for approximately 50 percent of onward transmissions [24]).

It is though only fair to recognise that HIV may not, on the face of it, lend itself to individual PCT action, especially when the numbers of people diagnosed with HIV resident in the PCT are so small. But if the public health needs of a larger area become the reference point, as it has in London, then the picture changes and the potential role of SHAs in facilitating collaboration across PCTs in their area is highlighted.

The Review of the National Strategy, 'Progress and priorities', identified in Priority for Action One that sexual health warranted action at all levels, including at regional level.

In the report, 'No time to wait: How many HIV-infected homosexual men are diagnosed late and consequently die?'[25], Tim Chadborn and colleagues concluded "The continued late diagnosis of one in four MSM means these individuals lose the option to start therapy early, miss opportunities to prevent further transmission and are approximately ten times more likely to die within a year of diagnosis. Early diagnosis of all MSM in 2001 could have reduced short-term mortality by 84 percent and all mortality in that year by 22 percent."

Further, they noted that: "Late diagnosis disproportionately affected individuals diagnosed outside London, of non-white ethnicity, and of older age." In terms of cost, a study in the US reported by Krentz HB, 'The high cost of medical care for patients who present late (CD4 <200 cells/ l) with HIV infection'[26] indicated that early diagnosis and treatment is also cost effective, with direct care costs for late presenters (CD4+ cells <200/ l) estimated to be 200 percent higher than for early presenters. Although in England provision of HAART for people with CD4 cell counts of 200 or less has been policy since 2001, the issue is still how to ensure that people access testing services.

This is an issue being examined by other countries. The French National AIDS Council recently released their findings which led to recommendations for a major push on testing, an approach many groups in England share.

London PCTs and NHS London have committed to work together, with a focus on reducing levels of undiagnosed HIV. To this end, they have developed an HIV Prevention Performance Indicator, which the Sexual Health Strategy Review has recommended as a pilot for an indicator nationally. This is within a care pathway to reduce onward transmission by earlier diagnosis of HIV; appropriate referral to HIV treatment and care; counselling; positive self-management, and other support for healthier lives and choices for people with HIV.

At the same time, the Department of Health has funded a MedFASH booklet 'HIV for non-HIV specialists: Diagnosing the undiagnosed' and the recent 'Tackling HIV testing' resource pack. It is also funding pilots to explore interventions to reduce late diagnosis. The sequencing of activity is unclear but we would like to see the early development of policy and guidance that can be informed by the pilots as the results emerge. This is especially important given the high level of experience that exists in this area internationally.

Our work indicates that there is tremendous opportunity to have a major breakthrough in the response to HIV by tackling undiagnosed levels of HIV and onward transmission by 'normalising' HIV testing and the promotion of greater access to testing, supported by the creation of cross-PCT collaboration to achieve locally applied indicators.

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[24] Brenner at al Journal of Infectious Diseases 2007:195

[25] AIDS 2005;19:513-20.[ISI][Medline]

[26] HIV Med 2004;5:53-98

This recommendation on HIV awareness is not a calling for the large-scale public education campaigns of the late 1980s and early 1990s. The need for more targeted HIV prevention work is not in any doubt. But what was once called the 'invisibility' of HIV was on numerous occasions, especially in the regional meetings, referred to as pertinent today.

Arguably, as most people now are at low risk of HIV transmission, this may not be so much of an issue. However, monitoring and evaluation of the large-scale campaigns of the past has shown that the general public campaigns on HIV were not just effective in informing the general population of the existence of HIV and how it is transmitted, but an essential source of information for gay men who were not regular frequenters of the gay scene and younger men just becoming aware they may be gay.

There also seems to be a view, among some African groups, that the special attention afforded them in the targeted work does not always help with tackling stigma and discrimination. In fact, it may inadvertently contribute to reinforcing it, especially in the absence of any broader awareness activity.

A theme throughout this report is the need, if we are to reduce onward transmission and create an educated and informed population that deals with the facts and not the myths about HIV, for an HIV-literate society. It may be that some on-going low-level exposure to information on HIV of the general population as part of the overall programme on sexual health awareness could play an important role in achieving this goal.

4 Evidence and dissemination

The IAG recommends:

- A costed HIV research and development strategy that ensures the best evidence base for interventions and planning at the local, regional and national level, developed by the Department of Health, along with a reference group to monitor its progress and implementation.
- A central point of reference, with the necessary resources to support the role, for research; reports on new interventions, and developments on HIV, with the goal of promoting their availability. Suggestions include NAM and the HPA or a partnership building on their respective expertise.

Rationale:

HIV in England and the UK continues to evolve. The face of HIV in the UK is not just that of a gay man but also one that includes Africans living in this country. However it is among the group of MSM where the picture remains most complex. HIV reports have increased which may reflect the positive impact of prevention campaigns and the promotion of testing it may not indicate an increase in incidence. It may also demonstrate other changes in activity or behaviour that as yet is not clear. With longer life expectancy and continuing developments in treatment, the need to know which interventions in prevention work, which messages should be communicated, and how to encourage access to both social and medical services, grows in direct proportion.

In the past two decades, there has been a major advance in the range of and access to treatments for people living with HIV, both in developing and developed countries like the UK.

These treatments are not cures. They are extending and improving the quality of people's lives but people still continue to live with the virus. Developments in treatment offer new opportunities in prevention and reducing viral loads which, in turn, reduce the risk of ongoing infection.

New ideas of how treatment will evolve and contribute to the management of risk of HIV transmission through Pre-Exposure Prophylaxis (PREP), as well as the development of prevention technologies, are outlined in 'The potential impact of Anti-Retrovirals and new prevention technologies on HIV transmission in the UK', prepared for this report by Keith Alcorn from NAM.

But as long as neither a cure nor a vaccine exists, prevention, provision based on the best social research evidence, and experience of health promotion or social marketing will be needed to reduce new infections. Evidence related to prevention and supported by research was in fact an area highlighted in the workshops and there was clear representation that more effective prevention based on clear evidence was needed.

This area is addressed more fully in 'Investment in behavioural and biomedical research for an improved UK response to HIV', by Professor Graham Hart from University College London, which concludes:

> "With the loss of the Sexual Health and HIV Research Strategy Committee, there exists in England and Wales no overarching body to direct research and surveillance efforts for HIV prevention. Despite progress in our understanding of the epidemic in the UK, new research challenges have arisen in recent years that require urgent attention if we are to progress HIV prevention science and practice.
>
> "A first task is to ensure that research funding bodies acknowledge that targeted efforts to address the HIV research and health promotion agenda are necessary, and that they begin a process of addressing this problem soon." The full report is available on page 28.

We are aware that even where evidence is available, this is not always known about, let alone used. This has been addressed in part by the Department of Health in its revisions to the national HIV prevention contracts. However, as demonstrated in our discussions, many people responsible for HIV in all settings around the country welcome a central point for research papers and evidence of effective interventions for HIV. This also reflects the recommendation in 'Progress and priorities' Priority for Action One, which called for a central register of research and good practice on sexual health. We see no problem if such a service was managed by different agencies, so long as there is a unifying brand and common approach in the provision of information.

5 Stigma and discrimination

The IAG recommends:

- Renewed commitment to cross-departmental action to address HIV stigma and discrimination. This should identify responsibilities for key government departments, including the Department of Health, the Home Office, the Department for Work and Pensions, the Ministry of Justice and the Department for Children Schools and Families.
- Workforce development in the NHS to achieve an HIV-literate workforce and incorporate training on HIV within sexual health for staff working across all aspects of healthcare and social care. Particular focus should be given to those specialties that particularly come into contact with people living with HIV, and settings

such as primary care where there is scope for the development of HIV services. These groups need to receive basic training on HIV (including HIV stigma and discrimination, homophobia and racism).

- The Government should review as a matter of urgency policies and practices that reinforce stigma and discrimination. These include the law relating to prosecutions for HIV transmission.

Rationale:

Stigma and discrimination have played an important part in the response to HIV. This is a powerful combination: fear of a new sexually transmitted disease, death, and the connection with marginalised and stigmatised groups such as gay and bisexual men and injecting drug users. This has contributed to creating a hostile and discriminatory climate towards people with HIV.

The fear of being faced with stigma and discrimination at work or at home are major obstacles for people coming forward for testing. Research[27] suggesting that one in three people with HIV have directly experienced HIV-related stigma or discrimination substantiates these fears.

This research also shows that it is in the non-specialist healthcare settings, particularly in primary care, that discrimination is most likely to occur. This is precisely the setting where community-based services for people with HIV will be located.

It is, however, important to recognise how quickly social attitudes can change. NAT's surveys of public attitudes to HIV have, since 2000, identified a decline in stigma in certain areas. The survey cites as an example that people expressed more willingness to work with someone with HIV. In addition, they highlight a point that emerged in some of the earlier campaigns that there may be a strong association between improved understanding of HIV; how HIV is transmitted and how you can prevent transmission, and more supportive attitudes towards people living with HIV.

As indicated by NAT for the Working Group, "the last ten years have also seen a significant shift in discrimination law. The Disability Discrimination Act 2005 defined HIV as a disability and thus, from the point of diagnosis, it prohibited discrimination against all people with HIV in employment, education, housing, provision of goods and services."

MSM legislation such as the Equality Act (Sexual Orientation) Regulations 2007 prohibits discrimination on the grounds of sexual orientation in employment and provision of goods and services. This, along with the right to civil partnerships and the right to adopt, has contributed to important progress for gay men in civil liberties. These changes have also been a factor in changing attitudes to gay men and may well have led to an improved social climate for gay men with HIV.

In contrast, the legal context presents challenges to migrants from Sub-Saharan Africa trying to access appropriate services that will not only provide the right medical care for people with HIV but also assist in preventing onward transmission by offering support and advice. In 2004, the Government tightened up NHS (Charges for Overseas Visitors) Regulations. The indications are that this deprived a significant number of migrants – including refused asylum-seekers, visa over-stayers and undocumented migrants – free secondary healthcare, including HIV treatment.

HIV transmission is taking place within black African communities here in the UK and this is also a group presenting for diagnosis some time after they have been infected. The experience from groups around the country is that the charging policy has caused confusion and fear around access to prevention, testing and treatment services.

