HIV and AIDS in the United Kingdom

Written Evidence from witnesses A-M
Memorandum by the African Health Forum (HAUK 81)

This submission draws on two consultation processes:

a) The African Health Forum meeting 31st March 2011


a) Summary of African Health Forum Members’ Evidence Feedback on 31st March 2011

Monitoring:

a) How robust is the current system for monitoring the number of UK people with HIV?

The current system is not robust enough as undiagnosed people living with HIV are not recorded. Other issues such as housing, immigration issues and general poverty need to be addressed to ensure a climate in which people feel more enabled to come forward for testing and can subsequently be monitored.

b) Will the proposed public health reforms impact on this system?

Yes, with a focus on GPs leading in the future, and with so many people unable to or unwilling to register with GPs in the first place. This is partly down to GPs having a lack of expert knowledge around HIV, leading to late diagnosis where they fail to recognise symptoms early and push patients forward for testing. The reforms may well lead to an increase in late diagnosis, therefore.

c) Could anything be done to improve monitoring?

Where monitoring has been strong in pockets of the country, harness this best practice and learn from it to be applied nationally. Sustainability and longevity of intervention projects should be reassessed. Duplication of needs to be addressed and a “bottom-up” instead of a “top-down” approach should be employed on HIV programmes.

d) What groups in particular are at risk from HIV?

BME in general and more specifically African and Afro-Caribbean communities including Men who have sex with Men (MSMs)

Prevention:

a) Is Government policy sufficiently focused on HIV prevention?

There is confusion and lack of knowledge, even amongst those in the HIV sector about precisely what is the UK Government’s policy in the first place.
Funding seems to have been steadily reduced in this area over the last decade inspite of year-on-year increases in HIV incidence in UK.

\[b\] Have the right groups been targeted in recent campaigns?

No, as there is evidence that the right people are being missed such as those diagnosed with other STIs and who don’t automatically receive any information on HIV and AIDS. There is a need to first of all ensure GPs understand which groups are at most risk, and to even use community representatives to spread messages amongst the wider community. Large groups seem to dominate campaigns meaning many smaller BME organisations lose out and their service users often miss vital messaging as a consequence.

\[c\] To what extent have initiatives targeted at injecting drug users been effective?

Most injecting drug users (IDU) services seem to have been closed down with only Mainliners left to support IDUs. Therefore, there is a lack of effectiveness in this area, certainly in terms of numbers who can be reached.

\[d\] How could prevention be better delivered and evaluated?

By not neglecting grass roots organisations and supporting smaller groups in capacity building and growing their networks, prevention could be more effective.

Testing:

\[a\] Are current testing policies adequate across the country?

No, as they do not adequately support community testing drives. Many people are also sceptical of testing in hospital settings as they are often barred form accessing treatment there, and hence they question what is the point of testing in the first place is.

\[b\] What can be done to increase take-up rates?

Awards for testing and better support to people would be effective at increasing take-up. Wider availability of community testing centres, with proper support, and a focus on confidentiality are key to increasing testing rates from communities.

Treatment:

\[a\] How can the NHS best commission and deliver HIV treatment?

By making treatment free at point of delivery regardless of a patient’s immigration status and by continually promoting treatment as a fundamental human right. The short-sighted implementation of PCT Charge Officers to assess eligibility amongst some of the country’s poorest people who present at A&Es is absurd and causes increase in onward transmission rates. This is especially pertinent nowadays with evidence pointing to massively reduced infection levels of those with low viral loads who are responding well to HAART. Decentralisation of treatment would be one way of improving treatment effectiveness, by having PEP available from pharmacies, for example.
b) **What impact might the proposed new commissioning reforms have on HIV treatment?**

Commissioning reforms may see GPs overloaded and less able to focus on HIV as a single subject, thus reducing the effectiveness of any potential treatment intervention.

c) **In what settings can treatment most effectively be delivered?**

In hospitals but where it’s free to all regardless of residency status and also at new venues such as pharmacies or other local medical facilities.

**Cost:**

a) **Have cost considerations been satisfactorily balanced with public health imperatives in HIV prevention and policy and treatment policy?**

No, by way of a lack of proactive testing, which could include “testing-for-all” initiatives. Furthermore, with increasing numbers of HIV tests being carried out by charities, there is concern over the impact of cuts to third sector organisations’ budgets around the ability to keep testing at current rates. A lack of national awareness and public sector messaging around the risks of HIV, it is apparent that cost is leading the drive to inform citizens about the need to adhere to safe practices. Sexual health is obviously not prioritised and where it is, HIV seems to be the last STI on the list to be given and attention.

b) **Is research funding correctly prioritised?**

No, as there needs to be a focus on prevention technologies such as microbicides, even where they are long term efforts and won’t yield quick results. Medication and vaccine pushes need to have more focus on them, too from government as well as pharmaceuticals.

**Stigma:**

a) **What impact does stigmatisation of those with HIV have on people infected and on addressing HIV as a public health problem?**

Increased isolation, lack of confidence and low self-esteem inhibit the lives of people living with HIV. Many report feeling suicidal and have depression and related physical ill-health caused by mental stresses from the rejection faced from friends, family and colleagues.

b) **Where is stigma most acute?**

It’s most acute amongst BME groups and specific faith groups such as Muslim and Christian communities.

c) **What measures are currently taken to tackle stigma and what more could be done?**

Partnership work such as the SAFER HIV Prevention initiative in Lambeth, Southwark and Lewisham and specific interventions involving faith groups are effective anti-stigma drivers.
However, more outreach work involving community mobilisation and increased dialogue still needs to be forthcoming to have wider impact.

More work engaging young people needs to be done, particularly in schools and other learning environments, to normalise the subject matter from a young age. This could be particularly effective if comprised within the teaching curriculum.

[Compiled by Denis Onyango and Ian Leckie from focus group findings from AHF meeting held at Shaka Services on March 31st 2011].


The evidence we wish to present relates to HIV Prevention, question d) how could prevention interventions be better delivered and evaluated?

2.0 Context for HIV Prevention targeting Africans in S London

2.1 HIV prevention with African communities relies on the co-ordinated efforts of many community organisations. This is because many people at risk of HIV infection (because they come from a high prevalence country, have multiple sexual partners, do not use condoms consistently) are also facing other significant barriers to their health and wellbeing.

2.2 Two thirds of Londoners living in poverty live in Inner London. Whereas c. 20-25% of people in White and Indian households live in poverty, this rises to 35% for Black Caribbean and 50% for Black African and Pakistani and 65% for Bangladeshi households. The 2007 IMD lists Lambeth, Southwark and Lewisham as the 5th, 9th and 11th most deprived boroughs in London. All three have high African populations living in some of the most deprived neighbourhoods with over half of the Lower Layer Super Output Areas being in the 20% most deprived areas in England.

2.3 The Lambeth, Southwark and Lewisham AHF was set up with support form the NHS in recognition of the fact that some African people have worse health outcomes and lower health aspirations. Life expectancy in Lambeth is still below the national average. Lambeth has the highest level of HIV in the country and the three boroughs are widely recognised as having some of the worse sexual health outcomes in England with high teenage pregnancy rates and Chlamydia infection rates.

2.4 Two consultation exercises led by the AHF in 2010, identified a core set of health issues within our community. All participants thought that the health of African people living in S London is adversely affected by poor overall levels of fitness, slow take up of interventions to counter obesity and to promote healthy eating, poor management of stress, hypertension, depression and feelings of isolation.

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1 London’s Poverty Profile Summary, page 4
2 Index of Multiple Deprivation
2.5 The need for high quality, easily accessible and community based sexual health promotion is understood by both the statutory and the voluntary sector. What is less clearly understood, however, is that the impact of sexual health promotion is highest when the intervention is delivered at a critical learning moment for the service users – such as after an STI screen, achieving leave to remain in the UK or at the start of a new relationships. Maximising opportunities for health promoters to capitalise on these learning moments requires the mobilisation of a wide range of services and frontline staff, all of whom need to have a basic awareness of HIV and a high degree of confidence in how to refer to a specialist worker in another community organisation. Most of these organisations will not be funded to deliver HIV prevention outputs.

2.6 This is very different to the structures delivering HIV prevention within the Gay community.

2.7 Over the past ten years, many of the London sub-regional forums delivering work to facilitate better collaborative working between specialist agencies in receipt of HIV prevention funding and other specialist and generic community services have had their own funding cut. In LSL, we have benefited from the continuing support of the HIV Commissioning team, but fear that this budget will come under intense pressure to focus solely on the delivery of direct HIV prevention outputs.

2.8 We conclude that commissioning plans for HIV prevention targeting African communities should specify how multi-disciplinary collaboration and co-ordination across a wide range of stakeholders is to be achieved. We recommend that the infrastructure costs of co-ordinating multi-agency and multi-disciplinary collaborative working are recognised as a legitimate and essential component of local HIV prevention strategies for African communities. We believe that this will best be achieved if Commissioners are required to invest in these costs as part of the national strategy to minimise new HIV infections among Africans living in the UK.

We suggest, that the LSL African Forum could be seen as a model of good commissioning practice for other areas facing the same combination of social and economic factors.

3.0 Health Promotion Messages

3.1 A local review, carried out by NHS Lambeth to support the development of new Commissioning Intentions for HIV prevention in 2011-14 highlighted the provision of mass and small media within the national and the Pan London HIV prevention programmes. It was noted that there a plethora of different brands and messages targeting Africans at risk of HIV infection.

3.2 AHF’s consultation on the health needs of member’s service users noted that some African people prefer to rely on ‘off the shelf’ remedies sent from home countries for their health problems rather than going to their GP. This may be because they do not have time to go to the doctor or it may be because they think they will not be understood. This group of people includes second-generation African people and older people. We conclude that health promotion materials need to promote the NHS as the main source of health treatment and care.
The consultation also noted that some HIV prevention messages, for example ‘always use a condom’ may have little impact on risk behaviours even if service users are skilled to negotiate safer sex because of the cost of condoms and problems with accessing free condoms. We conclude that the provision of free condoms should be tailored to meeting the needs of people without recourse to public funds or who are reliant on others for their shelter and food.

The national programme (NAHIP) re-tendered for delivery and strategy partners in 2010. A London bid, developed with three members of the Forum and one other London agency, was successful. This bid has the support of the Forum and media messages are disseminated widely. We conclude that health promotion messages targeting African communities should be developed in partnership with African community organisations and recommend that future investment in African mass and small media campaigns is managed by the NAHIP programme with the active support of co-ordinating agencies such as the African Health Forum. This will minimise duplication, maximise dissemination and ensure consistency while at the same drawing on the real HIV prevention needs of African people at most risk of HIV infection.

Evaluation of HIV Prevention with African Communities

Community organisations do not have reserves or dedicated funds to finance evaluation work. At the same time we are aware that there are very few evaluated European HIV prevention interventions targeting African communities. There are, therefore, very few reliable conclusions that can be drawn about the effectiveness of the range of interventions we commonly adopt – outreach work; condom and information resource distribution; one-to-one and small group work or community workshops.

Last year, NHS Lambeth produced an HIV Prevention Evidence Briefing. This emphasised that the absence of evidence for some behavioural interventions is not an absence of effectiveness, but indicative of the lack of evaluation of UK programmes. It also noted that where outcomes from interventions are reported, they are largely self-reported behavioural outcomes rather than health promotion or biological outcomes.

In light of the steady rise in numbers of new infections in the UK and, therefore, the increasing urgency around the need to make every HIV intervention as effective as possible we conclude that national and regional support to build a strong evidence base to support intervention design and delivery is now essential. The African Health Forum will actively support any work programme to achieve this outcome.

Targeting HIV Prevention Work

The Forum agrees with the general consensus that HIV prevention work should be tailored for those who are at most risk of HIV infection. The Forum also agrees with the five-priority population groups for HIV prevention targeting African people identified in KWP.
5.2 Several of the Forum members are providing services to target group 1, African people living in England with diagnosed HIV.

KWP notes that ‘since they are in the minority, people with HIV have much more opportunity for HIV sero-discordant sex than do people without HIV. Given that HIV infection cannot be cured and that NAHIP partners agree that it is unethical to try to stop people with HIV from having sex, it is vital that the HIV prevention needs of people with HIV are met. Since interventions can only be targeted at people with HIV if they have their infection diagnosed, these people are the first priority group for prevention programmes.’

5.3 The impact of poverty on people living with HIV has been well documented. The loss of the ring fence for the AIDS Support Grant is expected to remove funding for community-based support for people living with HIV from April 2011. We conclude that HIV prevention targeting African people with diagnosed HIV infection, including those diagnosed late with an associated illness, needs to acknowledge the impact of poverty on the motivation within this group to manage their viral load; ensure consistent safer sex practices and where appropriate disclose their status.

5.4 The Forum is aware that one of the main challenges facing communities who are dispersed from their families and other extended relationships that they have grown up with is that they do not always know where to go to get support and advice. As a consequence, some people are not able to benefit from NHS treatment services because they don’t know that they are there or that they are entitled to use them. **Newly arrived people and people without leave to stay are therefore a priority group for all members of the Forum.**

**NOTES:**

**African Health Forum**

The African Health Forum (AHF) was initiated in 1991 by a group of 5 community organisations who recognised the growing crisis of HIV among African refugee and migrant communities. The success of the Forum is evidenced by the growth in its membership; currently more than 100 organisations including the majority of African community, refugee and migrant and other black and minority ethnic community groups; some national providers; London mosques and Churches; statutory services and the Local Involvement Networks. The forum engages a range of professionals including mainstream charities, hospitals; adult community services and statutory and voluntary sector health services. The AHF benefits from on-going financial support from Lambeth, Southwark and Lewisham Sexual Health Commissioning. The Forum has recently been joined by the leading African HIV Prevention networks in Enfield & Haringey, Westminster and Kensington & Chelsea and is looking to take on a London wide remit over the next three years.

The Safer HIV Partnership is both a strategic network of seven HIV Prevention Providers (all of whom are also members of the Forum) targeting African and the Caribbean communities and a co-ordinated programme of time limited collaborative projects designed to enhance the accessibility, impact and relevance of each provider’s HIV prevention

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3 The Knowledge, The Will and The Power: sigma research; AHPN and NAHIP 2008 page 16
delivery. Safer was established in 2007. In 2010, Safer piloted a community led rapid HIV testing service in Kennington under clinical governance provided by Kings.

**AHF Steering Group Members**

- **Clement Musonda**  Director-Rain Trust
- **Agnes Baziwe**  Chief Executive-Africa Advocacy Foundation
- **David Musendo**  Capacity Building Manager- Restless Development
- **Sam Robin Coker**  Director- West African Networking Initiatives
- **Godswill Udo**  Chief Executive- Ethnic Health Foundation
- **Gertrude Othieno**  Coordinator- African Culture Promotions
- **Denis Onyango**  AHF Coordinator

5 April 2011
Memorandum by African Health Policy Network (AHPN) (HAUK 57)

Evidence being submitted from the African Health Policy Network (AHPN) to the committee’s questions in relation to HIV and AIDS amongst Africans living in England. The AHPN considers an African to be anyone who identifies as African, regardless of whether this is someone that has lived in the UK their whole life or whether they are a newly arrived immigrant.

Monitoring

a. How robust is the current system for monitoring the number of people with HIV in the United Kingdom?

The HPA reported in 2010 that the number of people living with HIV in the UK reached an estimated 86,500 in 2009, but more than a quarter - almost 22,500 - were unaware of their infection. It also found that over half of newly diagnosed people in that year (3,450) were also diagnosed late - after the stage when effective treatment should have started.

The AHPN suggests that if such a high proportion of those living with HIV are unaware that they are infected, then their treatment, care and support cannot be monitored effectively and or robustly.

The danger is that those reported to be diagnosed late are likely to have infected others unknowingly. Thus implying that that there may be many more living with undiagnosed HIV than is reported and monitored.

The information reported by our Ffena members, our membership and strategic partners also illustrate this point. They regularly report that many Africans fear HIV testing and its implications and would rather not test. For example, many of our Ffena members report that they were only diagnosed HIV positive at A&E having presented with an acute stage of an opportunistic infection such as TB. Additionally these groups find that expectant mothers who have been diagnosed HIV positive struggle to and are sometimes unable to get their partners to test.

Anecdotal evidence from our membership and Ffena claim that many undocumented migrants are aware that on testing positive for HIV they will not get access to treatment as they have no recourse to public funds. This cohort will most definitely not be included in any monitoring systems.

Similarly, it is not specified how many people in detention centers awaiting deportation are living with HIV. It is also not known how regularly testing is conducted for those who have been detained for long periods of time in these centers.

Whilst the data captured by UK’s surveillance and monitoring process led by the Health Protection Agency (HPA) is robust and comprehensively sourced there are many living with

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4 Ffena: (formerly known as Vital Voices) is an inspiring network of African HIV champions living with and affected by HIV in the UK. This enables their experiences to be shared and their voices to be heard collectively at various levels. Ffena is a Luganda word meaning ‘we’ all together’. Read more at: www.ahpn.org/ffena
HIV that are under the radar of this monitoring system. The AHPN therefore stresses that whilst access to treatment, support and care are only available to the exclusion of undocumented migrants, certain visa holders and people in detention; and if the causes of stigma and discrimination towards living with HIV; as well as lack of information exchange regarding the number of detainees are not addressed, then the systems for monitoring will not report accurate prevalence of HIV in the UK.

b. Will the proposed public health reforms impact on this system?

The Department of Health White Paper proposes the creation of a new public health body, Public Health England, into which the Health Protection Agency (HPA) will be incorporated. This aims to “strengthen public health surveillance” and “develop and enhance the public evidence base” (para 4.78) by integrating all the public health monitoring systems. If this is achieved, and it results in better HIV monitoring, as the White Paper suggests, the public health reforms will have a positive impact.

However, there are potentially three main negative potential impacts and unintended consequences of these reforms:

- According to the proposals, Public Health England will take on the current functions and powers of the HPA, as this will be a new service, AHPN is concerned that this does not result in a loss of quality or quantity of HIV surveillance data.
- As the HPA will no longer be an independent body, there will be a loss of independence and autonomy, and possibly transparency, in HIV monitoring. Even after incorporation into Public Health England, HIV surveillance and analysis must remain free from a potentially politicised agenda.
- Whilst some impacts of the proposed reforms are not yet clear as, the Department of Health has however promised to safeguard the income generating activities of the HPA and it is not yet clear how much these funds will be spent on public health monitoring.

c. Could anything be done to improve monitoring?

Encourage more people to test for HIV, to ensure more accurate data is captured and less estimated numbers of unreported cases. NHS information systems need to improve as they are quite limited for HIV surveillance at primary care.

To achieve this we suggest the following steps are taken:

1. Greater levels of training and awareness raising for Healthcare professionals and community of interest groups in high prevalence areas, as well as service planning for GP consortia (in particular, expanding HIV testing or HIV long-term condition service planning).
2. Strengthening the relationship between national surveillance and HIV testing through enhancing local HIV reporting procedures while maintaining world-class national surveillance capability.
3. Stigma, discrimination and access to testing and treatment should be prioritized and addressed at both national and local levels. For example, the AHPN would like to see a clear plan of action that each GP Consortium will implement that aims to improve access to HIV testing, treatment, care and support. Such plans should be targeted at those disproportionately represented such as Africans living in the UK as they are usually overrepresented in late diagnosis statistics.
4. The causes or situations that perpetuate stigma and discrimination towards those living with HIV should be redressed to motivate more people to acknowledge testing as part of ordinary living. All of this will help to get more accurate monitoring information as there will be many more willing to test.

5. The AHPN would also like to see more qualitative data linked with the largely quantitative data that is currently being captured. This will help in planning services as it will provide greater insight into the multidimensional and complex set of issues that many living with HIV have to face. There should be universal access to treatment; support and care available to all people living in the UK regardless of the fact that they may be undocumented migrants, certain visa holders and people in detention.

d. What groups are in particular at risk from HIV?

Africans living in England are still disproportionately affected by HIV (second only to men who have sex with men). Black Africans account for 33% of all people living with HIV in the UK and 40% of all new diagnoses. Between 1995 and mid 2010, black Africans accounted for 41% of the UK’s total HIV diagnoses, of which the majority (93%) were attributed to heterosexual sex.

In 2009, there were 22,220 black Africans diagnosed as living with HIV in England (HPA, 2010). The HPA estimates that 26% are unaware of their infection. This takes the total to 27,997 (although estimates vary within HPA data). Prevalence is estimated to be 3.7% or approximately 1 in 20 Africans in England (though this varies as population estimates vary and compares to prevalence of 0.09% among the white population). Also in 2009, 54% of all new diagnoses in the UK were acquired through heterosexual sex, of which 63% were in black Africans (HPA, 2010).

African Health Policy Network recognises that some sub-groups of Africans are more likely to be at risk of HIV acquisition, as neither sexual HIV risk nor unmet HIV prevention need is evenly distributed. Interventions must be targeted towards and tailored to address the particular needs of:

- **African women**: In 2009, twice as many black African women were diagnosed with HIV than African men (HPA, 2010). This reflects the gendered nature of the epidemic in sub-Saharan Africa. Women have additional biological vulnerability to acquisition in heterosexual sex and behavioural factors and socio-economic status, such as negotiation of condom use, also contribute.

- **African Men who have Sex with Men (MSM)**: Among African men in England, men who have sex with men are twice as likely to have HIV as those who do not have sex with men (Mayisha II Collaborative Group 2005). A study by Hickson et al. 2004 showed that African MSM are twice as likely to be living with HIV as white MSM.

- **Discordant couples**

- **People with multiple sexual partners** and people in relationships with people who have multiple sexual partners.

- **Those with low levels of education** (AHPN: Bass Line, 2008)

AHPN believes that targeting HIV prevention interventions to those most likely to benefit is the most efficient use of limited resources.

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Prevention

a. Is Government policy sufficiently focused on HIV prevention?

The proposed Government policy is focused more on sexual health, and focuses little on HIV and/or HIV prevention. In terms of funding this could result in HIV being sidelined and not getting the focus that it deserves. Despite the fact that a third of people infected with HIV do not know they have the virus, there is still much emphasis on prevention alone and the policy needs to focus on both (early) testing and prevention as the two complement each other. Therefore the government HIV prevention policy needs to incorporate ‘treatment as prevention’ and encourage changes to testing policy to accord with treatment policy. This should include offering free treatment for HIV to those with irregular immigration status.

The Public Health White Paper consultation proposes sexual health/HIV prevention and sexual health services to be commissioned locally through local authorities. HIV treatment services, however, are expected to be commissioned nationally through the National Commissioning Board. The resulting prevention and treatment split provides few incentives for prevention-treatment pathway developments.

AHPN’s position is that the government policy on prevention should reflect the prevention needs of Africans in the UK as suggested by the Baseline survey 2008. In particular, black Africans and men who have sex with men are critical groups to focus HIV prevention policy and services. There is, however, another important factor: the fact of living in a high prevalence area is a surrogate risk in itself and so the concept of routine testing in these areas is important and efficient for case-finding and transmission reduction.

b. Have the right groups been targeted in recent prevention campaigns?

Recent prevention campaigns have been delivered through the national prevention programmes, including the National African HIV Prevention Programme (NAHIP) which AHPN manages. These programs are targeted at high risk groups; Africans and men who have sex with men however there are still gaps on targeting African men who have sex with Men and prevention work on this group has been insufficient and inconsistent.

AHPN sees targeted prevention campaigns as the most effective way to meet the unique prevention needs that a particular group has, as it enables campaigns to incorporate tailored information in a culturally appropriate way. However, the NHS' general sexual health campaigns, which are aimed more widely, still need to include information about HIV and increase support to targeted HIV campaigns.

c. To what extent have prevention initiatives targeted at injecting drug users been successful?

The number of Africans diagnosed as acquiring HIV through IDU in the UK is very low (98 diagnoses between 1995 and mid 2010\(^6\)).

Transmission via IDU remains a small problem in the UK (of the 111,882 HIV diagnoses since the start of the HIV epidemic in the UK, only 5%, or 5332 diagnoses have been as a result of IDU\(^7\)). Incidence has remained stable since 1995 (between 110-215 new diagnoses per annum\(^8\)) and prevalence is estimated at about 1.5%\(^7\). This represents a huge decline

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\(^6\) Health Protection Agency: HIV/STI Department, “United Kingdom: New HIV Diagnoses to end of June 2010), 2010: Table 11

since the beginning of the 1990s when prevalence was at nearly 6%. The decline in prevalence shows that consistent, targeted prevention initiatives towards one high prevalence community can be very successful and have long-term impact.

Injecting drug use is now seen as a declining trend in England. However, substance misuse, including IDU, alcohol and other non-injectable drugs, contributes to increased risk of sexual acquisition and transmission of HIV and other STIs. Therefore, substance misuse treatment programmes have an important role in consolidating sexual HIV prevention initiatives.

d. How could prevention initiatives be better delivered and evaluated?

To better deliver and evaluate prevention initiatives the following challenges must be overcome:

• There is little funding available for evaluation within most programmes and this limits the scope of evaluation possible. Reporting requirements for monitoring and evaluation are becoming more rigorous across the sector but delivering more thorough evaluation incurs extra costs, whilst funders are demanding bigger impact. For small community based organisations the lack of funding for evaluation and the increasing reporting burden is particularly acute.

• Evaluation should aim to improve prevention delivery by applying lessons learnt. Yet the current economic climate is also not conducive to innovation. This can restrict the usefulness of an evaluation once it has been completed and this can affect improvements in delivering future prevention interventions too.

• There is inherent difficulty in assessing progress towards prevention targets because of difficulties in collecting data which shows widespread behaviour change or change in incidence, and which takes into account the time frames over which prevention work needs to be measured.

• More effective delivery requires investment into research which aims to identify which interventions are most effective for different populations.

However AHPN’s position is that prevention initiatives can be better delivered by incorporating the following factors:

✓ Testing history
✓ Gender and sexuality
✓ Level of education,
✓ Age
✓ Variations of residence in the UK, country of birth
✓ Religion and culture

Testing

a. Are current testing policies adequate across the country?

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8 Health Protection Agency: HIV/STI Department, “United Kingdom: New HIV Diagnoses to end of June 2010), 2010: Table 10 and Table 11

The fact that the number of late diagnoses and undiagnosed increase year on year, proves that testing policies are not adequate. Several prominent bodies have concluded that issues such as late-diagnosed and undiagnosed HIV can only be tackled if testing is performed in a wider range of settings than sexual health (GU) and antenatal clinics.

Various HIV testing guidelines including the 2008 the British HIV Association, the British Association for Sexual Health and HIV and the British Infection Society and the 2010 NICE guidelines have been published to help make the testing policies adequate across the country. AHPN would recommend that these guidelines are followed by all practitioners at every point of care.

Similarly, the AHPN would like to see the draft NICE 2010 public health guidance on HIV testing among men who have sex with men and Africans followed strictly. NICE recommends here that local strategies be developed to encourage individuals to consider testing - drawn up in consultation with local voluntary organisations and community members.

b. What can be done to increase take-up rates?

Firstly, regular testing should be offered in high prevalence areas and, realistically, this needs to be accompanied by a mixture of directives and incentives. Such testing should be open access for those at risk and routine in new GP registrants. This is a clear recommendation of the 2008 British HIV Association, the British Association for Sexual Health and HIV and the British Infection Society National Testing Guidelines.

Patient acceptability of the offer of testing has been repeatedly demonstrated; the principal barrier appears to lie in the lack of offers of testing from healthcare professionals.

If HIV testing were a national priority, many of the barriers to individuals requesting/taking tests and healthcare professionals actively promoting tests would be overcome. Healthcare professionals in primary care undoubtedly have many different expectations and targets to meet; however, the need for HIV testing to become a greater priority in general practice is clear.

The Quality and Outcomes Framework (QOF) has been successfully used to encourage general practice to meet national targets by the provision of financial incentives; in secondary care CQUIN has been used to similar effect. Rewarding good practice through existing incentive frameworks, both national and locally, is likely to be one of the most effective means of increasing, widening and normalising testing.

Regular offers of testing in general practice and other healthcare settings would help to normalise the practice, defuse notions of otherness and encourage understanding that HIV is just one of a range of causes of ill-health that should be considered when someone is at risk. Removing the stigma from HIV testing may also reduce late diagnosis in groups at particular risk such as men who have sex with men and black Africans.

There is good evidence from antenatal screening that normalising HIV testing through the adoption of an opt-out approach to testing can dramatically increase uptake. In 2009, the uptake of HIV tests reached 95% in antenatal clinics nationally and also 95% among patients tested in sexual health clinics as part of the unlinked anonymous HIV testing survey. This is a survey of residual syphilis blood samples in a sentinel network of sexual health clinics.

Since 2000, most pregnant women have been routinely offered HIV tests. Those testing positive are provided with a course of ART, may undergo a Caesarean section and are advised not to breastfeed.

Mother-to-child transmission rates have fallen sharply as a direct result of these interventions (Figure 1), which demonstrates the key role testing can play in HIV prevention.

Evidence from the Department of Health HIV testing pilots has consistently showed healthcare workers to be a bigger barrier to HIV testing than patients. In addition there are practical obstacles which must be overcome to expand HIV testing in primary care settings in high prevalence areas. For example, there are currently no primary care National READ codes for point-of-care tests (POCT).

Current proposals are that HIV prevention and testing should be commissioned by local authorities within their broad ‘public health’ remit/budget. As it has now been announced that local authorities will be responsible for commissioning GUM services it will be important that they do not see this as fulfilling their requirements to commission testing as, in addition to GUM, we need to see testing made available in a wide range of healthcare settings, including community settings. The GP consortia will be responsible for

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commissioning other secondary care services, so it will be important that they include a requirement for HIV testing in service specifications.