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[27] Weatherburn P. et al. (2009) What do you need? 2007-2008 Findings from a national survey of people with diagnosed HIV. Sigma Research, London

This seems to many to be at odds with the work of DFID on access to HIV treatment and care. The IAG and the Working Group on HIV welcome the decision announced in the recent debate on the Health Bill to review this policy.

Prosecution for HIV transmission is another legal development which, it can be argued, has created problems for the national public health response to HIV. This was not envisaged when the National Strategy was drafted. There has been a significant number of police investigations but the actual number of cases to have reached court since 2003 is only 15. The whole process has however resulted in uncertainty and confusion amongst healthcare workers as to what information they are legally bound to provide and what liability they have.

The latest guidance from the Crown Prosecution Service, following extensive advocacy and discussion with leading voluntary organisations and others, is welcomed as an improvement on what was available previously.

In addition, the Department of Health developed a Stigma and Discrimination Implementation Plan in 2007. This highlighted what support had been offered and projects developed to address stigma and discrimination in the media, employment and healthcare, along with advice or information on HIV for non-HIV specialists. The latest survey by NAT indicates that there has been some improvement, but this remains a live issue.

6 Services

The IAG recommends:

- Existing guidance and advice on HIV service provision should be consolidated and updated where necessary. This should be with the engagement and support of key stakeholder organisations, notably BHIVA, BASHH, BIS, leading voluntary organisations, patient groups and other relevant professional bodies committed to shaping future service development. The guidelines should accommodate lower as well as higher volume HIV treatment and care services, with different patient profiles; offer guidance on the full care pathway for diagnosed and undiagnosed people living with HIV, and highlight the benefit that networks can have in the management and development of HIV services across geographical areas. They should be accompanied with accessible advice and guidelines for Commissioners.
- The ring- fenced AIDS Support Grant (ASG) should be retained to ensure the development of appropriate services that reflect the growing and often complex social needs of people with HIV.

Rationale:

Health Protection Agency data suggests that approximately 20 percent of people with a CD4 count of 200 or below are not accessing ART. This percentage will inevitably be much greater for those at a CD4 of 350 or less. The reasons for this may be varied (and include for example those only very recently diagnosed). But it is clear that significant and strategic effort must now be put into maximising the uptake of HAART, as clinically recommended. It is possible, for example, that more can be done to communicate the effectiveness and greater tolerability of current HAART regimens.

The developments in the treatment of people with HIV referred to in this report are remarkable and, as indicated, have changed the needs of people living with HIV, both in terms of their health but also their social care, providing new opportunities for changes to the way this is delivered.

BHIVA has identified the four 'faces' of HIV. These are classified as: the 'ideal' where HIV treatment and care is relatively straightforward and there are no major social or medical issues complicating HIV care. This offers scope for increased self-management, so long as there are clear links and support from clinical services.

Second is the 'co-morbid' face where the person's care is medically complex as a consequence of co-infection, ageing, effects of long-term treatment such as osteoporosis, cardio-vascular disease, HIV or non-HIV malignancies, and neurological conditions. This person requires specialised care but the needs are mostly predictable.

The third face is of those people with complex social problems such as housing, drug or alcohol use, significant mental health issues or neuro-cognitive impairment. This group is characterised by erratic attendance, poor adherence, failure to achieve and maintain virological suppression. Their needs cannot be met in a traditional, clinical setting as it is often difficult to retain them within services

Finally there is the 'wild card', which is previously undiagnosed; presents as an emergency at a centre without HIV specialism with for example Pneumocystis Pneumonia (PCP), and is difficult to plan for.

These differences in people with HIV who require care have implications for the design of services. Different settings and strategies may, for example, be necessary to meet the healthcare needs of some individuals who are harder to reach.

It is increasingly apparent that although people with HIV enjoy substantially improved (and still improving) life expectancy, they are more vulnerable to a range of health conditions linked to HIV infection or the effects of treatment. These include cardio-vascular disease, certain cancers, kidney and bone problems. At the same time this model illustrates the existing and potentially growing importance of social care in the effective management of HIV infection.

This is particularly important for those people who have multiple issues to contend with. The recent closure of HIV-specific services in some local authorities will create gaps that health services will not be able to cover, potentially adding to care and treatment costs. The ASG has been an important catalyst in the development of services in local authorities and, as clinical experience illustrates, its continuation, indeed the monitoring of its use, is an important part of the package of care that is needed now and in the future.

The experience of the working group is that the 'four faces' description developed by BHIVA is well-received. Clearly this has implications for the commissioning of services. As indicated in our recommendations, it highlights the need for clear advice and guidance for commissioners on how accessible HIV services can be provided, that are relevant and effective for changing and growing needs.

Three working group meetings were held during 2008 and 2009 to cover the following subjects:

Group One: HIV Prevention
Group Two: HIV Service Development
Group Three: HIV-Related Stigma

These groups provided invaluable expert testimony across these areas, and their contributions both as a group, and in individual discussions after the meetings, provided the bedrock for the development of the key recommendations in this paper.

A brief précis of some of the outcomes of the three working group meetings will be available from the IAG on Sexual Health and HIV website hosted on **www.dh.gov.uk**

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Appendices

The potential impact of anti-retrovirals and new prevention technologies on HIV transmission in the UK

Keith Alcorn
NAM

Anti-retroviral therapy: the evolution of care

1. Since its introduction in 1996 anti-retroviral treatment has been very successful in reducing death and illness among people diagnosed with HIV infection.[1] Currently, available treatment regimens can shut down ongoing HIV replication almost completely, preventing disease progression and allowing immune restoration.
2. HIV treatment has evolved and simplified substantially over the past decade. When combination therapy was introduced in 1996 it was based on the use of protease inhibitors, which had complex dosing requirements and numerous side-effects. The first generation of protease inhibitors have been superseded by more potent protease inhibitors and other drug classes have been introduced that provide potent, well-tolerated agents with more convenient dosing requirements. Current guidelines recommend treatment with a combination of three drugs; first-line treatment is usually taken once-daily and is well-tolerated.[2]
3. Second and third-line treatment combinations are proving increasingly effective in people who develop resistance to first-line treatment. Historical data show that after ten years, approximately ten percent of patients in the UK had developed resistance to at least one drug in each of the three major classes used in Anti-Retroviral Therapy.[3] However those data summarised the position before the introduction of a number of potent new agents that have greatly improved the outlook for patients with extensive drug resistance. Long-term viral suppression is now a realistic option for all patients, providing that treatment is well-tolerated and consistently good adherence can be achieved.
4. Over the next ten years, treatment is likely to evolve in the direction of weekly or twice-weekly dosing of drugs, with further competition between manufacturers to develop products for first-line use that are well-tolerated and have a high barrier against resistance. There is also growing interest in determining whether a single, highly potent protease inhibitor can maintain long-term viral suppression after a 6-12 month phase of three-drug induction treatment. Niche products for patients with drug resistance will continue to be developed, but are likely to be priced at higher levels than current therapies. Some patients, particularly those with Hepatitis C co-infection, high cardiovascular risk, diabetes and cancer, will continue to have complex needs that will require specialist management.
5. Survival estimates based on responses to treatment and death rates during the first ten years of Highly Active Anti-Retroviral Treatment (HAART) availability suggest that a male aged 25 diagnosed with HIV infection today can expect to live a further 35 years as a result of effective treatment.[4] Nevertheless, individuals with HIV infection will continue to have a diminished life expectancy in comparison with the general population, and appear to have a higher burden of morbidity and mortality due to modifiable

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[1] Mocroft A et al. Changes in the cause of death among HIV positive subjects across Europe: results from the EuroSIDA study. AIDS 16(12): 1663-1671, 2002.

[2] British HIV Association

[3] Phillips AN et al. Risk of extensive virological failure to the three original anti-retroviral drug classes over long-term follow-up from the start of therapy in patients with HIV infection: an observational cohort study. The Lancet 370: 1923 – 1928, 2007.

[4] Lohse N et al. Survival of persons with and without HIV infection in Denmark, 1995-2005. Annals of Internal Medicine:146: 87-95, 2007.

conditions such as hypertension, smoking and diabetes.[5] HIV infection itself is an additional risk factor for cardiovascular disease.[6]

6. The current prospects for a cure for HIV infection remain limited. HIV integrates its genetic material into the DNA of immune system cells that may live for the lifespan of the host, providing a reservoir from which HIV replication can rebound to pre-treatment levels if ART is halted. Several decades of research are likely to be necessary to determine whether it is possible to eliminate this reservoir or maintain it in an inactive state after the removal of treatment. ART will thus remain a lifelong commitment for the foreseeable future.
7. The prospect of an HIV vaccine also remains far off, due to the difficulties inherent in developing a vaccine against a pathogen with such a high rate of genetic mutation as HIV. The time-scale for development of a successful vaccine should be considered in decades, indicating the need to consider other biomedical prevention interventions as interim measures.
8. HIV prevalence continues to rise in the UK, due both to the increased life expectancy of people with HIV and a substantial rate of new infections. While current HIV prevention activities appear to have contained HIV incidence in UK MSM at a stable level over the past ten years, there is no evidence of a downward trend in either new infections or risk behaviours among the two most affected groups, MSM and heterosexual Africans living in the UK.
9. Given the continued growth in HIV prevalence and a likely move towards earlier treatment of HIV infection, demand for treatment and care will grow substantially. There is a need to consider all possible opportunities to prevent new infections. This paper discusses the contribution of anti-retroviral treatment and other biomedical interventions to HIV prevention in the UK.

HIV transmission by undiagnosed individuals

10. A high proportion of people with HIV remain undiagnosed; the most recent estimate derived from the anonymised sero-prevalence survey shows almost 35 percent of MSM in the UK with HIV infection who attended a sexual health clinic in 2007 left that clinic with their infection undiagnosed.[7] Mathematical modeling suggests that around half of these undiagnosed men would have been infected in the previous year, underlining the importance of increasing the frequency of HIV antibody testing among this population[8].
11. The majority of HIV transmission appears to occur from undiagnosed people. An analysis of the likely source of HIV infections in gay men attending a major London clinic between 1997 and 2003, using genetic sequencing, estimated that 25 percent of infections were transmitted by a person infected less than six months previously, and around 90 percent of all infections could be attributed to individuals infected less than four years previously, and thus less likely to be diagnosed.[9] Reducing the time between infection and diagnosis, with a particular emphasis on primary infection, could have a substantial public health impact if knowledge of HIV status has a subsequent effect on risk behaviour or earlier treatment becomes the norm.

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[5] Smith C et al. Association between modifiable and non-modifiable risk factors and specific causes of death in the HAART era: The data collection on adverse events of anti-HIV drugs study. Sixteenth Conference on Retroviruses and Opportunistic Infections, Montreal, abstract 145, 2009.

[6] Grunfeld C et al. HIV infection is an independent risk factor for atherosclerosis similar in magnitude to traditional cardiovascular disease risk factors. Sixteenth Conference on Retroviruses and Opportunistic Infections, Montreal, abstract 146, 2009.

[7] Sexually transmitted infections and men who have sex with men in the UK: 2008 report. Health Protection Agency, 2008.

[8] Phillips A Epidemiology of undiagnosed infection and its implications for onward transmission of HIV in the UK. Joint BHIVA/BASHH Ordinary General Meeting, BHIVA autumn conference, London, 2008.

[9] Hughes G et al. Episodic sexual transmission of HIV revealed by molecular phylodynamics. PLoS Medicine 5(3):e50, 2008.

12. Those in the early, or primary, stage of infection are of particular importance in epidemiological terms because they have a very high viral load, making them more likely to transmit to sexual partners. Primary infection is of particular epidemiologic relevance where infected individuals have multiple or concurrent partners during this 1-4 month period. Epidemiologic modeling suggests that somewhere between nine percent and 50 percent of all infections are attributable to those in the primary stage of HIV infection.[10-12] Although primary infection is accompanied in the majority of individuals by an often severe flu-like illness, it is rarely identified as such by the sufferer or by primary care practitioners, and an important opportunity for diagnosis and prevention is lost. A study of Accident and Emergency (A+E) attenders in Brighton, for example, found that 2.5 percent of those presenting with flu-like symptoms had primary HIV infection.[13]

13. The laboratory diagnosis of primary HIV infection is complicated by a delay in the emergence of antibodies known as the "window period". Currently available antibody-antigen assays have narrowed this window period to 18-25 days after exposure. HIV RNA (ribonucleic acid) assays, which detect virus itself rather than antibodies, can be used to detect infection prior to sero-conversion, but are more costly. The cost-effectiveness of strategies for earlier identification of primary infection needs to be evaluated. Possible interventions include pooled nucleic acid-based testing in sexual health clinic and A+E attenders; and opt-out HIV RNA testing for all people in higher prevalence areas with a high risk sexual exposure within the past month presenting to primary care with flu-like symptoms.

14. After a period of very high viral load during primary infection, the immune system mounts a partially effective response to HIV that brings virus levels down. The level of viral load after this point, known as the "set-point", is strongly associated with the subsequent rate of disease progression. The subsequent risk of onward transmission is strongly associated with an individual's viral load at any given time, and most individuals in the asymptomatic phase of HIV infection will continue to be capable of transmitting the virus, particularly if they have a sexually transmitted infection.

15. While there is some evidence that knowledge of HIV status results in changes in sexual behaviour, there is also consistent evidence in the UK that a proportion of men diagnosed with HIV continue to have unprotected anal intercourse (UAI) with partners of unknown HIV status. In 2005, for example, a national survey among gay men found that 31 percent of men with diagnosed HIV infection reported UAI with a partner of HIV-negative or unknown HIV status in the previous year.[14]

The clinical impact of late diagnosis

16. Recent health promotion activities have focused on improving rates of HIV diagnosis among sexual health clinic attendees in order to minimise late HIV diagnosis, together with expanding the range of settings in which opt-out HIV testing is offered.[15] Late HIV diagnosis is currently defined as diagnosis at a CD4 cell count below 200, below which threshold there is a substantially increased risk of developing an AIDS-defining opportunistic infection. Around 42 percent of Africans with HIV were diagnosed late in 2007,

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10 Brenner BG et al. High rates of forward transmission events after acute/early HIV-1 infection. J Infect Dis 195: 951-59, 2007.

11 Yerly S et al. The contribution of individuals with recent infection to the spread of HIV-1 in Switzerland: a 10-year survey. Fifteenth Conference on Retroviruses and Opportunistic Infections, Boston, abstract 512, 2008.

12 Fraser C et al. Variation in HIV-1 set-point viral load: Epidemiological analysis and an evolutionary hypothesis. Proc. Natl. Acad. Sci 104 (44)17441-17446, 2007.

13 Nambiar K et al. Diagnosing the undiagnosed: identifying symptomatic primary HIV infection (PHI) presenting to primary and emergency healthcare physicians. Fourteenth BHIVA Conference, Belfast. Abstract O5. 2008.

14 Consuming passions: findings from the UK Gay Men's Sex Survey 2005. Sigma Research, 2007.

15 British HIV Association. National HIV testing guidelines. BHIVA, 2008.

with a substantially higher rate of late diagnosis in men compared to women, which is attributable to the introduction of opt-out ante-natal HIV testing.[16]

17. Africans with HIV infection in the UK are diagnosed later than gay men (as measured by CD4 cell count at the time of diagnosis), and a higher proportion have a 'late' diagnosis.[17] Recent research suggests that between 25 percent and 35 percent of prevalent infections among Africans in London may have been acquired in the UK.[18]

18. Updated UK treatment guidelines now recommend that individuals should start anti-retroviral treatment when the CD4 cell count falls below 350, since there is evidence of an elevated risk of non-AIDS defining serious illnesses below this level. Recent cohort analyses in the US suggest that there may be additional benefit to beginning treatment at a CD4 count below 500, or even above this level,[19,20] but a European/US cohort analysis failed to confirm that treatment at a CD4 count above 400 had additional benefit.[21]

19. The primary benefit of earlier diagnosis and treatment is to the individual, and to the health system, and these are sufficient reasons for greater focus on earlier diagnosis, but there is also suggestive evidence that earlier treatment has prevention benefits.

The prevention impact of anti-retroviral treatment

20. There has been speculation that earlier treatment may also have prevention benefits, by reducing infectiousness. Evidence to support this view comes from several types of investigation:

    i. Studies of HIV incidence in HIV-discordant couples show a very low risk of transmission from the untreated index partner when viral load is below 1500 copies/ml.

    ii. Studies of HIV incidence in HIV-discordant couples show very low incidence where the index partner has persistently suppressed viral load on treatment (<50 copies/ml).[22,23]

    iii. Studies measuring virus levels in semen and vaginal fluids show that when HIV is suppressed below the limits of detection in blood, it will be similarly suppressed in semen and vaginal fluids in the majority of individuals.[24,25]

    iv. Mathematical modeling using input data from South Africa suggests that where the efficacy of treatment in reducing the risk of infection is 99 percent, HIV incidence would be reduced by 90 percent within ten

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[16] Sexually transmitted infections in black African and black Caribbean communities in the UK 2008, Health Protection Agency.

[17] Sexually transmitted infections in black African and black Caribbean communities in the UK 2008, Health Protection Agency

[18] Burns FM et al. United Kingdom acquisition of HIV infection in African residents in London: more than previously thought. AIDS 23: 262-6, 2009.

[19] Kitahata M.M. et al. Initiating rather than deferring HAART at a CD4+ count between 351-500 cells/mm3 is associated with improved survival. 48th Interscience Conference on Antimicrobial Agents and Chemotherapy, abstract H-896b, Washington, 2008.

[20] Kitahata M et al. Initiating rather than deferring HAART at a CD4+ count > 500 cells/mm3 is associated with improved survival. Sixteenth Conference on Retroviruses and Opportunistic Infections, Montreal, abstract 71, 2009.

[21] Sterne J for the When To Start Consortium. When should HIV-infected patients initiate ART? Collaborative analysis of HIV cohort studies. Sixteenth Conference on Retroviruses and Opportunistic Infections, Montreal, abstract 72, 2009.

[22] Reynolds, S. et al. ART reduced rate of sexual transmission of HIV among HIV-discordant couples in rural Rakai, Uganda. Sixteenth Conference on Retroviruses and Opportunistic Infections, Montreal, abstract 52a, 2009.

[23] Sullivan, P. et al. Reduction of HIV transmission risk and high risk sex while prescribed ART: results from discordant couples in Rwanda and Zambia. Sixteenth Conference on Retroviruses and Opportunistic Infections, Montreal, abstract 52bLB, 2009.

[24] Sheth P et al. Persistent HIV RNA shedding in semen despite effective ART. Sixteenth Conference on Retroviruses and Opportunistic Infections, Montreal. Abstract 50, 2009.

[25] Marcelin A-G et al. Detection of HIV-1 RNA in seminal plasma samples from treated patients with undetectable HIV-1 RNA in blood plasma. Sixteenth Conference on Retroviruses and Opportunistic Infections, Montreal. Abstract 51, 2009.

years if 90 percent treatment coverage could be achieved, and all infected individuals diagnosed within one year.[26] Similar modeling using data from the Canadian province of British Columbia concluded that two-thirds of projected infections could be averted up until 2030 if all individuals with HIV were diagnosed and began treatment by the time their CD4 counts had fallen to 350 cells.[27]

21. There are several important caveats that must be considered:
    i. Studies continue to find intermittent viral shedding in men and women despite suppressive anti-retroviral treatment, indicating a potential risk of transmission.
    ii. Untreated sexually transmitted infections will increase viral shedding.
    iii. It is not proven that all anti-retroviral regimens have an equally suppressive effect on HIV shedding in semen, due to differing penetration of some drugs into this fluid.
    iv. Consistent viral suppression in blood is dependent on very high levels of treatment adherence (<95 percent).
    v. Mathematical modeling that assumes a risk of transmission even at very low viral load levels has projected that HIV incidence would increase four-fold over ten years in a cohort of HIV-discordant heterosexual and homosexual couples if treatment alone was relied on to prevent HIV transmission, when compared with a scenario in which condom use persisted.[28]
    vi. Further modeling is needed that takes into account potential risk compensation effects, such as more frequent sero-discordant IAU as a result of wider awareness of the prevention effects of treatment. Research in the Netherlands shows that an increase in risky sexual behaviour among gay men has probably negated any prevention benefit of the use of ART since 2000.[29]

22. Taking these caveats into account, there is a growing consensus that treatment may have important prevention benefits, and that population-level studies in a variety of settings need to be conducted in order to evaluate the potential benefits.