There is a need for more training for GPs and other healthcare professionals likely to offer a HIV test. Directors of Public Health, local authorities and local Health and Wellbeing Boards will be the key local policy co-ordinators of the future, with opportunities to develop local GP training programmes. This is especially relevant for HIV, where much of the burden arising from late diagnosis for patients and services is localised, such as in the cities of Brighton, London and Manchester.

There is still a misconception among many healthcare professionals that specialist counselling is required before the offer of an HIV test can be made. In addition to this, the poor communication between specialist HIV services and primary care means that many primary care staff feel very uncomfortable discussing HIV as they feel this is outside their area of expertise and is the role of specialist services.

Several prominent international bodies have also concluded that issues such as late-diagnosed and undiagnosed HIV can only be tackled if testing is performed in a wider range of settings than sexual health and antenatal clinics. In the same year that the UK Chief Medical Officers wrote to healthcare professionals urging them to offer and recommend HIV tests to patients if they may have been exposed to HIV infection,\textsuperscript{15} WHO issued guidance on provider-initiated HIV testing and counselling in health facilities\textsuperscript{16}. The WHO guidance recommended a greater level of provider-initiated implementation in settings ranging from medical inpatient and outpatient facilities, services for younger children and adolescents, surgical services, in addition to health services for the most at-risk populations.

The WHO guidance was followed in 2010, by the European Centre for Disease Prevention and Control (ECDC) publishing guidance on increasing the uptake and effectiveness of HIV testing.\textsuperscript{17} The ECDC guidance recommended that, in order to increase uptake, HIV testing should be offered in a variety of medical and non-medical settings, in co-operation with non-governmental organisations, and outside normal working hours. The guidance also recommended the implementation of outreach HIV testing services for marginalised groups in the community.

**Treatment**

a. How can the NHS best commission and deliver HIV treatment?

AHPN would like to see delivery of free HIV treatment to those with irregular immigration status. Standards for quality of HIV treatment and care need to be implemented nationally.

b. What impact might the proposed new commissioning reforms have on HIV treatment?

The proposed commissioning reforms would see HIV treatment funded by the NHS while Public Health England responsible for commissioning prevention. By funding HIV treatment

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separately, there is less likelihood of funding cuts to prevention work if treatment costs rise. This is important for stability in both commissioning of treatment and prevention. However, it may cause a fragmented response to treatment as prevention. Treatment and prevention go hand in hand and the new commissioning proposals are likely to disrupt that unless there is proper co-ordination in the way the two are commissioned. As migrants can find the NHS difficult to navigate, it is important that all NHS patients are aware of how commissioning and policy changes may alter the mechanisms an individual has to complain if they are unhappy with the treatment and care they receive.

c. In what setting can treatment most effectively be delivered?

Currently most treatment is delivered in HIV clinics by expert clinicians and this has worked well for many people. This needs to continue to ensure people living living HIV get the best expert treatment in terms of both advice and choice. However, there is a need to investigate alternative settings for treatment delivery to minimise the number of patients who drop out of care and this should be done in two-way consultation between expert clinicians and those who are on treatment. Migrants can find the NHS difficult to navigate and there can be a reluctance to engage with ‘official’ services amongst those with irregular immigration status and those that fear stigmatisation. More research is needed in this area. There is also a need for cohesive policy to mitigate the disruption to treatment and care caused by migrant dispersal systems and detention.

**Cost**

a. Have cost considerations been satisfactorily balanced with public health imperatives on HIV:

(i) prevention policy and (ii)treatment policy?

A recent study has suggested that by 2013, the cost of providing treatment and care in the UK will exceed £720 million per annum or more than £1000 million if the cost of community care is included\(^\text{18}\). Improvements to testing policy should result in more and earlier diagnoses, which will initially increase the amount spent on HIV treatment and care in the UK.

It is estimated that lifetime care for a person living with HIV costs between £280,000 and £360,000\(^\text{19}\). When compared with the sum currently spent on prevention in the UK, it is evident that the Government needs to think in the longer-term to understand the value for money that investment in prevention provides.

Cutting treatment and care costs is not the way to balance the cost: the same study goes on to say that any savings made would have very limited impact and could potentially compromise patient care. It concludes that a “concerted effort to reduce the ongoing transmission of HIV is much more likely to have a significant impact on costs”.

Investing more in prevention will reduce future treatment and care costs by reducing the future overall case load. Investing in early diagnosis will prevent the additional costs associated with emergency and complicated treatment and care, and will reinforce investment in prevention.

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b. Is research funding correctly prioritized?

There is an absence of any clear strategy for HIV research in the UK (which there was historically). There has been very little research AHPN would like to see more qualitative research funded to investigate issues such barriers to testing amongst African communities in the UK, and the stigma and discrimination that these groups face.

Stigma
a. What impact does stigmatization of those with HIV have on those infected, and on addressing HIV as a public health problem?

It well known that HIV Stigma and discrimination remains the single most important barrier to HIV prevention because it prevents people from accessing services. It also makes it difficult for people living with HIV to take action to raise awareness of the virus, stigma is arguably the main reason why the HIV infection continues to rise and devastate societies around the world.

Stigmatisation has serious and varied impacts on people living with HIV. Studies have shown that African men and women’s experiences following disclosure include domestic violence, homelessness, social isolation or rejection and unemployment. People with diagnosed HIV infection can internalise stigma, which can cause low self-esteem. This may affect an individual’s motivation to seek support, disclose or protect sexual partners; all of which are detrimental to addressing HIV as a public health problem.

Reluctance to disclose one’s status or talk openly about HIV has serious consequences for addressing HIV as a public health problem. It hides the realities of HIV and can lead an individual disassociating from HIV, by seeing it as something that only happens to ‘other people’. This was evident in the findings of Bass Line: the majority of respondents underestimated HIV prevalence and 52% of respondents who had never tested for HIV said they ‘have no reason to think they have HIV’. Distancing reduces the likelihood of recognising one’s own risk of transmission or acquisition, the need for testing, and acting to reduce risks all of which make HIV harder to address in public health.

There is also evidence that fear of stigma and discrimination prevents some African people from testing (26% of Bass Line respondents who had never tested cited reasons related to fear and stigma or accessing services, both of which have public health consequences. Misinformation and HIV-related stigma tend to reinforce one another

b. Where are problems of stigmatization most acute?

HIV related stigma has many layers and every individual has different experience. However, Stigma is most acute in already marginalised groups, such as women and asylum seekers, as it can act to reinforce existing stigma and discrimination against a marginalised community

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20 Doyal & Anderson 2005
22 Weatherburn et al. 2009
24 Elam et al. 2006, Dodds et al. 2008
25 Bass Line
27 Anderson & Doyal 2004, Dodds et al. 2004
and then reinforces the stigma connected to the virus by association. This can happen at multiple levels from within and without a community and disproportionately affects those who are then multiply marginalised (e.g. an African, gay asylum seeker). There is also self-stigmatisation which in most cases has resulted in isolation because an individual blames themselves for being HIV. A lot of this type of stigma has lead to mental health illnesses. Stigma is further worsened when it taps into pre-existing cultural taboos and it acts to reinforce social inequalities. For the UK African community, this may include racism, immigration status, xenophobia, homophobia, sexism and assumptions about sexual behaviour such as promiscuity or infidelity (Dodds et al. 2004).

c. What measures are currently taken to tackle HIV stigmatization? What more should be done?

Measures currently taken to tackle HIV stigma are varied and include legislation against discrimination, research, educative campaigns and engaging people living with HIV to talk about their experiences. AHPN has attempted to tackle stigma through two settings where it is particularly acute in the African community by producing training materials for both for the media and faith leaders/community.

HIV is still treated differently to other STIs and long term health conditions by the public and NHS alike; for example, NHS policy that requires those with irregular immigration status to pay for HIV treatment but not for treatment for other STIs or serious infectious diseases. Measures that tackle stigma need to balance normalisation with accurate information about HIV that still recognises the virus as lifelong, incurable and focused on marginalised communities. Prevention initiatives and fair, carefully testing and treatment policy can successfully reinforce anti-stigma work. To fully address stigma, there must be more interventions that aim to tackle the wider social inequalities and discrimination that permeate society.

References

1 Health Protection Agency: HIV/STI Department, “United Kingdom: New HIV Diagnoses to end of June 2010), 2010: Table 11
1 (Doyal & Anderson 2005). African men with HIV can feel isolated and emasculated by ill health and often experience difficulty providing financial support for their family (Anderson & Doyal 2004, Doyal et al. 2005).
1 Weatherburn et al. 2009
1 (Chinouya & Davidson 2003, Mayisha II Collaborative Group 2005).
1 Elam et al. 2006, Dodds et al. 2008
1 Bass Line
1 Anderson & Doyal 2004, Dodds et al. 2004

February 2011
Memorandum by the All Party Parliamentary Group on HIV and AIDS (HAUK 104)

Introduction:

The APPG welcomes the formation of the House of Lord’s select committee on HIV and AIDS by Lord Fowler and is very grateful to have the opportunity to submit evidence to this committee.

Founded in 1986, The All Party Group on HIV and AIDS is one of the largest and most active APPGs in parliament. It has over 100 MPs and Peers amongst its membership, who are all concerned about the impact that HIV and AIDS both in the UK and overseas. The APPG retains close links with people living with HIV healthcare professionals and voluntary sector organisations outside of parliament.

The APPG is a member of the Halve it campaign, and worked alongside other members of the coalition to produce the policy paper “Early Testing Saves Lives,” in 2010 which calls for the number of people being diagnosed late with HIV to be halved by 2015.

Over the past year the group has:

- Secured recognition of the challenge of late and undiagnosed HIV in the Public Health White Paper and in Hansard. Our MP members met with health Ministers and talked to the Secretary of State to raise this issue.
- Initiated a 90 minute parliamentary debate on World AIDS Day on HIV in the UK, raising the profile of late diagnosis, the importance of mental health support for people living with HIV, the need to prepare for the aging cohort of people living with HIV, and challenges of HIV commissioning.
- Won official support from the Government for the campaign to end mother to child HIV transmission by 2015.
- Ensured that the UK perspective on HIV and AIDS is represented at the UN High Level meeting on HIV and AIDS in June 2011, raising specific concerns around the human rights of key populations with the minister
- Pushed for a large donation from the UK to support the Global Fund for combating HIV and AIDS, TB and Malaria in developing countries, and will continue to do so until there is a specific announcement from the Government.

Section 1: Monitoring

a. How robust is the current system for monitoring the number of people with HIV in the United Kingdom?

- We currently have one of the best systems in the world for monitoring the number of people in England living with HIV. The Health protection agency provides extremely valuable data and analysis.

b. Will the proposed public health reforms impact on this system?
Memorandum by the All Party Parliamentary Group on HIV and AIDS (HAUK 104)

- Concerns have been raised about the implications of splitting up the health protection agency, which at present plays a valuable role in providing independent data and analysis on HIV in the UK. It is important that this body should retain a central monitoring function, and remain independent of central government.

c. **Could anything be done to improve monitoring?**
- HIV co-infection status is not currently recorded in TB surveillance.
- Wales has no data regarding late diagnosis of HIV

d. **What groups in particular are at risk from HIV?**

HIV can affect anybody, but in the UK the majority of people fall within two groups: Men who have sex with men (MSM), and people of sub-Saharan African origin.

**Men who have sex with men**

- According to the Health Protection Agency, 42% of new HIV diagnoses in 2009 were among men who have sex with men (MSM). Gay men remain the group at highest risk of contracting HIV in the UK, making up 67% of those acquiring the infection in this country. Diagnoses among MSM remain high at 2,760. However, numbers appear to have plateaued to some extent.

- 2009 was the second year in a row with no significant change reported. If the scale of the HIV epidemic in the gay community was replicated in the general population, there would be over 4 million people with HIV in the UK.

- MSM will continue to be a group at particular risk of HIV. The epidemic has established itself in this community, and there is a particular higher risk of HIV transmission from anal sex which increases the need to promote safer sex to this group.

- With this group, it is important from a health promotion perspective to be aware of sub-groups with higher HIV prevalence. Amongst MSM, 27% of diagnoses were amongst men in their 20s. **59% of diagnoses were in men in their 30s and 40s**, and 12% were amongst men in their 50s. HIV infection therefore appears to occur at a higher age on average compared with occurrence of other STIs, which are most commonly found among 15-24 year olds.

**People of sub-Saharan African origin**
• 34% of new diagnoses in 2009 were among heterosexual black Africans, accounting for two thirds of all heterosexual diagnoses. The majority of heterosexual infections were probably acquired abroad (68%).

• There are also strong geographical differences in HIV prevalence rates. In 2010, 52% of all new HIV diagnoses in the UK were reported in London.28

One in seven gay men on the London gay scene has HIV, compared with one in 14 nationally29

2. Prevention

a. Is Government policy sufficiently focused on HIV prevention?

• The APPG is concerned about the levels of awareness about HIV in the UK. For example, 20% of people surveyed did not know that HIV was transmitted by sex without a condom between men and women. This is a 10% decline compared to 10 years ago.30

• National prevention programmes have been critical to maintaining national focus and coordination on HIV prevention amongst at risk communities. Each new case of HIV costs the NHS between £280,000 and £350,000 in lifetime treatment and care, so there is a strong financial incentive to undertake prevention work.

b. Have the right groups been targeted in recent prevention campaigns?

• The APPG believe that there is a need to expand prevention beyond the 2 main groups of people affected by HIV and AIDS, (Men who have sex with men and Black Africans), particularly amongst young people.

• HIV should feature more prominently in more generic sexual health campaigns, typically those targeted at young people. There is evidence of increasing transmission amongst heterosexuals in the UK and campaigns must therefore not give them the impression that they are not at risk.

c. To what extent have prevention initiatives targeted at injecting drug users been successful?

• The UK has a good track record of minimising the spread of HIV amongst injecting drug users. This is in large part thanks to early harm reduction measures, particularly during the early years of the epidemic. Nevertheless, injecting drug users who share needles continue to be at an increased risk of HIV, and account for a significant minority of 3.1% of people living with HIV in the UK.

29 According to figures provided by the Terrence Higgins Trust.
30 According to a poll taken by Ipsos MORI for the National AIDS Trust of public understanding of and attitudes to HIV.
• There is also a serious failure in HIV prevention for those injecting drug users who at some time enter prison. Prison does not mean necessarily the end of injecting drug use but it is done unsafely, thus increasing the risk of HIV and Hepatitis transmission.

d. How could prevention initiatives be better delivered and evaluated?

A number of approaches would be useful to help prevent HIV transmission amongst the wider public:

• We should integrate HIV information and advice into wider sexual health work

• We should consider in areas with high HIV prevalence (for example, parts of London) wider HIV prevention work amongst the general public which will both be another way of reaching those in most at-risk groups but also others who may be at risk.

• We should introduce consistent high-quality sex and relationships education in all schools which teaches fully and effectively the facts of HIV and how to prevent transmission, as well as the wider social issues involved. A report carried out by the Office for public management in 2010 revealed a strong appetite amongst pupils for education about HIV in their schools.

• We should encourage more and better quality of reporting on HIV in the media. When HIV is reported it is often sensationalised- for example in a recent article in the Leicester Mercury a woman claimed that she is “terrified” after being accidentally pricked by a needle in her garden:


• Under the Government’s new proposals, HIV prevention is to be funded at the local level by local authorities from their ring-fenced health improvement budget. This budget is to fund GU services as well as wider public health interventions in smoking, obesity, alcohol etc. In the absence of a HIV prevention outcome indicator it is difficult to see whether many local authorities will fund targeted HIV prevention to most at-risk communities. GU services are an essential element of NHS secondary care provision.

• If local authorities are to commission GU services, funding for this purpose should be calculated and provided separately (though also protected by a ring-fence) from the ring-fenced fund for health improvement.

3. Testing

a. Are current testing policies adequate across the country?

• Current testing policies are not adequate across the country, as is evidenced by the late 26% of people living with HIV in the UK do not know that they have
the virus. In 2009, 52% of people were diagnosed late, after they should have already started treatment.

- There is evidence that we are missing crucial opportunities for testing of HIV and AIDS- In a 2008 study by the SONHIA Collaboration Group found that more than three quarters of Black Africans with diagnosed HIV in London had seen their GP in the year prior to their diagnosis, but that only 18% had had a discussion about HIV or testing with them. This means that significant numbers of people are falling through the gaps.

b. What can be done to increase take-up rates?

- The APPG believes that there should be a normalisation of HIV testing, particularly in high prevalence areas such as Lambeth and Brighton. New registrants in some practices are now routinely asked to take a HIV test. The UK National Guidelines for HIV testing recommend increased testing in high prevalence areas (>2 per 1000) for medical admissions, new GP registrants and patients presenting for healthcare. The HPA has identified 35 PCTs where diagnosed HIV prevalence is over 2 in every 1,000 people.

- There is also a need for education amongst healthcare professionals, many of whom still see HIV as a specialist area which is treated outside of general practice and there is much anecdotal evidence of healthcare professional. The NICE guidelines that HIV tests should be carried out with informed consent in the same way as testing for other diseases such as diabetes.

- All new registrants in areas with High HIV should be tested. Estimates have shown that for each new HIV case averted, we could save up £260,000 in direct healthcare costs.

- Financial incentives (such as CQUINS and QOF) should also be considered in order to facilitate increased take up rates of testing at a local level

Treatment

a. How can the NHS best commission and deliver HIV treatment?

- The APPG welcomes the decision to retain HIV commissioning within the NHS commissioning board, rather than devolve it to the GP consortia.

- Government proposals to separate out the commissioning of HIV treatment and care (NHS Commissioning Board) from local sexual health services (local authority commissioning) do, however run the risk of producing fragmented and uncoordinated services.

b. What impact might the proposed new commissioning reforms have on HIV treatment?
Memorandum by the All Party Parliamentary Group on HIV and AIDS (HAUK 104)

- The APPG welcomes the proposal to include early HIV diagnosis as one of the key public health outcome indicators, and believe that it is vital that the late HIV diagnosis is retained in the final version of the Public Health Outcomes Framework.

- Greater attention should be given within the planned commissioning arrangements to ensuring targeted HIV prevention work is undertaken at the local level with most affected communities.

- The APPG believes that Public Health England should require local authorities to provide comprehensive sexual health services, and that such services must include the vital work in the community to prevent HIV transmission.

Cost

a. Have cost considerations been satisfactorily balanced with public health imperatives in HIV:

(i) Prevention policy; and

- Under the Government's new proposals, HIV prevention is to be funded at the local level by local authorities from their ring-fenced health improvement budget. This budget is also, however, to fund GU services as well as wider public health interventions in smoking, obesity, alcohol etc. In the absence of a prevention outcome indicator it is difficult to see whether many local authorities will fund targeted HIV prevention to most at-risk communities.

(ii) Treatment policy?

- Concerns have been raised by patients around the prescribing of treatment in the London area, and the APPG would recommend that the BHIVA treatment guidelines are followed robustly, ensuring that no patient is switched unwillingly onto different medication.

Stigma

a. What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?

- Stigma and discrimination has a hugely detrimental impact on those who are living with HIV and also acts as a barrier to HIV testing as people are discouraged from coming forward for tests. This undoubtedly has an impact on late diagnosis in the UK.

- Stigma can hamper access to HIV services, because people living with HIV fear that if their colleagues and friends find out, they may reject them. Stigma can also have a negative effect on treatment: if people are afraid to reveal their status, they may find it difficult to take their medicine or adhere to treatment regimes.

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Memorandum by the All Party Parliamentary Group on HIV and AIDS (HAUK 104)

- Significant numbers of people living with HIV are affected by depression and other psychological problems which are exacerbated by problems of stigmatisation. ³²

B. Where are problems of stigmatisation most acute?

- Stigma towards people living with HIV can, and does exist within all communities.

- A 2008 survey of people with HIV in London found that one third of people encountered discrimination because of their HIV status. Of those reporting discrimination, half said it had come from a healthcare worker, 26% from a dentist, 18% from a GP and 10% from hospital staff.

- Asylum-seekers living with HIV have become some of the most marginalised people in the UK. They are ‘doubly stigmatised’ based on both their HIV and their immigration status.

c. What measures are currently taken to tackle HIV stigmatisation? What more should be done?

- All the recent HIV testing pilots (for example those funded by the Department of Health and Gilead) have demonstrated the high acceptability of HIV testing to people when offered. There is much more we can readily do to increase testing uptake simply by offering the test more widely and consistently, and explaining the value of knowing one’s HIV status given the effectiveness of early diagnosis and treatment.

- Normalisation of HIV testing by healthcare professionals would also make a huge difference towards tackling HIV stigma. The evidence above illustrates the need for training amongst healthcare staff about the impact of stigmatisation.

- There is also a need to communicate to people that receiving a HIV positive diagnosis is no longer tantamount to a death sentence. Attempting to frighten people into taking a HIV test will be counter-productive and perpetuate the problems of stigma, and self-stigma.

- More work needs to be done to tackle stigma and discrimination within faith based communities. A study of African men living with HIV in London concluded that ‘religion is a powerful coping mechanism for many people from African backgrounds, and that more effort and resources should be dedicated to involving black and African faith organisations in prevention strategies and into activities to reduce HIV related stigma’ ³³

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• There are many examples of good practice where faith communities are engaged in HIV prevention, awareness and support, (for example in Mosques in South east London), but there is a need to develop a more strategic approach to this area of work.

June 2011
Letter from Dr Sris Allan, Consultant GU/HIV Physician, Honorary Associate Clinical Professor, Department of GU Medicine Coventry & Warwickshire Hospital (HAUK 20)

I am extremely pleased that a select committee will be considering issues related to HIV and AIDS in the United Kingdom. I would like to submit the following evidence to the sub committee:

**Monitoring**

2.1 Our monitoring system in the U.K is one of the best in the world and we have timely robust data from HPA however, if the HPA is abolished then another organisation should be given the responsibility of collecting and disseminating the information.

2.2 The group at particular risk in the U.K are people from sub sharan Africa and men who have sex with men. This includes all the ethnic groups who lived in sub sharan Africa.

**Prevention**

3.1 Antenatal HIV screening is a well established cost effective service in the U.K. I would like the sub committee to consider the option of screening partners of high risk HIV negative mothers. At present HIV positive mothers are offered and encouraged to have their partners tested. As we know some ethnic groups in the U.K have a disproportionately high prevalence of HIV (up to 10%) therefore, even if the high risk mother is HIV negative her partner may be positive and there is a risk of transmission during the antenatal and post partum period. (Evidence BMJ 21 June 2007, Jayasuriya & Allan – Are we doing enough? 334:1287)

3.2 U.K National guidelines for HIV testing published in 2008 by British HIV Association, British Association of HIV and British Infection Society should be summarised and circulated to all the medical and surgical specialities in the U.K.

**Testing**

4.1 Some healthcare professionals are unaware that they can request an HIV test without counselling from HIV counsellors. This needs further education of health care workers and dissemination of information to all the specialities within the Health Service.

**Treatment and Cost**

5.1 HIV out-patient care can be provided in community clinics or in large health centres where confidentiality and anonymity can be maintained. Cost of HIV medications can be minimised by a national pricing system.

15 February 2011
The ABI is the voice of insurance, representing the general insurance, investment and long-term savings industry. It was formed in 1985 to represent the whole of the industry and today has over 300 members, accounting for some 90% of premiums in the UK.

Executive Summary

Insurers want to make more insurance products available to people with HIV. Insurers are proactive and are working hard to include more risk assessment in the market. A barrier to this is a lack of data on life expectancy. The ABI want to work with Government to get better data. As insurers become more confident in the data, they will be able to write more products in a prudent way and open more markets. In turn, this would help reduce any stigma associated with HIV by enabling more people with HIV to take out insurance.

Insurers do not ask questions about an applicant’s sexual orientation or request an HIV test be taken because of sexual orientation, and will not take into account sexual orientation in assessing an application if it is inadvertently revealed by an applicant. Insurance is based on assessing and pricing risk. Insurers will look at particular characteristics, called rating factors, and assign that individual a level of risk. The level of risk is reflected in the terms and conditions, scope of cover and limitations on the policy and/or the premium. Insurers may ask questions about HIV risk, including about blood transfusions outside the EU, injecting non-prescription drugs, risky sexual behaviour and about travel to, or residency in, areas of the world with high prevalence of HIV.

Monitoring

How robust is the current system for monitoring the number of people with HIV in the United Kingdom?

The Health Protection Agency Infection Rates report of November 2010 mentions testing in STI clinics but does not mention HIV testing by GPs where patients present in the local surgery with an STI. This may be because HIV has the stigma of a sexually transmitted infection and the reputation for being incurable.

Could anything be done to improve monitoring?

There is scope to improve monitoring and avoid further spread of the disease by closer follow-up of any previous partners of HIV positive individuals. The HPA figures indicate that TB rates are increasing in the UK and with 6.7% of TB cases also having HIV one other potential area for testing may be people presenting with Tuberculosis.

What groups in particular are at risk from HIV?

It is the experience of the insurance industry that the risk of infection is influenced by risk factors such as a person having a blood transfusion outside of the EU and/or
having risky behaviour such as injecting non-prescription drugs, rather than belonging to a particular group.

Prevention

1 Is Government policy sufficiently focused on HIV prevention?

1.1 The Health Protection Agency Infection Rates report of November 2010 estimated that 26% of the HIV infected population is unaware of their infection. The ABI believes that more needs to be done to raise awareness.

2 Have the right groups been targeted in recent prevention campaigns?

2.1 More needs to be done, the ABI supports education and targeted campaigns, for example, on teenage safe sex and the use of clean needles if an individual is injecting non prescription drugs.

3 How could prevention initiatives be better delivered and evaluated?

3.1 More could be done to focus on education about environment and behaviour that is associated with high risk of infection, for example the use of needles, countries with a high prevalence of HIV and risky sexual behaviour.

Testing

1 Are current testing policies adequate across the country?

1.1 The entitlement to NHS care should be nationally consistent. We support the Health and Social Care Bill’s intention to reduce inequalities between patients with respect to their ability to access health services and the outcomes achieved for them by the provision of health services.

2 What can be done to increase uptake rates?

2.1 Education on the long term mortality implications of HIV could reduce the fear associated with having a positive test. In turn, this could encourage people to be tested by avoiding the "I don't want to know bad news" reaction which probably holds down take-up rates of testing.

Stigma

1 What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?

1.1 Insurers do not have data on overall completion rates of HIV testing. It may be that the stigmatisation of HIV reduces the number of people who take an HIV test when they are at risk of having HIV.
2 Where are problems of stigmatisation most acute?

2.1 Insurers underwrite all customers with serious conditions in the same way, using available mortality data. For example, liver cancer may affect people who have used alcohol excessively more than other people. However, the underwriting of HIV continues to be an emotive issue in the media.

3 What measures are currently taken to tackle HIV stigmatisation? What more should be done?

3.1 HIV can affect any individual. Publicising information on the range of people affected by HIV and the long-term health and life expectancy implications of HIV and AIDS may reduce the fear-factor and stigmatisation of HIV.

3.2 The stigma and misinformation of HIV could be reduced if the focus of media and educational campaigns was on the risk factors, such as safe sex for all people including teenagers.

February 2011
Memorandum by the Association of Directors of Adult Social Services and the Local Government Association (HAUK 69)

The Association of Directors of Adult Social Services (ADASS) represents Directors of Adult Social Services in Local Authorities in England. As well as having statutory responsibilities for the commissioning and provision of social care, ADASS members often also share a number of responsibilities for the commissioning and provision of housing, leisure, library, culture, arts and community services within their Councils.

ADASS members are jointly responsible through the activities of their departments for the well-being, protection and care of their local communities and for the promotion of that well-being and protection through the use of direct services as well as the co-ordination of and liaison with the NHS, voluntary agencies, private companies and other public authorities.

ADASS members have leadership responsibilities in Local Authorities to promote local access to services and to drive partnership working to deliver better outcomes for local populations. They participate in the planning of the full range of council services and influence Health Service planning through formal and informal partnership arrangements.

Local Government Association (LGA) – is the voice of the local government sector. We work with and on behalf of our membership to deliver our shared vision of an independent and confident local government sector, where local priorities drive public service improvement and every councillor acts as a champion for the people they represent. The 422 authorities that make up the LGA cover every part of England and Wales. Together they represent over 50 million people. They include county councils, metropolitan district councils, English unitary authorities, London boroughs, shire district councils and Welsh unitary authorities, along with fire authorities, police authorities, national park authorities and passenger transport authorities.

Monitoring:

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**a.** The extent of current national (and local) monitoring of HIV/AIDS activity and prevalence rates is fragmented, reflecting the limited extent of national strategy, the degree of local flexibility in how HIV/AIDS services are organised and delivered, and the extent of “denial” and associated under reporting within community groups.

It is noted that Adult Social Care, through the application of Fair Access to Care criteria, only accounts for approximately 10% of the anticipated HIV/AIDS population.

In terms of national analysis, it is noted that there are a number of collections which assist in understanding the extent of HIV/AIDS prevalence, although these returns are either based
upon surveys or retrospective activity collections, resulting in a degree of statistical error in the calculations (particularly when the stigma associated with HIV/AIDS conceals numbers of individuals with HIV/AIDS from these collections). This analysis is summarised in the Health Protection Agency Annual Report on HIV [Health Protection Agency- HIV in the United Kingdom 2010 Report].