23. The issue of HIV transmission by treated individuals has been addressed by the Swiss Federal AIDS Commission, which issued a statement in 2008 noting that, in its view, individuals with fully suppressed viral load on treatment, with no sexually transmitted infection, had a negligible risk of HIV transmission. This view of current evidence has not been endorsed by other medical authorities.

24. A clinical trial due to conclude in 2012 is investigating the question of whether earlier anti-retroviral treatment reduces the risk of HIV transmission in HIV-discordant heterosexual couples.

Individuals

25. Anti-retroviral drugs are also being tested as a prevention tool in HIV-negative people. Post-exposure prophylaxis (PEP) – the use of anti-retroviral drugs to block infection up to 48 hours after a potential exposure – is already offered in occupational settings and for non-occupational exposures through sexual health clinics.

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[26] Granich R et al. Universal voluntary HIV testing with immediate anti-retroviral therapy as a strategy for elimination of HIV transmission: a mathematical model. The Lancet (online publication, November 26 2008): doi:10.1016/S0140-6736(08)61697-9

[27] Lima VD et al. Expanded access to highly active anti-retroviral therapy: a potentially powerful strategy to curb the growth of the HIV epidemic. J Infect Dis 198 (online edition), 2008.

[28] Wilson DP et al. Relation between HIV viral load and infectiousness: a model-based analysis. Lancet 372: 314-20, 2008.

[29] Bezemer D et al. A resurgent HIV-1 epidemic among men who have sex with men in the era of potent anti-retroviral therapy. AIDS. 22(9):1071-1077, 2008.

26. Pre-exposure prophylaxis (PREP), the use of anti-retroviral drugs prior to exposure to prevent infection, is being tested in large clinical trials in a variety of populations, and using a variety of products. A range of studies is necessary because PREP might have differing effects according to exposure route. Up to seven studies could report results by 2012; if any studies have positive results (>50 percent reduction in risk of infection), the findings could have important implications for HIV prevention.

27. The first studies to report, probably in late 2009, are testing a single drug (tenofovir, marketed as 'Viread') in two populations, MSM and injecting drug users. It is likely that neither study will produce evidence of protection, and that proof of concept will await results from studies of two-drug PREP conducted in MSM, discordant heterosexual couples or in high-risk women in Sub-Saharan Africa.

28. If the two-drug study in MSM due to report in late 2010 were to show a protective effect there is likely to be immediate interest in the use of PREP in high-risk groups of MSM:

    i. HIV-negative men in sero-discordant partnerships;

    ii. Men with a history of recurrent UAI and a history of multiple negative antibody tests;

    iii. Men with a high number of sexual partners and a history of UAI.

29. It is also possible that none of the studies currently in progress will produce conclusive results that would allow public health recommendations to be made about PREP. Further studies are already being planned looking at intermittent dosing and other drugs, with a view to identifying lower cost regimens that are less vulnerable to resistance and more practical to take.

30. PREP will need to be prescribed within the clinical setting and monitored carefully. HIV antibody status will need to be checked frequently to ensure that the drugs are working and that they are not being taken by a person who has already become infected with HIV. Use of oral PREP by a person with HIV could lead rapidly to drug resistance. PREP users will also need to be monitored for the emergence of potential long-term toxicities (kidney problems and bone loss) that may be linked to the drugs used for PREP. Clinical trials will define the frequency of these toxicities in HIV-negative populations, but the anticipated frequency is low.

31. It is important that sexual health services, health promotion agencies and policy makers anticipate the possibility of a positive result from one or more PREP study, and address the potential demand for PREP by agreeing a process for establishing guidelines on use; communicating the limitations of PREP, and educating about safe use within the context of other harm reduction. Failure to do so may result in informal adoption of PREP using channels such as the internet to obtain the relevant drugs, in the absence of safety monitoring, regular antibody testing or counselling.

32. PREP use also has the potential to undermine current messages about HIV risk reduction if it is not administered within the clinic setting as part of a structured approach to risk reduction.

33. PREP may present different challenges for HIV prevention with heterosexuals. There is also likely to be strong interest in PREP among Africans in the UK, especially women. The potential availability of PREP for Africans in the UK needs to be considered in the context of high levels of stigma which prevent disclosure of HIV status, a lack of ability to negotiate condom use among a significant minority, lack of knowledge about HIV testing and treatment, and a low rate of HIV testing.[30] There is also evidence that unprotected sex in sero-discordant heterosexual partnerships is associated with a desire to conceive. The availability of PREP may provide opportunities for partner testing and for support around conception decisions.

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[30] Dodds C et al. BASS Line 2007 Survey: assessing the sexual HIV prevention needs of African people in England. Sigma Research, 2008.

34. The potential cost of PREP means that careful cost-effectiveness analysis will be required before it can be implemented beyond a highly targeted population. Trials currently underway are using daily doses of drugs, although there is some evidence from animal studies that twice-weekly dosing may be effective. At current prices daily dosing of two-drug PREP would cost approximately £4,800 per year. Twice-weekly dosing would cost £1,500 per year. (These costs could decline by up to 90 percent after tenofovir's patent expires in 2017). A US cost-effectiveness analysis in high-risk MSM found that, assuming 75 percent effectiveness, PREP could prevent between 4 percent and 23 percent of projected infections over five years in New York, at an incremental cost of US$31,970 per quality-adjusted year of life [QALY] saved.[31] In contrast, at 50 percent effectiveness, PREP showed poor cost-effectiveness when extended to all high-risk MSM in the US, and if the effects on secondary transmission due to reduced prevalence are not taken into account.[32]

Microbicides

35. Microbicides are gels which can be used during sexual intercourse to reduce the risk of HIV transmission. A range of products is being developed, some of which employ anti-retroviral drugs. At present most products in development are for use as vaginal microbicides, but rectal testing of a number of products is beginning.

36. One product, PRO2000, has already shown a trend towards efficacy in a study conducted in southern Africa, and results due in late 2009 from a larger study are awaited to confirm this trend.[33] Other products, including a microbicide gel containing tenofovir, are now entering large human studies and may generate results by 2012/13. Future prospects include the development of a vaginal ring that can be used to dispense a microbicide over the course of a week or month without the need for daily gel applications.

37. Microbicides may offer particular advantages to women whose partners do not wish to use condoms, and so could have particular importance within African communities in the UK. Non-ARV containing microbicides could be made available over the counter.

38. ARV-containing microbicides are increasingly being viewed as a variant of PREP, albeit considerably more cost-effective owing to the much smaller volume of drug used in the product. Their use will require more supervision than non-ARV containing microbicides, due to the need to test regularly for HIV in order to avoid the risk of drug resistance. They raise similar implementation issues to PREP for UK sexual health services.

Circumcision

39. WHO has recommended that circumcision should be offered as part of integrated HIV prevention programmes in settings where HIV is endemic, following the results of three studies in Sub-Saharan Africa showing a significant reduction of around 50 – 60 percent in the risk of HIV infection for heterosexual men if they underwent circumcision at the beginning of the study.

40. Circumcision has not been tested as an HIV prevention intervention in settings with low HIV prevalence. Epidemiological evidence on the protective effect varies by population. Circumcision was found to be protective against HIV infection in African-American men in a US clinic population with a very high

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frequency of circumcision, but a meta-analysis of studies of risk factors associated with HIV infection in MSM in the US and in developing countries did not find conclusive evidence that circumcision reduced the risk of infection in this population.[34,35]

41. There is no published evidence of increased demand for circumcision among users of sexual health services in the UK, suggesting that this intervention has low acceptability in the UK.

Conclusions

42. While it is unrealistic to expect that any biomedical intervention will stop the HIV epidemic, there is a clear need to identify the most effective means of reducing the number of new infections that are occurring in the UK. If prevention technologies such as PREP and microbicides show efficacy in clinical trials, they will offer important additional tools for HIV prevention with the highest risk groups, but their introduction will need careful consideration and communication.

43. Earlier diagnosis and treatment, as well as significantly reducing the burden of morbidity and mortality associated with untreated HIV infection, could have significant effects on onward transmission. Given the UK's unique advantage in possessing a network of sexual health clinics and a robust surveillance system, there is a strong case for attempting to assess longitudinal changes in HIV incidence among a large prospective cohort of gay men in the UK, in the context of a comprehensive package of interventions that seeks to:
    i. Promote more frequent antibody testing and earlier diagnosis of HIV;
    ii. Achieve timely initiation of treatment;
    iii. Reduce levels of untreated sexually transmitted infections;
    iv. Increase the level of focused face-to-face interventions with repeat risk-takers, either in the clinical setting or through referral to NHS-accredited Health Trainers.[36]

44. Efforts to reduce late diagnosis among Africans in the UK are also likely to have prevention benefits. The UK may have a considerable amount to learn from Sub-Saharan African countries currently seeking to increase rates of HIV testing in how to tackle socio-cultural barriers to earlier diagnosis, such as stigma and lack of risk perception.

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Investment in behavioural and biomedical research for an improved UK response to HIV

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Introduction

From 1986 to 2002, the Department of Health's Policy Research Programme (PRP) contributed funding to the Medical Research Council (MRC) for epidemiological, social and behavioural studies to help tackle the HIV/AIDS epidemic. It did this under the aegis of the MRC's Committee on Epidemiological Studies in AIDS (CESA). In 2002, the Health Departments and MRC widened the remit of the research programme to encompass sexual health as well as HIV. CESA was disbanded, and a new Advisory Group was constituted: the Sexual Health and HIV Research Strategy Committee (SHHRSC). The PRP allocated £1m per annum on a rolling programme basis to the MRC for this co-funded programme of research on sexual health and HIV. From 2002 – 2007, SHHRSC issued four 'Highlight Notices', calling for proposals in specified areas of policy concern. In total over 150 submissions were made, of which 28 were funded. Studies include improved surveillance, epidemiology, clinical science and health services research, with most focusing on populations at high risk for HIV and/or other STIs or unwanted pregnancies. The programme also supported longitudinal cohort studies: for example, on transmission of HIV from mother to child; and on HIV treatments.

The SHHRSC was disbanded in 2008, along with its 'parent' board at MRC, the Health Services and Public Health Research Board. This is because health services research is now the responsibility of the National Institute for Health Research (NIHR). This leaves a gap in the strategic overview of the evidence base, and recommendations and action to address these, for research to support HIV prevention. There is now a much improved evidence base in UK sexual health (see below) but the absence of an oversight body to direct research and surveillance efforts will hamper future efforts to generate the evidence base in support of HIV prevention.