B. The proposed PH Outcome Framework includes a HIV/AIDS measure (Proportion of persons reporting with HIV at a late stage on infection) within Domain 4 (Prevention of Ill Health). This will enhance the profile of HIV/AIDS within the remit of Public Health focus. C. There are several recommendations to improve monitoring, namely:

- Specific reference to HIV/AIDS monitoring within the scope of the Joint Strategic Needs Assessment (JSNA), the production of which is to be a statutory duty for the Health and Wellbeing Board (HWB). Furthermore, GP consortia will be required to have regard to the JSNA in their commissioning plans.

- Strengthened role of Health Watch and the Health and Wellbeing Boards to hold providers and commissioners to account for health and social care outcomes and health inequalities detailed in the Healthy Lives, Healthy People and the Public Health Outcomes Framework consultation.

D. Groups at risk - HIV remains prevalent in the gay community, which is at odds with the public perception that HIV/AIDS is reducing as a consequence of improvements in medical treatment. Additionally, as acknowledged by the Department of Health (DH paper-HIV and AIDS in African Communities: Jan 2005) HIV/AIDS is increasingly prevalent amongst the Black African community, although issues relating to stigmatisation and “denial” within this community masks the extent of prevalence.

Prevention

a. Is government policy sufficiently focused on HIV prevention
b. Have the right groups been targeted in recent prevention campaigns
c. To what extent have prevention initiatives targeted at injecting drug users been successful
d. How could prevention initiatives be better delivered and evaluated

A. Prevention: Since the mid 1990’s when the Government embraced a high profile preventative campaign, the welcomed advancements in medical treatment have change emphasis towards the medical model of treatment. This shift is believed to have had limited effectiveness in prevention and we draw on three trends to support this view: first, the continued incidence of HIV/AIDS (See HPA - HIV in the United Kingdom 2010 Report); the increasingly poor public awareness; and the changing nature of the groups being affected.

B. Effectiveness of targeting. There are several groups that, it is suggested, would benefit from preventative campaigns. These are:

- Marginalised groups within Gay Community HIV/AIDS - ‘awareness’ and services are still clustered in places with substantial and influential gay populations at the expense of more isolated and less connected groups, dispersed across the
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- **Black Africans** - as previously noted, this community is experiencing increased prevalence of HlIV/AIDS, compounded by reluctance within this community to recognise this increase, combined by ongoing discrimination towards Black and Ethnic Minority communities.

- **Vulnerable adults** - As a consequence of demographic changes, there are increasing numbers adults with physical disabilities and learning disabilities, and older people, who are eligible for social care services, and who are experiencing and expressing higher expectations regarding choice and independence. Adult Social Care fully supports these outcomes, through personalisation.

D. Prevention Initiatives - the proposals in the Public Health White Paper, give local authorities a more central, leadership and coordination role in prevention strategies. They can do this by including in their strategies a range of related local services such as housing, education, youth services and social care to significantly contribute to early prevention and behavioural change initiatives, particularly for vulnerable families and young people.

D. Evaluation - we note that it is extremely challenging to measure success of prevention initiatives, even when it is widely accepted that prevention is better than cure. The absence of any reliable measure which assesses upstream social and economic impact, combined by the difficulties in attributing accountability for interventions and the fact that the vast majority of upstream benefits are likely to be experienced by completely different organisations at a later point, undermines incentives to conduct preventative activity. The Department of Health, through its recent Outcome Framework consultations has recognised the importance of “outcome measures”, although we note that the proposed set of measures do not address the issue of preventative benefits and we will continue to work with the Department of Health to tackle this.

Testing

a. **Are current testing policies adequate across the country**

b. **What can be done to increase take-up rates**

A. **Current Testing Policies**: The current arrangements are Councils are best placed to target their testing programmes to their communities.

B. **Take-up rates**: There are a variety of influences which can impact upon the success of take-up rates. These are as follows:

- **Stigma of setting**: Given the sensibilities and potential stigmatisation experienced by HIV/AIDS individuals, the context of the setting is critical. In terms of Social Care (through which individuals can be encouraged to undertake tests) although most councils operate Single Access Points, it is recognised that HIV/AIDS specialist teams also operated more “sensitive” low key access arrangements to encourage engagement and referral.

- **Accessibility**: It is suggested that new models of accessing HIV testing could be considered to include retail settings i.e. chemists. This may reduce barriers to” take
up” associated with clinical settings as well as encourage new ways of regarding HIV/AIDS in a more socially accepting way, although any such approach needs to take into account access to pre/post-test counselling.

- **Front line differences:** Despite many examples of excellent partnership working, there is some tension between the ‘medical’ and ‘social’ models in HIV care, which impacts upon the referral pathways to testing, treatment and social care support.

- **Routine testing:** Alongside the current offer for HIV Testing made to pregnant women as part of their antenatal care, it is suggested the offer of routine testing could be extended for all new GP patients (the new GP Consortia may create further opportunities) as well as all STI Testing to also include routine HIV Testing, although any routine approach has to take into account whether this itself creates barriers to people coming forward for testing.

- **Insurance Guidelines:** It is suggested that the Government should clarify guidelines to Insurance companies and citizens as to HIV/AIDS testing requirements.

### Treatment

| a) | How can the NHS best commission and deliver HIV treatment |
| b) | What impact might the proposed new commissioning reforms have on HIV treatment |
| c) | In what setting can treatment most effectively be delivered |

**A.** In terms of commissioning HIV treatment, social care is critical partner in the care pathway. Firstly in terms of successful intervention and prevention activity (in partnership with Public Health) to reduce incidence; secondly in creating the supporting framework for adherence to treatment programmes (i.e. emotional support) and third, sustained recovery or successful maintenance of long-term conditions associated with HIV/AIDS through improved life choices and chances (access to services, info and advice) – **no point treating symptoms only, you must also treat the cause.**

**B.** The new reforms places the NHS at the centre of commissioning and there is concerns as to the level of awareness that the NHS has of the offer that Social Care can make to supporting people with HIV/AIDS and their carers, as well as the range of preventative work undertaken by Social Care.

**C.** As previously noted, the stigma of institutional clinical settings (hospitals / clinics) is believed to create barriers to individuals presenting themselves for HIV/AIDS testing or treatment. Social Care can provide the supportive holistic framework to assist individuals (and local communities) in breaking down these barriers and to seek (or sustain) an improved quality of life.
Cost

- Have cost considerations been satisfactorily balanced with Public Health imperatives in HIV
  
i. Prevention policy; and
  
ii. Treatment policy

- Is research funding correctly prioritised

Although the Public Health White Paper includes improved outcome measures for HIV/AIDS and a Health Premium will be introduced to incentivise a reduction in health inequalities (possibly including improved outcomes for HIV/AIDS), it is not clear if HIV/AIDS will be prioritised over other competing outcomes. We also have associated concerns of how to attribute improvements in Health Inequalities relating to HIV/AIDS and that Health And Wellbeing Boards will not be able to “direct” GP Consortia commissioning intentions. That said, GP consortia will be required to have regard to the JSNA and the Joint Health and Wellbeing Strategy in developing their plans, both of which will need to identify and address the challenges related to HIV/AIDS.

Further, it is noted that the National HIV Strategy was refreshed in 2009, although it is not clear as to status of this strategy in the context of the Government’s approach to HIV/AIDS.

Stigma

a. What impact does stigmatisation of those with HIV have on those infected and on addressing HIV as a public health problem

b. Where are the problems of stigmatisation most acute

c. What measures are currently taken on tackle HIV stigmatisation? What more should be done

A. From the perspective of Social Care we note the increasingly close association between mental ill health and HIV/AIDS. This association is results from isolation and low expectations experienced by people with HIV/AIDS, particularly by marginalised groups within the wider HIV/AIDS community.

B. The stigmatisation of people with HIV/AIDS is most acute within the Black African community, driven by a culture of denial within the community itself. This can further isolate and marginalise Black African people with HIV/AIDS and it is an area to which Adult Social Care is addressing through it’s presence within the community setting and the broader community cohesion programmes undertaken by councils, although it is recognised that further work is required to acquire the full community confidence in accessing social care services and support. This confidence is highly dependent upon customer experience of a seamless, coherent and focused service, and reinforces the need for an integrated approach.

C. Social care is well positioned to tackle stigma head on as opposed to the medical model operated within health, which is restrictive to the treatment of conditions. The historical basis for HIV-specialist social care, specifically the prejudice and discrimination and consequent stigma and shame experienced by people with HIV/AIDS, remains as much of a factor in many of their lives.
### Supplementary Questions:

1. Under new arrangements, local authorities will be responsible for commissioning a full range of sexual health services, but not HIV treatment and care. Do you believe that this distinction in commissioning is justified?

   a. Is there a case to be made for a holistic approach to all genitourinary medicine services?
   
   b. Is there any danger of service fragmentation arising from the new arrangements, thereby undermining the control of STIs and HIV? Specifically, how will the national network of HIV/GUM services be maintained?

   1. Local Authorities have historic experience of promoting public health, which can be equally applied to commissioning HIV/Sexual health promotion

   a. Social care is critical to successful intervention (and prevention) in partnership with health. Social care provides the supporting framework for adherence to treatment programmes (i.e. emotional support) and sustained recovery through improved life choices and chances (access to services, info and advice) – **no point treating symptoms only, you must also treat the cause.**

       It is noted the social care has not undertaken commissioning of medical treatment, so this distinction would seem justified from a pragmatic perspective. However, keeping treatment & social care integrated as a holistic solution based upon mutual understanding and respect is key

   b. Fragmentation HIV/GUM services is more likely when commissioned through health where the medical model dominates and there is limited awareness of the value of social care input. The limitations of explicit national expectations is likely to exasperate current post code lottery of service availability.

2. Are local authorities ready for the delegation of public health responsibilities? How do you think that governance arrangements will ensure the quality of clinical services commissioned?

   a. Is there any risk of local politicisation of public health issues, particularly around a stigmatised condition such as HIV?

   2. There remains significant concern as to the inter-relationships between Public Health and Local Authorities. The Public Health White Paper is still at live consultation, and the Health and Social Care Bill does not mention the responsibilities of Public Health England and how it will operate with the National Commissioning Board, GP Consortia or Health and Wellbeing Boards.

       We have already noted concerns as to HealthWatch and the Health and
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Wellbeing Boards not having statutory powers to hold commissioners to account. Further, the role of CQC as regulator of quality is perceived as becoming more withdrawn from front line engagement and increasingly reliant upon desk top analysis.

The role of NICE to develop and introduce Quality Standards across NHS, Adult Social Care and Public Health is welcomed, but there is concern that the emphasis will be based upon the health model. Although this may address issues relating to commissioning of clinical standards, the critical value of social care input must also be addressed and we welcome opportunities to work with NICE in developing holistic Quality Standards.

2a. Stigma remains prevalent and ever changing (for example, new communities experiencing HIV/AIDS). Commissioning of HIV/AIDS and STI are very likely to result in fragmented services, particularly where commissioning is to be dependent upon local awareness.

It is suggested there is a programme of awareness (amongst professionals and the public) and that national expectations are clearly expressed to direct service development, but balanced with local flexibility (Localism), combined with a refreshed HIV Strategy.

In terms of supporting full service availability, it is suggested that Local Authorities safeguard the commissioning of niche “Cinderella” services and that the NHS and GPs should work with their Local Authority partners to ensure that services for people with HIV/AIDS do not slip through the cracks.

3. The Health and Social Care Bill has a strong focus on integrated working, with a lot of emphasis placed on a seamless experience for the patient. How could this work in practice, using HIV and sexual health services as an example?

3. Many areas of good practice already exist and there are increasing patterns of integrated services across the country.

It is noted that HIV services tend to enjoy enhanced collaboration when they are closely focused upon the needs and interests of service users within a “practice” rather than a “strategic” setting, and such settings can lead to further innovative solutions to collaborative working, benefiting service users and the wider community.
4. Under existing arrangements in areas such as in Manchester, Primary Care Trusts have formed voluntary regional networks for commissioning HIV and STI services. To what extent do you anticipate that local authorities will seek to do the same?

Voluntary regional network are very likely to expand within Local Authorities

5. How will local authorities maintain focus on HIV/STI prevention work, given the many competing priorities that new public health responsibilities will bring; especially given that money saved on expensive HIV treatment will benefit the national NHS budget, rather than the balance sheets of local authorities?

The proposed move towards an Integrated Outcome Framework (as described in DH Business Plan 2011-15) could create synergy across NHS, Public Health and Adult Social Care and create opportunities to work collaboratively, and this may equally create a platform to maintain a focus upon preventative work.

Further, it is suggested that the HIV Strategy is refreshed to provide clear national expectation upon the level and quality of HIV/AIDS services, to be then designed and commissioned locally.

The shift towards increasing pooled budgets and integrated commissioning teams, plus the development of both “Total Place Budgets” and measures which describe the economic / social impact of preventative interventions, can all help to address the current limitations of working collaboratively on “upstream costs”, although there is no universal approach.

It is suggested that further work is conducted nationally to establish a transparent methodology to achieve enhanced efficient and effective use of public money across organisational boundaries, and this should also cover the inclusion of a social/economic impact measure within the Integrated Outcome Framework to incentivise prevention, rather than responding to “failure demand” characterised by the existing set of national measures.

In terms of moving towards pooled budgets (as opposed to shared budgets), it is important that the role of prevention is clearly recognised and discharged, and that there should be equality of decision making between commissioners of prevention and of treatment.

The proposed introduction of “payment by results” within the Health and Social Care Bill, presents opportunities to incentivise prevention and early intervention, but this needs to be predicated upon clear national (and local) expectations, which are still in development. Any financial rewards system (payment by results) needs to take into account the multiple influences upon the health choices and outcomes of individuals, and the rewards need to be balanced with resources to support communities that
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| have the least assets and the greatest challenge in relationship to addressing health inequalities. |
| In terms of preventative initiatives taken by councils, it is suggested that the main area of focus should be young people, through the schools curriculum. There is concern however that the current curriculum does not fully address HIV/AIDS awareness (only 60 minutes dedicated within year 9) and the proposed opportunities for the emerging Academies and Free Schools to have more discretion over their curriculums, which when seen in the context of concerns of local awareness of HIV/AIDS, raises further questions about an effective “national” preventative programme. |

| 6. Under the arrangements proposed in the Health and Social Care Bill, increased patient and public engagement is proposed. One avenue for this is through a national HealthWatch England structure, with local authority-funded local units. What role do you envisage for these Local HealthWatch organisations, especially for HIV where local prevalence may be low? |
| a. Do you consider there to be any conflict of interest in local authorities funding an organisation that holds the services that they commission to account? |

| 6. HealthWatch needs to align its work programme with the local JSNA and relevant Health and Wellbeing Strategies and consequently ensure it’s membership is inclusive of all groups, including those marginalised groups (likely to include people with HIV/AIDS) identified within the local JSNA. This membership should also include links to representative groups to ensure wide coverage. |

| B. There are potential conflicts, but these can be addressed through procurement and contract arrangements with HealthWatch. Local Councils are accustomed to identify and mitigate against conflict of interests and fund a range of organisations engaged in conflict resolution, i.e. Service User Panels, Neighbourhood Assemblies etc. |

| 7 Much of the responsibility for public health has been delegated locally, but there are designated roles in the Health and Social Care Bill for a number of central bodies: Monitor in economic regulation; the Care Quality Commission in quality control; NICE in quality guidance. Is there any concern over the potential degree of input from central bodies into devolved responsibilities? |

| 7. Whilst we support the important functions these central bodies hold, particularly in the context of providing a transparent national framework to support improved outcomes for citizens and local populations, we are concerned that there remains a degree of ambiguity as to the balance between national and local direction/discretion. We support a balance which clearly allows for a high degree of local discretion and minimal national interference and we seek assurance that resources will be available to ensure that local decisions are appropriate to meet requirements expressed by local people. |

18 February 2011
The Association of Directors of Public Health (ADPH) is the representative body for directors of public health (DPH) in the UK. It seeks to improve and protect the health of the population through DPH development, sharing good practice, and policy and advocacy programmes. [www.adph.org.uk](http://www.adph.org.uk)

ADPH has a strong track record of collaboration with other stakeholders in public health, including those working within the NHS, local authorities and other sectors.

In 2009, ADPH and Terrence Higgins Trust produced a joint report *Five steps to better sexual health and supporting people with HIV* and this can be found at: [http://www.adph.org.uk/downloads/policies/Sexual_Health_policy_2009.pdf](http://www.adph.org.uk/downloads/policies/Sexual_Health_policy_2009.pdf)

The ADPH welcomes the opportunity to input to the Select Committee on HIV and AIDS in the UK.

The focus should be on reducing the spread of a communicable disease and how it is controlled as part of the wider health economy. To this end there are three priorities:

- **A coordinated approach to prevention and the management of the messages.** Messages need to be decided nationally/regionally and then tailored slightly to meet local needs. Local use must reinforce the overall impact of the message.
- **Better coordination between prevention, testing and treatment services during a time in which funding streams are becoming increasingly fragmented.**
- **In the vast majority of cases HIV is transmitted sexually.** Associating HIV prevention with good sexual health is important. If we focus too much on only one sexual transmitted disease it will be to the detriment of the populations understanding of others.

**What will the impact of the public health reforms be on prevention and treatment of HIV and AIDS?**

- In general the priority given to and emphasis on public health is strongly supported
- The creation of Public Health England is positive
- The transfer of responsibility for public health from PCTs to Local Authorities makes strategic sense as the local authority is best placed to influence the factors that have the biggest impact on health such as employment, housing, education etc.
- The creation of a ring fenced budget for public health is positive, particularly in providing protection for public health resources during transition. However, clarification of the budget is needed in general and in relation to sexual health.

Current costs of sexual health services are estimated at around £700-£750 million: potentially between 17% and 20% of the outlined £4 billion budget for Public Health.

However there are a number of issues to be worked through in the transition:
• The magnitude of reorganisation of staff and structures will create disruption on an unnecessarily large scale and, based on experience from previous reorganisations, risks loss of substantial expertise.

• The size of the ring fenced budget is unclear and public health is transferring at a time when many Local Authorities need to make significant budget cuts. In this context there is a risk that local authorities facing a future with markedly reduced resources may seek to “re-designate” some existing activities as public health.

• The relationship between the different parts of the system is complex and for instance there is a risk that DsPH will be distant from GPs and the NHS more generally.

• Currently the NHS Outcomes Framework for assessing the performance of the NHS Commissioning Board is focused on clinical outcomes with a separate public health outcomes framework. Not including public health and health improvement in the NHS outcomes framework risks diluting the roles of the NHS and general practice, and may give GP consortia little motivation to engage in public health.

There are a number of specific issues in terms of sexual health

• The current proposals potentially will result in a fragmented approach to sexual health. It is intended that responsibility for contraceptive services will be commissioned through the GP contract HIV treatment through the NHS Commissioning Board and everything else through the Local Authority. This means that there will be a separation of responsibility and funding for HIV treatment from HIV prevention and similarly of contraceptive services from TOP and GUM services.

• The inclusion of sexual health targets within the public health outcomes framework is positive. The shift in focus for Chlamydia screening from uptake of Chlamydia screening to diagnosis of Chlamydia is also welcomed. The inclusion of an indicator on late diagnosis of HIV is also welcome. However the performance management arrangements for these indicators are unclear and it seems likely that there will be a delay of at least a year before the NHS / Local Authorities are held accountable for delivery on these targets. Given the separation of the NHS Outcomes framework and the Public Health outcomes framework highlighted above there is a risk that the NHS (which will need to do most of the testing) will fail to engage in this target.

• There will be a year long gap between the current Operating Framework targets ending and the new Public Health outcomes coming into effect. During this time there is a real risk that sexual health and HIV services will suffer. It is important, both in economic and public health terms, for continuity of services to be maintained until the Public Health Outcomes are agreed.

• The Government intends to publish a document on sexual health and teenage pregnancy during spring 2011. This provides an opportunity to outline the approach to sexual health and HIV and clarify some of the issues outlined above.

1. **Response to specific questions**

   **Monitoring**

   a. How robust is the current system for monitoring the number of people with HIV in the United Kingdom?
The Health Protection Agency (HPA) provides accurate and highly useable data in the form of the Survey of Prevalent HIV Infections (SOPHID). This data forms a key part of the evidence base for the commissioning of treatment and care services for HIV positive people. The monitoring of the undiagnosed prevalence of HIV is also provided by the HPA and is useable on regional scale, for example, the whole of London, but it is not useable for lower level modelling because of the increasing inaccuracy of the model at borough and then ward level. Increasing sentinel surveillance could increase the accuracy but the marginal gain from doing this is currently unclear.

b. Will the proposed public health reforms impact on this system?
In principle current reforms should not impact on the collection and production of the HIV intelligence. However reductions in the funding in capacity of the Health Protection Agency that are currently proposed may impact on collection and dissemination of the data. Similarly the proposed changes to sexual health commissioning and funding discussed below mean that a wider range of organisations and individuals will need to receive understand and make use of the information.

c. Could anything be done to improve monitoring?
There are two main areas which could be improved for local level commissioning:

- The data flow between the various service providers could be improved. Currently many service providers have systems that do not talk and, for example, this has an impact on monitoring HIV testing in primary care.
- Data on country of origin for the planning of targeted testing and prevention services in boroughs with a high ethnic diversity. The use of the concept of Black African to describe the population of a large and diverse continent has limited use in tailoring local prevention messages.

d. What groups in particular are at risk from HIV?
- Men who have sex with men
- Black Africans

Prevention

a. Is Government policy sufficiently focused on HIV prevention?
No. HIV is an incurable, communicable disease that is incredibly expensive to manage once a person has become infected. London spends over £200 million on the centrally commissioned provision of Anti Retroviral Therapy and specialist medical services for the 28,285 HIV positive people living in London\(^{34}\). This does not include the money that PCTs and local authorities spend on local level treatment and care services. Each new infection that is diagnosed will incur a lifetime cost of between £280,000 and £360,000\(^{35}\).

Put simply, well planned spending in effective, targeted and consistent communications is a highly cost effective way of increasing HIV testing and reducing transmission.

It must also be remembered that the overwhelming majority of cases of HIV are the result of sexual transmission. This means that investment in appropriate messages will have a positive impact on reducing sexual ill-health.

b. Have the right groups been targeted in recent prevention campaigns?
To an extent. Serious investment has been made in targeting prevention at MSM and Black African groups but there are some issues on how well this targeting has been done. One of

\(^{34}\) HPA ‘HIV in the United Kingdom: 2010 report’
\(^{35}\) HPA ‘HIV in the United Kingdom: 2009 report’
the biggest current issues is the lack of coordination on the type and content of the communications messages that go out and this risks undermining the overall impact of the message.

Having a national/regional message tailored to local conditions will have a much greater impact in the long run.

c. To what extent have prevention initiatives targeted at injecting drug users been successful?

The numbers of Injecting Drug Users with HIV are low in the UK reflecting the success of strategies such as needle exchanges in preventing HIV in this group. The high prevalence of blood borne viruses in this group however highlights the prevalence and risks of needle sharing amongst injecting drug users.

d. How could prevention initiatives be better delivered and evaluated?

Coordinated Public Health Programmes There is a need to establish well funded and coordinated public health programmes, and/or to strengthen existing ones, which are focused on helping people to maximise their sexual health. Such local programmes should:

- be targeted at those communities who need them most, especially young people, some Black African communities, sex workers and men who have sex with men (MSM)
- be coordinated across NHS, Local Government, Voluntary/Community sectors, as well as community pharmacies
- comprise printed and web based information, face to face services and make best use of new technologies and approaches such as web delivered services and social marketing techniques
- make best use of social networking sites to maximise the impact of safer sex work on communities in greatest need
- combine approaches to influence people to have safer sex, as well as providing easy access to STI testing and other clinical services
- be backed up by targeted national sexual health promotion programmes
- be linked with other health education initiatives, such as alcohol and drug education programmes

Evidence Base The evidence base and cost-effectiveness evidence of sexual health services is often incomplete. Directors of Public Health have a role in the promotion of robust evaluation and should seek every opportunity to support the R & D agenda around sexual health.

Robust commissioning systems Many PCTs will have well developed sexual health needs assessments but this is not universal, and data from GUM clinics or primary care may be difficult to access. Without this, an accurate assessment of needs and service gaps is difficult to construct. It is important that Public Health information must be adequate and that there is sufficient analytical and interpretive skill to utilise it appropriately. This includes the use of patient and public feedback and adequate Impact Assessment and Equality Audit mechanisms. Public Health Observatories may have a role here. PCTs need leadership and sometimes champions for sexual health and Directors of Public Health are well placed to develop this, utilising all the required economic, health improvement, performance target and policy levers. Dedicated and skilled commissioning for sexual health needs further development and support in many PCTs.
Testing

a. Are current testing policies adequate across the country?
Yes. The policies that have been produced by the DH and organisations such as MedFash, BASSH, BHIVA are comprehensive. However, local health economies need to take much greater responsibility in implementing these policies. Late diagnosis in London cost PCTs £8m in 2009. Earlier diagnosis could have saved PCTs £7.5m with improved health outcomes.

b. What can be done to increase take-up rates?
- Testing of all patients in high prevalence areas at first registration at a GP
- Routine testing in A&E.
- Role-out of testing in community settings.

The creation of two separate outcomes frameworks (one for Public Health and one for core medical function of PCTs) has allowed key public health targets, such as the reduction in Late Diagnosis for HIV, to fall off the priority lists for PCTs. This risks back-loading problems as organisations can leave a problem to fester rather than deal with it now. This target has already had a key impact in London where is has been running for some years. Since its inception London has reported a statistically significant reduction in very late diagnosis (CD4 cell count <200 cells/mm$^3$) from the 35% diagnosed late at baseline (2004/5) to 29%, a modest fall of six percentage points. Performance varied between PCTs with 30% of PCTs meeting their trajectories, 50% improved from their baseline and only 20% with no changes. It is critical that this target is taken seriously going forward.

Treatment

a. How can the NHS best commission and deliver HIV treatment?
Regional commissioning arrangements allow better coordination of the management of the medical aspects of a high cost and low volume condition. However, local arrangements need to be put in place to address the specific needs of local HIV positive people and these arrangements need to include representation from the service users themselves along with public health, local authority and medical professionals. Local issues such as housing, employment, immigration status all need to be addressed in managing HIV.

b. What impact might the proposed new commissioning reforms have on HIV treatment?
Greater involvement of primary care clinicians in the management of care for HIV positive people can only be a good thing particularly with an ageing cohort of HIV positive people. On the other side there appears to be a divide being formed between the management of sexually transmitted infections (moving to public health) and the management of HIV (staying with the NHS). In reality most HIV clinicians work in GUM clinics and will deal with both so this divide is slightly artificial.

Clarity is still needed on the commissioning plans for HIV as much remains unclear in the Public Health White Paper and once this has been given, it will be easier to take a view. See below for an overview of the role of Public Health in Commissioning.

c. In what setting can treatment most effectively be delivered?
Advanced treatment has transformed HIV over the past decade into a manageable long term condition for most people in the UK. It remains a serious medical condition and will require specialist medical oversight for the foreseeable future. However, current models of hospital
based care are likely to become unsustainable as they become overwhelmed by the rapidly growing numbers of people with HIV. There are a number of steps which are needed.

**Out of hospital delivered HIV clinical care for the ‘well person with HIV’**. It will of course remain vitally important that there is specialist clinical supervision of all HIV care, and specialist care for those with complex needs. However, the best way to ensure this is to establish community based service delivery for the majority of people with HIV who are well. Specialist nurse delivered clinical services should be established in a variety of community settings and these clinics should be integrated with GPs and other primary care clinicians with a specialist understanding of HIV. In addition, specialist e-consultation clinics should be considered for people to get easy access to specialist knowledge, and clinic opening hours should be changed so that they are open early in the morning and in the evening for the increasing numbers of people with HIV in work. Referral pathways should be established with other specialist services used by people with HIV, e.g. oncology and mental health services. Additionally there should also be a coordinated approach from clinical services and community organisations to encourage as many people as possible to begin their HIV treatment earlier, in line with national best practice guidelines.

**Integrated health and social care services for people with HIV in greatest need**. Unfortunately there are still too many people with HIV with high levels of social care need. This is because HIV disproportionately affects communities experiencing high health inequality. As such integrated HIV health and social care services should be established through close joint working between NHS, Local Authorities and VCOs, developing a one stop shop approach to HIV health and social care provision at the point of healthcare delivery. This will require work to establish, but it will also free up scarce clinical capacity from focusing on social care needs to focusing on clinical needs.

**Access to locally delivered and proactive long term condition management programmes for all people with HIV**. These should include easily accessible print and web based information. HIV specific newly diagnosed and expert patient programmes, peer delivered HIV health trainer services, accessible at the point of clinical service delivery.

**Cost**

a. **Have cost considerations been satisfactorily balanced with public health imperatives in HIV:**

(i) **prevention policy**;
Poor prevention costs more in the long run and currently the NHS has focused on treatment to the detriment of preventing avoidable conditions. However, prevention needs to be carefully planned, coordinated and evaluated for it to have the greatest impact. Prevention needs to reflect not just primary prevention, stopping people getting it in the first place, but also secondary prevention, stopping those that have been diagnosed from passing it on.

(ii) **treatment policy**
Because of the immediate need to focus money at the people who need treatment now, there has been a tendency to invest in treatment services to the cost of primary prevention, however good treatment policy needs to include a focus on secondary prevention.

b. **Is research funding correctly prioritised?**
At a local level, PCT initiatives, for both prevention and treatment, need to have a greater scrutiny and peer review. This may require greater funding for projects but will provide a greater evidence base for the role-out of best practice.
Stigma

a. What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?