Behavioural interventions

The UK produces high-quality observational studies of HIV risk behaviours in the two groups at most risk of infection, notably MSM and people of African origin. These data have informed prevention programmes at national and local levels, but there have been no randomised controlled trials demonstrating reductions in sexual risk behaviour or incident infection in either of these populations. The majority of prevention interventions for MSM that have been subjected to rigorous evaluation are from the US; some interventions effective in the US in reducing risk behaviours have not enjoyed the same success in the UK. There has been little change in the incidence of HIV infection in MSM over the past 15 years.

Although the majority of people of Sub-Saharan African origin living with HIV in the UK acquired the infection abroad, there is increasing evidence of transmission within the UK in this population. Again, there are many interventions from the US that report on programmes targeted at black and minority ethnic groups (particularly African American and Latino populations), but there are no randomised controlled trials of prevention for people of African origin in the UK.

Confusingly, HIV prevention interventions often use sexually transmitted infections as surrogate or proxy markers of HIV risk. This is because incident HIV infection in many settings is at a level that cannot be used as an outcome measure. At a population level, where interventions involve increased condom use and/or reduced partner numbers, it is likely that they will be effective in preventing acquisition or transmission of HIV and other STIs, particularly syphilis, gonorrhoea, chlamydia and genital herpes.

Most HIV prevention programmes are concerned with primary prevention; that is, helping people who are HIV-negative from becoming HIV-positive. However, there is increased interest in secondary prevention; that is, focusing prevention efforts on those who are already HIV-infected. It has recently been suggested that people with HIV, on treatment, are at relatively low risk of transmitting the infection (particularly those in heterosexual relationships, with no concurrent STIs). Moreover, it is estimated in some settings that up to 50 percent of HIV transmission is from people who are recently HIV-infected, and not on treatment. The STARHS test is able to identify those recently infected, but no interventions with this population are in place in the UK; they are urgently needed.

Biomedical interventions

One of the striking features of recent International AIDS Conferences (Toronto, 2006; Mexico, 2008) is the extent to which technology for preventing the sexual transmission of HIV has developed. The continuing global spread of HIV; the presence of endemic infection in some communities; its arrival in new settings and re-emergence in communities where it was thought to be under control, have raised questions about the current behavioural prevention paradigm. International support for the biomedical approach marks it as the most important shift in global HIV prevention in recent years. On the ground, it signifies a fundamental reorientation of practice, away from a prevention model reliant on behavioural and social change, to one that places biomedical and technological solutions at the heart of HIV prevention.

HIV prevention currently relies on a two-pronged behavioural approach which involves reducing partner numbers and using condoms for sexual intercourse. But a new range of biomedical options has emerged including:

- Routine (i.e. opt-out) voluntary counselling and rapid HIV testing;
- Adult male circumcision;
- Vaginal and rectal microbicides;
- Diaphragms (and potentially other intrauterine devices);
- Pre-exposure prophylaxis for HIV using anti-retroviral drugs (PREP);
- Post-exposure prophylaxis for HIV using anti-retroviral drugs (PEP);
- Pharmaceutical suppression of concurrent bacterial and viral STIs;
- Anti-retroviral treatment of all HIV-positive persons immediately on diagnosis;
- Vaccination against viral infections such as hepatitis, human papilloma virus, HSV 1 and 2 and, eventually, HIV.

Of these, only male circumcision in heterosexual men and pharmaceutical suppression of bacterial STIs have been demonstrated in randomised controlled trials to prevent HIV acquisition. These are also limited to Africa. There is emerging evidence that the microbicide gel PRO2000 is protective against HIV in women when applied vaginally, but results from a large Randomised Control Trial (RCT) will not be available until September 2009.

Combination prevention

A recent series of papers in 'The Lancet' argue for 'combination prevention'. That is, interventions that work at multiple levels (individual, couples, families, institutions and communities), using both behavioural and biomedical approaches.

These developments demand renewed engagement with the science of HIV prevention, informed by the research question: 'What is the optimum combination of new and established intervention technologies to achieve effective HIV prevention in the UK?'

An HIV prevention research agenda should address the following aims:

1) Identify successful HIV prevention technologies;
2) Combine technologies with the aim of achieving better outcomes (synergy);
3) Determine efficacy using RCTs and other evaluation methodologies;
4) Use process evaluation to better understand the mechanisms that underlie intervention success;
5) Model intervention effects;
6) Undertake translational/Phase IV studies for dissemination and policy impact.

To achieve these aims, it will be necessary to pursue the following objectives:

i) Identify key research findings in HIV prevention, from clinical and population sciences, and the means by which health technologies can be combined to improve the prevention and control of HIV;
ii) Develop innovative methodologies for HIV prevention research in clinical and non-clinical populations;
iii) Undertake efficacy research into different combinations of new and established intervention technologies for HIV prevention (Phase III);
iv) Undertake effectiveness research into the transfer and implementation of interventions for the prevention of HIV (Phase IV);
v) Determine the resource implications of current and future HIV service configurations using economic and disease modeling in relation to population and service level variation;
vi) Generate a resource to increase national and international expertise in health transfer in the HIV prevention field; deliver expert advice to government, health providers, patients and community groups; provide a national focus for capacity building in HIV prevention science.

Although the main focus of this proposed programme of research is HIV prevention, many of the objectives will have outcomes for and impacts on the prevention of other sexually transmitted infections, and the promotion of sexual health.

Conclusion

With the loss of the SHHRSC, there exists in England and Wales no overarching body to direct research and surveillance efforts for HIV prevention. Despite progress in our understanding of the epidemic in the UK, new research challenges have arisen in recent years that require urgent attention if we are to progress HIV prevention science and practice. A first task is to ensure that research funding bodies acknowledge that targeted efforts to address the HIV research and health promotion agenda are necessary, and that they begin a process of addressing this problem soon.

A gendered approach to HIV

Elisabeth Crafer
Positively Women

Worldwide, a gendered approach to HIV prevention is seen as vital, especially in prevention within African communities. Gendering HIV prevention addresses more than gender inequalities, in that it takes into account the vulnerabilities of both men and women that inhibit the success of prevention strategies and uptake of services.

The HIV epidemic in the UK is complex and consists of elements that reflect the global picture. HIV in the various African communities in the UK is proportional to that in the countries of origin.

A large component of the UK HIV population consists of black Africans and the norms and values of the country of origin will continue to play a defining role in their lives. So it is likely that difficulties experienced as a gay man in Kenya will be similar or even magnified in life in Britain, through association with the larger community from Kenya. The Sigma report, 'The knowledge, the will and the power', points out that like any other diaspora group, people from Africa will connect with others from their country of origin and that responses to HIV need to include consideration of country of origin. Equally, elements of pan-Africanism can be of benefit by forming supportive networks with a common cause.

A man from a culture which defines him as someone of status and importance in the family, will be stripped of this status if experiencing life as an asylum-seeker in the UK. He is vulnerable to exploitative employment in order to retain a sense of social importance. Gender constructs of manliness which include risky sex, alcohol and violence are all too likely to result in poor health outcomes.

Gender inequality

In the UK, where 35 percent of people living with HIV are women, and women accounted for 40 percent of new diagnosis in 2006, as opposed to 25 percent in 1997[1], we are failing to give serious consideration to a gendered approach to prevention and women as a group, are becoming absent from the list of those vulnerable to HIV.

Twice as many African women as men are diagnosed in the UK each year, and the vulnerability of women nationally and globally to the transmission of HIV is well-evidenced. This is due to:

- Biological susceptibilities including female genital mutilation (FGM);
- Gender inequities;
- Violence against women.

However, HIV impacts disproportionately on African gay men, MSM and bisexual men. Among MSM in England, African men are twice as likely to be HIV positive as white men.

Gender inequalities affecting women include negotiating safer sex and economic dependence. Similar behavioural and socio-economic issues such as exploitative relationships and low paid employment can also affect MSM and heterosexual men. Poverty or unresolved asylum status makes for gender-based vulnerability.

Gender and testing

There is a gender imbalance in the opportunities for HIV testing. Women with HIV are more likely to be diagnosed early through ante-natal HIV testing. We need to extend opportunities for testing to other clinic settings in order to reach non-pregnant women and men. Gay men's HIV prevention needs to be an active, integral part of gay health and social healthcare in the same way as ante-natal testing is integral to one aspect of being female.

Gender and safer sex

The gender-based power dynamics often make it difficult for women to implement the safer sex message of using condoms. Femidoms (female condom) can offer a shift in negotiating power for women, yet femidoms are all too often promoted as a quaint and unattractive alternative to the 'normal' male condom. They are expensive to buy, not universally available free from PCTs and if they are, they are likely to be rationed. Equal promotion and availability of femidoms would lessen women's vulnerability in negotiating safer sex.

Research

We have extremely sound HIV surveillance data in England but there is a need for investment in social research which takes more account of gender issues in order to accurately inform prevention and care initiatives.

Positive prevention

The importance of direct involvement of people living with HIV in prevention work has been widely acknowledged and was at the centre of the XVII International AIDS Conference in Mexico City in August 2008.

Positive prevention is not a single activity or intervention but part of a much larger process. The main obstacle identified as a barrier to participating in HIV advocacy, including positive prevention is the fear that HIV status may be suspected or revealed. Resources need to be targeted at gender-based advocacy and support for people living with HIV to challenge stigma and discrimination.

Gender and targeted groups

Targeting groups can have a negative impact. There have been reports that prevention and testing campaigns targeting people from Africa have been resented because they were seen to portray Africans as being irresponsible carriers of disease.

Messages aimed at heterosexual men need to take account of gender issues in the country of origin and should be accompanied by a message of equal strength aimed at heterosexual women.

The number of lesbians, bisexuals and trans-sexuals with HIV may be a small, but their needs are often overlooked. Research on lesbians and health shows uptake of mainstream health services is poor, so they are less likely to receive messages about sexual health and HIV from mainstream sources.

Recommendations

An approach to HIV which takes into account gender-based vulnerabilities and attitudes will result in improved accuracy in initiatives in testing, care and prevention.

Key areas

- Equal promotion of femidoms will increase women's ability to negotiate safer sex;
- Testing opportunities for MSM and non-pregnant women should be increased;
- Research should take more account of gender issues in order to accurately inform testing prevention and care initiatives;
- Promotion of people living with HIV in gender-based advocacy.