The stigma associated with HIV has a massive impact on the willingness of people to test, in the first instance, and then to disclose their status. This is not just restricted to traditional communities but is a widespread problem across most communities. The later that HIV is diagnosed, the worse the health outcomes. The more that a patient feels that they have to hide their condition, the more difficulty they will have in receiving the treatment that they require.

b. Where are problems of stigmatisation most acute?

There is still a major issue for ethnic minority groups but this remains a wide issue for much of the population. With poor levels of understanding about HIV amongst the wider population, stigma remains a problem.

c. What measures are currently taken to tackle HIV stigmatisation? What more should be done?

There are a great number of community organisations that work with local communities to explain and inform people about HIV. Much of this is very good work but often lacks a unifying theme. Many peer support organisations also work with users on public speaking to so that HIV positive people can take a major part in reducing stigma.

There are a number of steps that can be taken to increase understanding and reduce stigma.

- Better education, including as part of school education on PHSE.
- Routine testing in as many sites as possible. If HIV testing is embedded in the minds of the wider population then this reduce stigma.
- Targeted education and empowerment for HIV positive people.
- Education of key stakeholders such as GPs, acute clinicians, dentists etc. to spot the condition sooner and to be able to manage the disease more effectively.
- Begin to align HIV services with other long term conditions. The longer it remains special in the minds of healthcare professionals, the longer it will remain special in the minds of the wider population.

Overview - the role of Public Health in Commissioning

Public Health oversight of and public health input to commissioning at all levels is essential to achieve real improvements in population health outcomes and the reduction of health inequalities.

Commissioners should be required to demonstrate the use of a strategy covering high quality, universal services, targeted services for communities of interest at greater risk especially deprived communities and tailored services for people with multiple and complex needs. This should be underpinned by evidence base, public health intelligence and needs assessments.

Also needed is the demonstration of excellence in managed entry of new drugs, technologies and public health interventions. We recommend the promotion of Health Impact Assessment (HIA) and Health Equity audit as necessary components in commissioning service change (capital or design) alongside equality and diversity impact assessment.
Perhaps the greatest challenge to the new NHS will be how to put prevention at the heart of commissioning. Given that the new structure in England will put health care and prevention into separate organisations with different outcome frameworks, geographical boundaries, cultures and systems for accountability, there are considerable risks.
In relation to the reforms in England, urgent consideration will need to be given as to how best to structure and maintain clear lines of accountability, communication and access between the NHS Commissioning Board, Public Health Service, Public Health teams working within Local Authorities and the GP consortia. We believe that the Public Health England should provide public health expertise and input to commissioning, including:
- evidence-base advice and support function with input into GP consortia commissioning and service quality
- strategic expertise and input into specialist commissioning
- public health expertise into the NHS Commissioning Board to support its role in providing national leadership in commissioning for quality improvement, commissioning national and regional specialised services, and allocating NHS resources
- public health input to prescribing and medicines management
Public health expertise will be required by the NHS Commissioning Board to support its role in:
- providing national leadership in commissioning for quality improvement;
- commissioning national and regional specialised services;
- allocating NHS resources.

February 2011
Letter from Mr Sascha Auweiler, lead nurse specialist for HIV in the community for Tower Hamlets community health services (HAUK 1)

Thank you for inviting clinicians’ views on the matter. I am writing in my role as lead nurse specialist for HIV in the community for Tower Hamlets community health services. Our views are:

Monitoring
b) if the Health Protection agency (HPA) is threatened under the reforms, this will have a serious impact on monitoring, and interpreting data that is collected in Sexual Health and HIV-clinics and disable adequate targeting of high-risk groups. These can emerge quite unexpectedly like the recent increase of positive HIV, hepatitis B and C results in the Vietnamese community.

d) as before, Sub-Saharan heterosexuals and men who have sex with men (MSM), Caribbean heterosexuals and MSM, MSM of any ethnic background. In East London: Bangladeshi MSM and Vietnamese current or past intravenous drug users and their partners.

Prevention
a) No. We continue in not reaching marginalised groups like the above mentioned although considerate efforts are undertaken.
b) To a great extend, but not with the success expected.
c) Very successful, keeping in mind that IVDUs represent only a small fraction of people infected with HIV.

Testing
a) Testing policies are adequate but we continue to see the problem of those at highest risk not accessing services. A more proactive approach needs to be taken and testees should rather opt out of an HIV test than opt in, and at the appropriate points in the healthcare system. HIV tests should be offered to all patients registering with a GP practice or to all patients attending A&E.

Treatment
c) I perceive the current commissioning agreements are adequate and workable and cost-effective.
d) The current outpatient settings are appropriate although the role of nurses with prescribing capacities in monitoring and prescribing for “stable” patients should be extended to save doctors time and free resources for more complicated cases.

Stigma
- Stigma continues to pose significant problems especially for patients of a sub-Saharan background and translates into reluctance to test or seek treatment.

26 January 2011
The author is Professor of History and Director of the Centre for History in Public Health at the London School of Hygiene and Tropical Medicine, University of London. She is a partner in the History and Policy network. She has researched the history of AIDS policy making in the UK in the 1980s and 1990s. Her book *AIDS in the UK: the making of policy, 1981-1994* (Oxford University Press, 1996) is drawn on here.

**Summary**

- This memorandum analyses the initial response to HIV/AIDS in the UK from the early 1980s to the early 1990s. The action taken during the period up to the late 1980s and early 1990s helped to prevent Britain experiencing a much larger epidemic, so it is appropriate to re-examine it here. The response was informed by previous history, in particular the failure of punitive and discriminatory tactics in the nineteenth century. The response was marked by an absence of stigma and liberal policy messages such as ‘safe sex’ rather than abstinence.

- The involvement of voluntary organisations, most based in the gay community, was significant in policy making. Clinicians and scientists worked to raise awareness of the need for action. The public health function and its pivotal role within government, its relationship to expert advisory mechanisms, was important in elevating the response. High level political interest brought increased levels of resourcing and a focus on community based models of care.

- Health education and mass media campaigns formed a central component of the response. The formation of a central body responsible for AIDS education was a key development. The authority was inevitably the focus of conflicting objectives among different interest groups about the content of such education.

- HIV/AIDS provided a model of coordination between services at the local level between voluntary groups, the NHS and local government.

- Initial modelling, based on inadequate data, raised fears but the programme of anonymous surveillance provided more information on spread.

- The significance of drug use as a conduit for HIV/AIDS into the population at large brought a focus on tactics designed to bring the user into contact with services rather than alienate him/her.

**The history of prevention campaigns during the initial response to HIV/AIDS in the UK**

I. Introduction: The need for historical perspective

I.1 The Select Committee’s terms of enquiry require it to consider HIV and AIDS in the United Kingdom. The focus is on monitoring; prevention; testing; treatment; cost; and stigma and the aim is to look at these key issues as they operate now.
1.2 HIV/AIDS is now reaching its thirtieth anniversary as a syndrome which has affected the UK population and may have been in the population undiagnosed for longer. It is important to look back at the ways in which society and government responded in the early years in order to inform and give context to the present day reaction. This response in the years from c 1981 to the mid 1990s can be divided into three periods:

a) Policy making ‘from below’, 1981-5
b) a period of national crisis 1986-87
c) the normalisation of responses to HIV/AIDS, from 1988 onward

1.3 It is arguable that the action taken during the period up to the late 1980s and early 1990s helped to prevent Britain experiencing a much larger epidemic, and so this memorandum will focus on the actions taken during that time, in particular with reference to prevention.


2.1. An important feature of the early response to HIV/AIDS in the UK was the dissemination of knowledge through networks which operated outside government but which began to work with the public health function within government.

2.2 The virus HIV was not identified until 1983 and a test not available until 1984-5. But there was increasingly knowledge of the potential seriousness of the situation ‘on the ground’ and among clinicians and scientists who encountered seriously ill young gay men, drug users and those infected through blood products.

2.3. Many clinicians and scientists spread knowledge about the virus when it became available, often using the media or travelling widely to give lectures and talks.

2.4. Gay men also organised to spread knowledge about the disease. Although there was resistance to the idea of the new disease in the gay community as potentially remedicalising and stigmatising, others wrote and spread word about the dangers. Experience from other countries, in particular the US, was drawn upon. Television programmes and helplines, the latter then a relatively new development, played an important role.

2.5 Organisations such as the Terrence Higgins Trust and Body Positive were set up by gay men in order to spread knowledge, to influence policy, to interact with the media, and to ensure that stigma did not prevent the development of a high level response. AIDS was defined in these circles as an issue of human rights in health and social policy.

2.6 AIDS moved up the policy agenda as testing for the virus became available and revealed the extent of spread and the potential for rapid spread in the general population. An AIDS Unit was set up in the Department of Health to coordinate all AIDS preventive activities. The Chief Medical Officer, Sir Donald Acheson, also set up the Expert Advisory Group on AIDS, which brought together clinicians and scientists dealing with the syndrome and was able to offer rapid advice.

2.7 Initially punitive responses, for example notification or quarantine, were discussed. Regulations under the 1984 (Control of Disease) Act were extended to AIDS. But these were only used once. A more liberal response was established.
2.8. The tone of the response was strongly informed a number of factors;

- knowledge of the historical context of public health responses to sexually transmitted diseases in the UK, in particular the example of the nineteenth century Contagious Diseases Acts, which had attempted a punitive discriminatory response to prostitution and the subsequent open access non punitive treatment system established during the First World War. This helped to define what was seen as an appropriate form of response in the 1980s.
- advice from scientific advisory committees, in particular the Expert Advisory Group on AIDS
- the existence of a public health presence in government through the role of the Chief Medical Officer, his awareness of history, and liaison with gay groups.
- Political support from the Secretary of State for Social Services

2.9. Conclusions:

a. Self help and peer networks have been important in disseminating information
b. Voluntary organisations have played an important role
c. the interaction between such groups and the media, also the ‘new media’ of the time, was significant.
d. the role of scientific advice was important in formulating the response
e. the existence of a public health function within government and its networks helped to reinforce the response.
f. departmental political support was important

3. The period of national crisis, 1986-7

3.1. In 1986 a Cabinet committee on AIDS was set up under the chairmanship of the deputy Prime Minister, William Whitelaw. AIDS became a high level political issue with concomitant levels of public interest and resourcing.

3.2. National public education campaigns were central to the strategy of government. In early 1986, the Department of Health embarked on a national campaign organised by the Central Office of Information and developed by the advertising agency TBWA. In March 1986, full page advertisements aimed at presenting the facts to the public appeared in the national press and continued for the next eight months.

3.3. From autumn 1986 to spring 1987 a high profile campaign was launched culminating in ‘AIDS Week’ in February 1987. Extensive cooperation between the networks and the government aimed to bring the facts to the general public. This was a multi media approach including national posters and magazine advertising, radio, television and cinema commercials. A leaflet ‘AIDS: don’t die of ignorance’ was distributed to all 3 million houses in Britain in January 1987. This campaign was supported by a national telephone helpline.
3.4. This campaign later attracted criticism on a number of grounds: that it was alarmist; that its shock horror tactics (tombstones and icebergs) were not effective; that it should have been directed at the gay community rather than at the population as a whole.

3.5 There is no doubt that it raised awareness of AIDS and subsequent research showed that the numbers of sexually transmitted infections declined steeply in the period after the ads were shown.

3.6. A new central authority responsible for prevention campaigns, and specifically for HIV/AIDS, the Health Education Authority, was announced, replacing the Health Education Council.

3.7. This period also saw the initiation of coordinated research funding through the Medical Research Council (the AIDS Directed Programme) and the Economic and Social Research Council (ESRC) which were given substantial extra funding to mount a dedicated response to HIV/AIDS.

3.8. The House of Commons Social Services Committee began an enquiry into HIV/AIDS which reported in 1987 and which reinforced a liberal response.

3.9. Knowledge of the spread of the virus among drug users had emerged from Scotland. The 1986 McClelland Report articulated a response focussed on reduction of harm, the provision of clean needles and the expansion of treatment.

3.10. The AIDS Control Act of 1987 emanated from a private member’s initiative but served to bring together and reinforce the coordinated response at the local level.

3.11. The role of international links and cross national examples were important. Clinicians and scientists were aware of what was going on in other countries. Norman Fowler as Secretary of State visited San Francisco to see what initiatives were being taken at the community level. From the international connections also came a focus on models of care for HIV/AIDS which were community based and voluntaristic. The role of WHO and its response to HIV was also significant, through the charismatic leader of its AIDS programme, Jonathan Mann. WHO’s response was disseminated globally and reinforced the human rights approach.

3.12. Conclusions:

a. High level political support was vital and focussed on a non punitive response through mass media health education campaigns.

b. Some of the features of this response have since been replicated, for example in the leaflet and advertising campaign for swine flu in 2009. Governments always have to weigh up the advantages of swift and high level reaction to potential epidemics against the disadvantages of over reaction and consequent criticism. There is no doubt that the high level response of 1986-7 raised public awareness and had a positive impact on behaviour.

c. Messages were aimed at the population as a whole thus avoiding a ‘risk group’ approach and stigmatisation.
4. Normalisation of policy 1988 onwards

4.1. From 1988 into the early 1990s this approach was ‘mainstreamed’. A particular example was the reinforcement of a ‘hierarchy of objectives’ for dealing with drug use. The Part one report on HIV and AIDS of the Advisory Council on the Misuse of Drugs, published in 1988, stressed that dealing with the threat of HIV/AIDS was a national priority and that attracting the drug user into services was central to prevention of the spread of the epidemic. Abstinence, previously the aim of drug services, became seen as an ultimate aim which could be achieved through different interim strategies. Needle exchange schemes and maintenance treatment were expanded and their impact evaluated.

4.2. The Health Education Authority took over responsibility for campaigns in the autumn of 1987 and in early 1988 advertisements appeared which showed the excuses people used to avoid condom use. These dropped the earlier shock horror approach in favour of a more realistic tone. The HEA’s remit for HIV/AIDS was UK wide, although Scotland and Wales had their own health promotion/health education agencies.

4.3. Decisions about what messages to use in campaigns remained a subject of controversy. Different groups wished to influence the content and message of campaigns. There were tensions involving a moral lobby who wanted to stress monogamy, health education professionals, who wanted to see pragmatic messages, and gay groups who later argued for more targeted health education and the ‘regaying’ of AIDS.

4.4. AIDS itself changed from a rapidly fatal disease to one where treatment was becoming possible, in this period through the advent of AZT and later through combination therapy. The model of care also changed in line with this shift towards community care. The role of voluntary organisations such as Landmark in Brixton which opened in 1987, demonstrated new partnerships between the local voluntary sector, the health service and local government.