References

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PozFem UK report
www.poz-fem-uk.org/docs/WomenHIVandSexualHealth.pdf

Epidemiology: HIV in the UK today

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Since the beginning of the HIV epidemic in 1979 until the end of 2008, a total of 102,333 HIV diagnoses have been reported in the UK [1].

HIV prevalence in the UK

In 2007, there were an estimated 73,300 [68,800 – 78,500] persons aged 15 - 59 living with HIV in the UK, of whom 28 percent [16,300 – 25,800] were unaware of their infection [2]. The prevalence of HIV among 15 - 59 year-olds in the UK is estimated as 127 per 100,000 (170 per 100,000 men and 84 per 100,000 women). However, prevalence varies in different populations and, consequently, also geographically (Map 1). At the end of 2007, the communities with the highest estimates of HIV prevalence were:

- Black African communities: the prevalence of HIV has been estimated to be 5.1 percent [4.3 - 6.0 percent] among approximately 495,500 black Africans aged 15 - 59 years living in England [3], of whom an estimated 24 percent were undiagnosed (29 percent of males and 21 percent of females).
- Men who have Sex with Men (MSM): the prevalence of HIV has been estimated to be 5.3 percent [4.7 - 6.1 percent] among the estimated 415,700 MSM aged 15 - 44 years living in Britain [4], of whom an estimated 29 percent were undiagnosed.

New diagnoses of HIV

Reports of new HIV diagnoses do not represent incidence of infection but are a mixture of individuals with recent or long-standing infections. By the end of 2009, all new diagnoses of HIV will be tested for recent HIV infection using Recent Infection Testing Algorithm (RITA) which will allow HIV incidence to be estimated [5].

In 2007, 7,660 persons were diagnosed with HIV. This is lower than the peak of over 8,000 cases reported in 2005 yet remains one of the highest figures ever recorded (Figure 1). While trends in new HIV diagnoses have remained low and stable for injecting drug use and mother-to-child transmission (Figure 1), increases have been reported among:

- Heterosexuals: 4,270 people diagnosed with HIV in 2007 (56 percent of all new diagnoses) acquired their infection through heterosexual contact (1,670 men and 2,600 women). This is a 3.5-fold increase on the 1,201 new diagnoses in 1998 but a 15 percent decline from the peak in the diagnosis of heterosexually acquired cases reported in 2004 (5,000). The majority of these cases are among black Africans thought to have acquired their infection abroad. Nonetheless, heterosexual HIV transmission within the UK is steadily increasing, with 940 cases reported in 2007 up from 540 cases in 2003.
- MSM: 3,050 people diagnosed with HIV in 2007 (40 percent of all new diagnoses) acquired their infection through sex between men. This is more than double the 1,409 new diagnoses in 1998 and is the highest ever recorded. The majority (82 percent) of MSM probably acquired their infection in the UK [2]. Estimation of incidence in selected GUM clinics has shown no statistically significant changes between 1997 and 2004 [6]. However, since 1997 the proportion of MSM with a recent HIV infection attending a GUM clinic has increased [7] and significant increases in high-risk sexual behaviour have been reported [8,9].

Late diagnosis, defined as a CD4 cell count <200 per mm within three months of diagnosis, is an important determinant of HIV-related morbidity and mortality. It represents individuals accessing healthcare at a time after which treatment should have started [10]. In 2007, 31 percent of adults (aged over 15 years) diagnosed with HIV were diagnosed late, and this proportion was lowest among MSM (19 percent) and higher among heterosexual women (36 percent) and heterosexual men (42 percent) (Figure 2).

First diagnoses of AIDS, mortality and access to care

The introduction of Highly Active Anti-Retroviral Therapy (HAART) has contributed to a much improved life expectancy for people diagnosed with HIV. The numbers of AIDS diagnoses and deaths have declined dramatically since the mid-1990s when over 1,500 were reported annually. In 2007, 742 persons were reported with a first AIDS diagnosis and 567 persons infected with HIV died (Figure 3). Nonetheless, for a significant proportion of AIDS cases diagnosed with HIV at the same time (83 percent in 2007), the prognosis is much worse.

The improved life expectancy has contributed to an increase in HIV prevalence and the numbers of individuals seeking HIV care. There were 56,556 diagnosed people seen for HIV care in the UK in 2007, representing an 8.6 percent increase on numbers seen in 2006 (52,083) and more than a three-fold increase since 1998 (17,911) (Figure 3).

Monitoring and evaluating HIV prevention and control

Much of the control of HIV rests on either primary (e.g. behaviour change such as increased condom use) or secondary (e.g. increased HIV testing, improved partner notification) prevention interventions. Surveillance data inform, monitor and evaluate the impact of these interventions.

HIV testing

HIV testing is being widely promoted for its benefits both to the individual as earlier diagnosis leads to improved prognosis, and to the community through reduced onward transmission. The importance of HIV testing has been underlined through the publication of recent national guidelines [11]. Most HIV testing in the UK occurs in either GUM or ante-natal services.

In 2007, approximately 800,000 tests were performed in GUM clinics in the UK. Mandatory KC60 returns from GUM clinics have demonstrated an increase in the proportion of people attending GUM clinics that accepted the offer of an HIV test. This is up from 66 percent in 1998 to 75 percent in 2007 among heterosexuals; and 81 percent to 86 percent in the same period among MSM. This is in excess of the target of 60 percent uptake of HIV testing by 2007 set by the National Strategy for Sexual Health and HIV [12].

However, unlinked anonymous surveillance and HIV testing in sentinel GUM clinics revealed that in 2007, of individuals who were found to be HIV-positive, 40 percent of MSM and 30 percent of heterosexuals left with the infection still undiagnosed (Figure 4). Although the proportion of HIV-positive individuals who upon leaving a GUM clinic remain undiagnosed has declined, the national target of a reduction of 50 percent by 2007 has not been achieved.

Since the widespread introduction in 1999 of opt-out HIV testing among ante-natal clinic attendees, the uptake of HIV testing has increased to approximately 94 percent in 2007. Since more than 90 percent of HIV-infected pregnant women were diagnosed before giving birth, the proportion of infants born of HIV-positive mothers who themselves become infected has fallen to less than percent (Figure 5).

The guidelines also recommended that HIV testing should be offered in general practice and hospital general admission in those areas where the prevalence of diagnosed HIV infection is greater than two per 1000 15 - 59-year-olds[11]. In the UK, there are 42 primary care organisations where the prevalence exceeds this threshold either by the primary care organisation or unitary authority (Map 1).

Behavioural surveillance

Behavioural surveillance is important for understanding the HIV epidemic and the monitoring and evaluation of prevention initiatives. In the UK, surveys among the most important prevention groups demonstrate:

- MSM: a number of surveys in the UK have reported increases in high-risk sexual behaviour such as the proportion of men having unprotected anal intercourse (UAI) with one or more partners in the past year, UAI with casual partners and UAI with partners of an unknown or sero-discordant status [8,9]. However, there appears to be a plateau or decline in recent years in reported high-risk sexual behaviour [9].
- Injecting drug users: in 2007 approximately one quarter reported needle and/or syringe (direct) sharing in the previous month. The levels of direct sharing have declined in recent years following an increase in the late 1990s [13].
- Black African communities: information on HIV prevalence, sexual behaviour and use of health services among black African communities in the UK is based on two surveys [14,15]. Although levels of high-risk sexual behaviour appeared similar to other communities, the increased prevalence of HIV means there is a much higher risk of acquiring HIV infection.

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Maps and Figures

Map 1: Rates of HIV diagnosed persons seen in the UK for HIV care by primary care organisation of residence: 2007

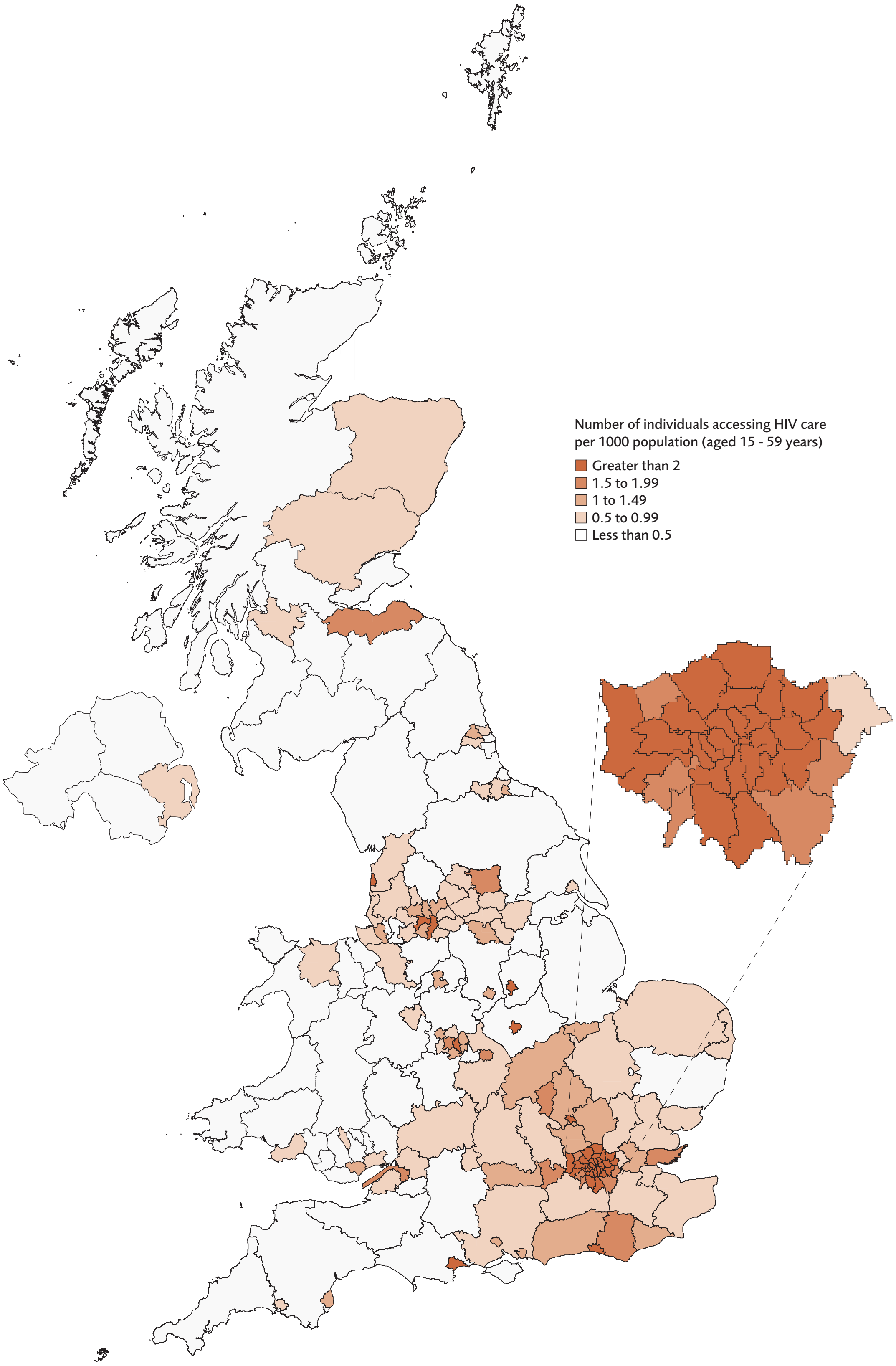
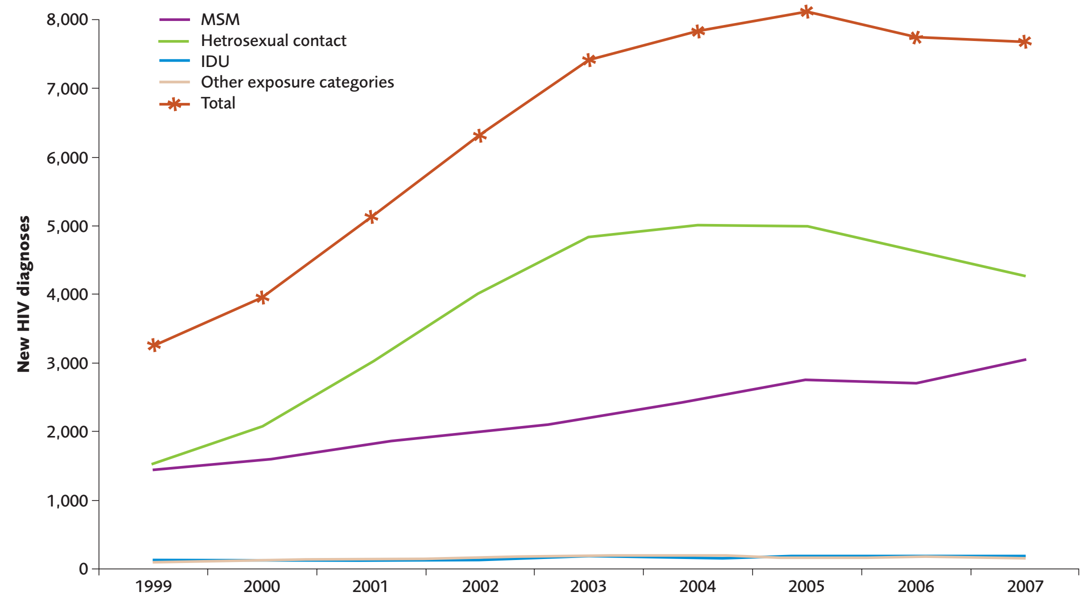


Figure 1: Adjusted* number of new HIV diagnoses by prevention group, UK: 1998-2007



1 Proportional adjustment for missing information

Figure 2: Estimated late diagnosis of HIV infection by prevention group, UK: 2007

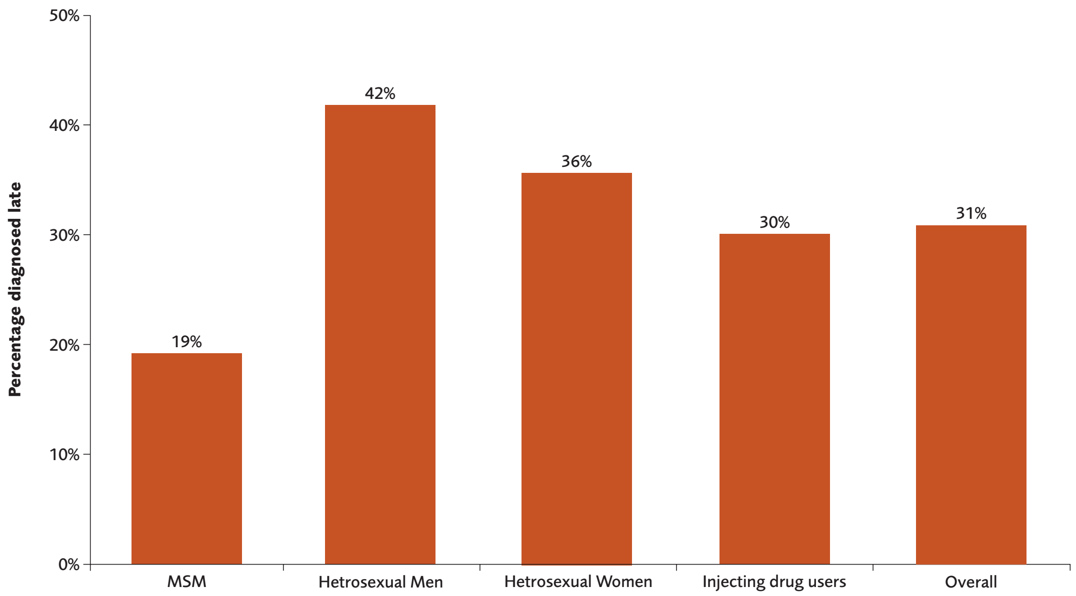


Figure 3: First AIDS diagnoses, HIV-infected persons accessing care and deaths among HIV-infected persons, UK: 1998-2007

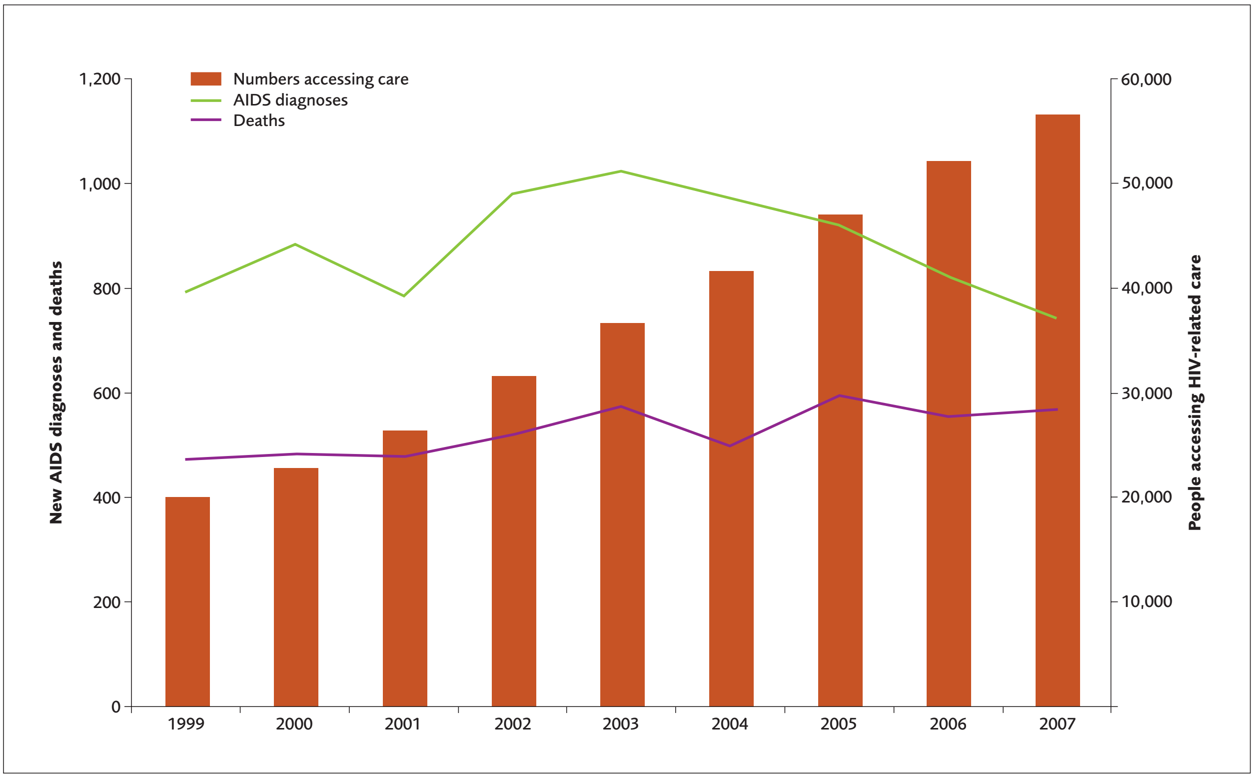


Figure 4: Trends in the uptake of HIV testing and remaining undiagnosed of attendees of sentinel GUM clinics, UK: 1998-2007

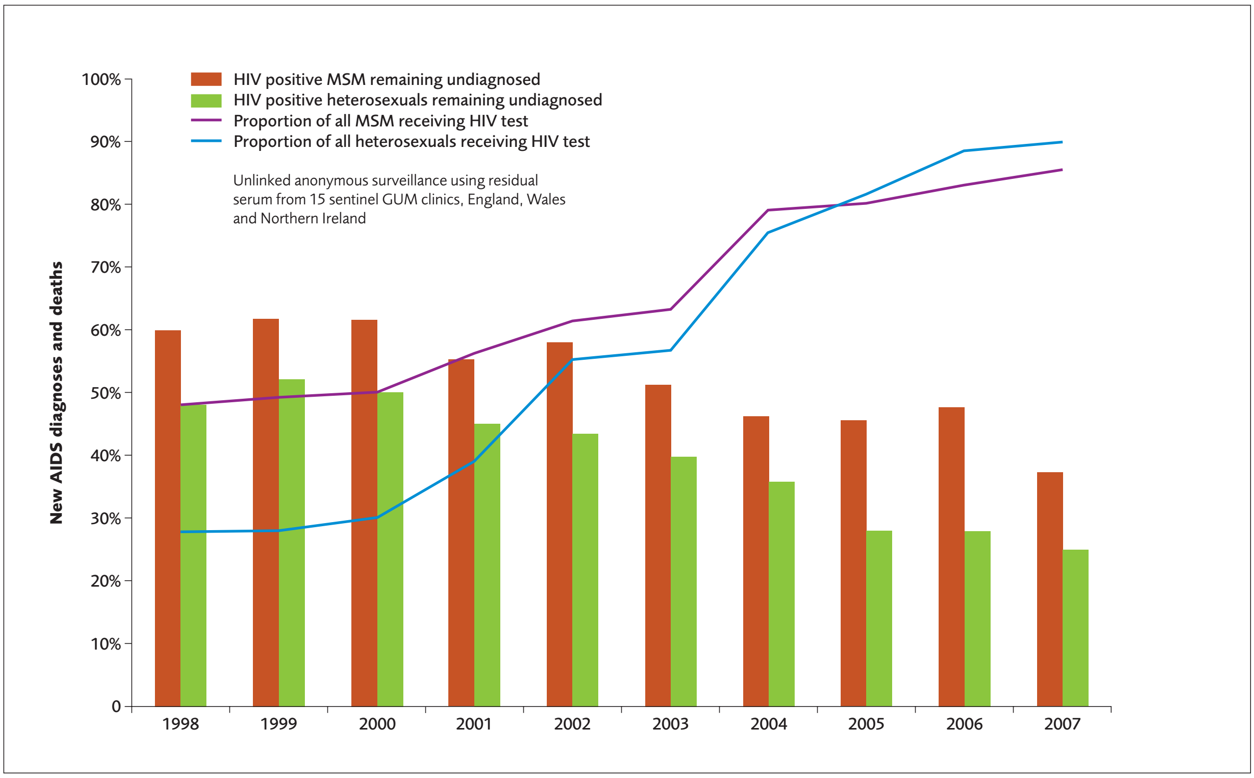
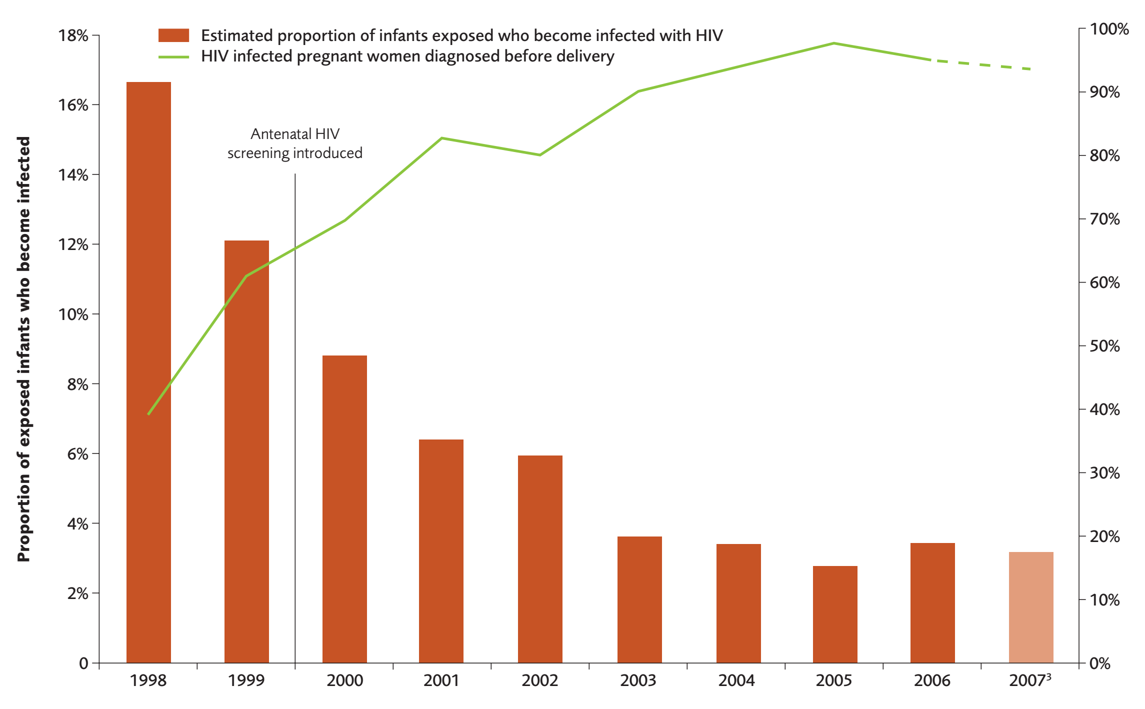


Figure 5: Estimated proportion of HIV-infected pregnant women diagnosed before delivery[1] and of exposed infants becoming infected with HIV[2], England & Scotland: 1998-2007



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1 Includes previously diagnosed and those diagnosed through ante-natal testing

2 Assumes vertical transmission rate of 26.5 percent in undiagnosed women and 2.2 percent in diagnosed women

3 These data contain reports received by the end of June 2008, data for recent years is subject to reporting delay.

Implications of a changing epidemic

One of the most important developments in the last decade has been the continued and significant increase in the numbers infected and diagnosed with HIV. By the end of 2007, there were over 52,000 people accessing HIV care in England (with a further 20,000 undiagnosed). This compares with 20,500 accessing care in 2000 when the National Strategy was drafted. This increase reflects not only continuing HIV transmission but also the welcome fact that effective treatments have substantially reduced the number of HIV-related deaths. People are living longer and this has had an inevitable impact on the numbers being seen for care.

As indicated in the earlier section on epidemiology, the increase alone in numbers of people infected has had several consequences. Not least of these is the cost to the NHS of treatment and care, as well as any wider costs for example in relation to loss of employment. There has been no diminishing of incidence rates amongst MSM in the last decade and to that must now be added growing evidence of significant transmission amongst African communities within the UK. In a world of constrained budgets and competing claims on NHS resources, cost issues also mean increasing pressure to do the same for less in treatment and care. Cost implications alone should encourage us to refocus on HIV prevention.

HIV remains for the foreseeable future a condition which affects a small minority of the general population. But as numbers grow, so increasingly, NHS staff, employers, services providers, lovers, friends and families, will know people with HIV. In addition, no strategy exists nationally for how to create an HIV-literate and HIV-supportive society.

Furthermore, not only has the epidemic changed in terms of absolute numbers, it has also altered in its distribution. London remains the region in England with most people living with HIV but the proportion of the national total is now 48 percent compared with 60 percent in 2000. This is partly due to a simple fact of continuing transmission in a country of very mobile populations. But it is also the result of Government policy to disperse asylum-seekers from London and the South-East of England to other parts of the country and changing patterns of settlement. As a result, while patient numbers have fallen in London, some areas in England have seen, in a very short time, massive increases in patient numbers and newly affected communities, in particular from Sub-Saharan Africa. These communities require different approaches to care and support.

The change in the epidemic is thus not only about absolute numbers and distribution, but also about the profile of those infected. The number of MSM with HIV in the UK is 30,800 (including both diagnosed and undiagnosed), with the figure for heterosexuals born in Africa, 25,850. For heterosexuals born in the UK and elsewhere (other than Africa), it is 14,050. Clearly this means a significant change in ethnicity (and there is of course great ethnic diversity among people from Sub-Saharan Africa within that). But there are also significant changes in other aspects of identity and experience – such as immigration status, faith/belief, and gender – which can greatly affect the needs of people living with HIV. Issues of family life and children, for example, require a range of new services and approaches.

There has been an understandable and proper focus in recent years on the two communities most affected by HIV – MSM and black Africans. But the figures show that heterosexuals not from Sub-Saharan Africa are an increasingly large and diverse population affected by HIV and they present distinct challenges for HIV prevention, diagnosis, treatment and care.

Glossary

AHPN African HIV Policy Network
AIDS Acquired immune deficiency syndrome
ARV's Anti Retrovirals
ASG AIDS Support Grant
BASHH British Association for Sexual Health and HIV
BBVs Blood-borne viruses
BHIVA British HIV Association
BIS British Infection Society
BME Black and minority ethnic
CDSH Common Data Set for Sexual Health
CHAPS Community HIV and AIDS Prevention Strategy
CHINN Children's HIV National Network
CMO Chief Medical Officer
CPS Crown Prosecution Service
DH Department of Health
DFID Department for International Development
EAGA Expert Advisory Group on AIDS
FE Further Education
GO Government Office
GMSS Gay Men's Sex Survey
GP General practitioner
GUM Genitourinary Medicine
GUMAMM Genitourinary Medicine Access Monthly Monitoring
GUMCAD Genitourinary Medicine Clinic Activity Dataset
HAART Highly active antiretroviral therapy
HIV Human immunodeficiency virus
HO Home Office
HPA Health Protection Agency
IAG Independent Advisory Group on Sexual Health and HIV
IDUs Injecting drug users
JSNA Joint Strategic Needs Assessment
LA Local authority
LAA Local area agreement
LDP Local Delivery Plan
LSPs Local Strategic Partnerships
MDT Multidisciplinary team
MedFASH Medical Foundation for AIDS & Sexual Health
MSM Men who have sex with men
MRC Medical Research Council
NAHIP National African HIV Prevention Programme
NAM National AIDS Manual
NAT National AIDS Trust
NGOs National Governmental Organisations
NHIVNA National HIV Nurses Association
NHS National Health Service
NICE National Institute for Health and Clinical Excellence
NIHR National Institute for Health Research
NIS National Indicator Set
NST National Support Team
PBC Practice based commissioning
PbR Payment by Results
PCP Pneumocystis Pneumonia
PCT Primary Care Trust
PEP Post-exposure prophylaxis
PHSE Personal, social, health and economic
POCTs Point of care tests
PREP Pre-Exposure prophylaxis
PSA Public Service Agreement
RCGP Royal College of General Practitioners
RCOG Royal College of Obstetricians and Gynaecologists
RCN Royal College of Nursing
RCP Royal College of Physicians
RITA Recent Infection Testing Algorithm (formally known as STARHS)
RPHG Regional Public Health Group
SCG Specialised Commissioning Group
SHA Strategic Health Authority
SHHRSC Sexual Health and HIV Research Strategy Committee
SLA Service level agreement
SRE Sex and relationships education
SSHA Society of Sexual Health Advisers
STARHS Serological Testing Algorithm for Recent HIV Seroconversion (See RITA above)
STI Sexually transmitted infection
STIF Sexually Transmitted Infections Foundation
TB Tuberculosis
THT Terrence Higgins Trust
UAI Unprotected Anal Intercourse

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