4.5. Testing and anonymous testing for the virus had been a matter of debate in the early stages of policy making and the Social Services committee had taken a strong stance on ethical grounds against the procedure. The report of the working group on monitoring and surveillance published in 1988 however, took a different view and, with the support of the Secretary of State, Kenneth Clarke, a programme of anonymous testing was established in January 1990. This led to increased confidence in predicting the future spread of the virus. The results of the national sex survey, funded by the Wellcome Trust, also ultimately fed into prevention strategies.

4.6. Conclusions

a. The establishment of a flexible and realistic approach to the treatment of drug use was characteristic of this phase of policy

b. A central organisation for health education was an important focus of campaigns but was also a focus of competing interests who wished to have influence on the messages which were conveyed.
c. AIDS, its funding and organisational structures at the local level provided a model of coordination and cooperation between voluntary, health and local government interests, with a strong focus on community based interventions.

d. Surveillance through anonymous testing and through other research led to a more complete understanding of the spread of the virus. The earlier focus on modelling, which had been based on interim data, became less central.

5. The need to preserve materials for understanding this response.

5.1. Although the archives of central government are held in the National Archives (TNA) and will give further insight into this period of response, other material which helps us to understand and assess this crucial period is under threat.

5.2. In particular the material produced by the Health Education Authority has suffered from the subsequent organisational changes and eventual abolition of a central arms length body in charge of campaigns. 36

5.3. Conclusion

a. There should be a concerted strategy to preserve the materials of health education campaigns in order to appreciate and evaluate strategies which have worked.

6. General conclusions

- It is now nearly thirty years since the first policy responses to HIV/AIDS in the UK and so it is appropriate to revisit the earlier responses even though much has changed in the interim. Features of the early response outlined here are relevant to the present.

- The early response was marked by an absence of stigma and was advanced through voluntary sector activity, clinicians and scientists in key specialities and the role of the public health function within central government.

- Expert scientific advice to government was important in formulating this response.

- Political support and interest was also important.

- Prevention campaigns were central to the government response and these were coordinated through a central health education arms length body, which no longer exists as a campaigns body. The records of its campaigns and tactics are at risk.

- Monitoring was initially over reliant on modelling based on inadequate numbers. A programme of anonymous surveillance provided more robust data.

• Community based treatment and other service activities developed and some were based on innovative partnerships between voluntary sector, health and local government.

• Drug policy underwent significant change towards a non stigmatising, treatment focussed approach.

March 2011
1. MONITORING

1:1. Question A: How robust is the current system for monitoring the number of people with HIV in the United Kingdom?
- The HPA does, in our opinion, an adequate job monitoring the number of people with HIV in the United Kingdom.
- Expanding testing will give a more accurate profile of the true prevalence of HIV in the UK.
- Ideally, health outcomes for different groups (ie, adolescents or newly acquired/diagnosed) would be more clearly monitored and reported.

1:2. Question B: Will the proposed public health reforms impact on this system?
- The HPA does, in our opinion, an adequate job monitoring the number of people with HIV in the United Kingdom. Since the exact impact of the public health reforms are unclear at this point, we can only hypothesize that Public Health England will continue with the monitoring strategies utilized by the HPA.
- While the focus on local responsibility is admirable, it is hoped that a coordinated, collaborative approach to care will continue. Given the complex, multiple needs of many HIV+ people and families, the resources needed to address issues and promote positive outcomes may not be available locally, which should be considering when formulating policy and allocating funds.

1:3. Question C: Could anything be done to improve monitoring?
- While there are some academic works (such as the CHIPS Cohort Study: http://www.chipscohort.ac.uk/default.asp) that track age-specific outcomes, this practice should be emulated by government practice.
- Mental health outcomes should also be monitored, and linked to patient HIV status.

1:4. Question D: What groups in particular are at risk from HIV?
- For a comprehensive discussion of HIV trends in the UK, including which groups have elevated risk, please refer to: http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1287145367237
- While some sub-populations have elevated risk for HIV due to elevated likelihood of exposure (for example, a recent immigrant living in an area of high HIV burden would more likely to come into contact with HIV than someone living in rural Scotland), it is important to note that anyone can be at risk for HIV if they are exposed to HIV. Since HIV is transmitted through unprotected sexual intercourse, contaminated injecting equipment, or from mother to child perinatally, a person who engages in these activities without knowing his or her personal status or that of their partner may be at risk for HIV exposure. While most countries regularly test blood products used in medical settings, such as those used for transfusions, it is important to note that some persons may still have been exposed via this method.
2. PREVENTION

2:1. Due to the fact that Body & Soul’s primary expertise is not prevention, we have chosen not to submit a response to this category. We would like to note, however, that behavioural practices acquired in adolescents often persist into adulthood, so early risk-reduction education and interventions must be emphasized.

3. TESTING

**Question A: Are current testing policies adequate across the country?**

1. It is the belief of Body & Soul that current testing policies and practice inadequately capture the true prevalence of HIV. This is especially true among communities that neither meet the basic NHS testing criteria nor access the two national settings with expanded testing, GUM clinics and antenatal care.

2. According to NHS testing criteria, people who are at risk of catching HIV include:
   - men who have had unprotected sex with men
   - women who have had unprotected sex with men who have sex with men
   - people who have lived in or travelled extensively in sub-Saharan Africa
   - people who have had unprotected sex with a person who has lived in or travelled in sub-Saharan Africa
   - people who inject illegal drugs
   - people who have had unprotected sex with somebody who has injected illegal drugs
   - people who have caught another sexually transmitted infection
   - people who have received a blood transfusion while in Africa, eastern Europe, the countries of the former Soviet Union, Asia or central and southern America

3. The NHS testing guidelines are more conservative and exclusive than those suggested by BHIVA, the British HIV Association, which can be found here: [http://www.bhiva.org/documents/Guidelines/Testing/GlinesHIVTest08.pdf](http://www.bhiva.org/documents/Guidelines/Testing/GlinesHIVTest08.pdf).

4. In Body & Soul’s experience, approximately 15% of our HIV+ population does not meet the aforementioned criteria. For example, the NHS criteria do not include the testing of previously untested children of HIV+ persons. It does not account for human factors, such as multiple partnering or infidelity. Current testing policies fail to demonstrate that people are at risk for HIV when they have exchanged blood or fluid products with someone who is HIV+, during sexual intercourse, IV drug use, or pregnancy, childbirth, or breastfeeding.

5. The rationale behind expanding testing is clear: When a person is unaware of his or her HIV status and is HIV+, that person is about 4 times more likely to onwardly transmit the virus. This is compounded by the fact that an HIV+ person who is unaware of status will not be taking treatment measures to control viral load. In addition to the increased risk of onward transmission, late diagnosis correlates with poorer outcomes. In the UK, 1 of every 2 people who are diagnosed HIV+ are diagnosed when the virus has progressed to the point that its impact on CD4 count

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is so great that the person will immediately have to start costly treatments. When CD4 count is lower, the patient is more costly to treat. 1 out of 3 HIV related deaths in the UK is a direct result of late testing.

Question B: What can be done to increase take-up rates?

1. In London alone, 26 PCTs meet the threshold for expanded testing of 2 infections in every 1000 people. Since the primary contact most people have with a health care provider is with their GP, all GPs should have the capacity and training to routinely administer HIV tests in their clinical setting. The core skills necessary for GPs to expand treatment are as follows:
   a. GPs maintain normal patient confidentiality and communicate their responsibilities regarding confidentiality to their patients.
   b. GPs recognize the ways HIV can or cannot be transmitted.
   c. GP practices have clinical capacity to test patients for HIV.
   d. GP practices offer quick tests for patients, so that the stress of waiting for an HIV test result does not deter people from getting tested.
   e. GPs encourage testing for patients at high risk (potentially at an opt-out basis, which will be discussed in paragraph 2 of this section).
   f. GPs provide HIV testing on patient demand even if patient HIV risk is lower.
   g. GPs discuss HIV prevention and health promotion, including healthy sexual expression, with patients.
   h. GPs provide adequate counselling before and after testing. For patients who are HIV+, they should immediately be given an appropriate follow-up appointment and referred to voluntary support services.
   i. GPs feel confident and capable to deliver HIV test results, regardless of the outcome.
   j. GPs treat all patients, regardless of HIV status, professionally.
   k. GPs provide HIV testing on patient demand even if patient HIV risk is lower.

2. Opt out testing strategies, which have been used in GUM and antenatal clinics to great success, should be expanded to other clinical areas. The success of these opt-out testing strategies “indicates that efforts to detect HIV infection in asymptomatic individuals are likely to result in earlier diagnosis, hence reducing morbidity and mortality in diagnosed individuals as well as reducing onward transmission”.

3. In areas of high prevalence (again, 1 in 500 or more), universal testing is considered cost effective.

4. HIV testing in communities and third sector organizations, such as THT, should continue to receive funding and are viewed in the sector as extremely patient-friendly.

5. Universal testing should be considered for higher-risk populations with low health service utilization, such as prison populations.

6. School-based SRE should emphasize the importance of HIV testing, rather than stigmatizing HIV+ individuals. Clinics should be accessible to adolescents by having

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39 NNRTI or PI-boosted as first-line HAART regimens in the UK?
41 http://www.bhiva.org/documents/Guidelines/Testing/GlinesHIVTest08.pdf
42 http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1287145367237
43 http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1287145497243
flexible hours of operation, adolescent drop-in hours and patient-friendly staff. Young people should understand laws and confidentiality prior to agreeing to an HIV test. Frasier guidelines apply.

7. Laws surrounding HIV should not deter people from testing. According to the UN, some possible detrimental effects of criminalization on public health initiatives include:
   a. Reinforcing HIV/AIDS related stigma
   b. Spreading misinformation about HIV/AIDS
   c. Disincentive to HIV testing
   d. Hindering access to counseling and support
   e. Creating a false sense of security

4. TREATMENT:

Question A: How can the NHS best commission and deliver treatment?

1. At Body & Soul our ‘whole person’ approach to delivering psycho social and well being services for our members is in line with our view that treatment for living with HIV should include access to psycho social support (including peer support, counselling, treatment support, active sessions, nutritional information and sexual and emotional health workshops). In the recently published cross-government strategy ‘No health without mental health’ (2 February 2011), this link is clearly acknowledged.

2. In our view, in addition to medication and care that an individual receives via their specialist HIV clinic, a range of providers should be delivering HIV treatment and care and decisions to commission should be driven by outcomes shown by services and numbers of people choosing to access those services. There is evidence to show the benefits of peer support for people living with HIV as a strategy for helping people to deal with medication adherence.

3. At present cuts across the statutory sector make in even more important that the sector works collaboratively and examples of good practice such as Body & Soul’s peer mentoring work in clinic for young people living with HIV should be supported as helping to achieve the best long term outcomes for patients.

Question B: What impact might the proposed new commissioning reforms have on HIV treatment?

1. Following the restructuring of the NHS and the dissolution of PCTs by 2013 it is our understanding that high level care such as HIV treatment and care provided by specialist clinics will be commissioned via GP consortia. At present it is very hard to gauge how well this will work when rolled out on such a large scale within a relatively short time period (particularly as there is still a lot of opposition to the measure from GP’s and hospital doctors.) Beyond this the HIV support services
currently receiving statutory income (such as Body & Soul) are likely to receive this money from Public Health England in the future as part of the public health remit will be to improve health and well being. We hope that GP Consortia will be able to work effectively with Public Health England to ensure joined up care and support for individual patients. If clear guidelines are not established for entitlements (such as mental health support, psycho social support) then we envisage this side of treatment to be inconsistent for people living with HIV dependent on where they live. This is often the case currently. This is likely to be exacerbated by the fact that the current National Strategy for HIV and Sexual Health in England has expired and there are currently no plans to replace it.

**Question C: In what setting can treatment most effectively be delivered?**

1. This has been covered in the responses above but to reiterate:
   a. Treatment for people living with HIV should include access to mental health treatment and psycho social support (including peer support).
   b. Commissioning should be joined up to ensure consistency and avoid individuals being offered different levels of treatment depending on where they live.

For more information on what people living with HIV have self identified their needs to be see the following survey:

- **What do you need? 2007-2008: findings from a national survey of people with diagnosed HIV**
  Sigma Research, 2009 (ISBN 1 872956 95 5)
  [http://www.sigmaresearch.org.uk/go.php?/reports/hiv](http://www.sigmaresearch.org.uk/go.php?/reports/hiv)

5. COST

**Question A: Have cost considerations been satisfactorily balanced with public health imperatives in HIV:**

(i) **prevention policy?**

a. Given that the average age of sexual debut for a teenager in the UK is 16, it is essential that young people learn about abstinence, safe sex, condom negotiation, and preventing STIs like HIV prior to becoming sexually active.

b. Amongst heterosexuals, 15-24 year old females and 25-34 year old males are the age group that has the highest proportion of recent infections. This highlights the need for providing prevention information to young people before risk behaviour initiation.

c. Young people are not receiving accurate information in a timely matter about sexual health, risk reduction, and HIV. Only 48% of Body & Soul’s teen members have ever been taught anything about HIV or AIDS in school or college. Yet 2/3 of them are HIV positive and 50% are currently sexually active. Many of our young people only receive information about sexual health from Body & Soul.

d. Each new infection will cost roughly £315,000 per person. This cost is solely treatment cost, and does not include disability-related loss of productivity, social services, or onward transmission. To add perspective, Body & Soul’s entire operating budget is £1.3 million per year, which basically shows that if we are able to prevent 4 onward transmissions a year by providing support,

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encouragement and education to HIV+ persons, we are saving the government money.
e. It is cost effective to fund services that provide onward transmission prevention strategies to HIV+ communities. The social support and practical information provided by these services enable people living with HIV to be proactive about health promotion

(ii) treatment policy?

a. In order to meet public health goals, treatment policies must reflect the complex needs of HIV+ populations. In our view, in addition to medication and care that an individual receives via their specialist HIV clinic, a range of providers should be delivering HIV treatment and care and decisions to commission should be driven by outcomes shown by services and numbers of people choosing to access those services. There is evidence to show the benefits of peer support for people living with HIV as a strategy for helping people to deal with medication adherence.

b. Since the overhead required to fund clinical services is so substantial, cost benefit analysis should identify areas of care that would be better covered by external sources, such as voluntary services.

Question B: Is research funding correctly prioritized?

1. As a voluntary organization committed to excellent service delivery, we seek to employ best practice in all of our work. Unfortunately, despite the fact that HIV has become a chronic condition there is little research on the impact of psychosocial services on the wellbeing of HIV+ and affected persons.

2. To ensure the appropriate allocation of HIV funding, there must be sufficient evidence to prove which services work.

3. This paralyzes the ability of voluntary organizations to obtain funding: they cannot prove the impact of their services without research, but cannot research the impact without funding.

6. STIGMA

a. What impact does stigmatisation of people living with HIV have on those infected, and on addressing HIV as a public health problem?

1. The effects of HIV related stigma are widespread, entrenched in our social consciousness and can be hugely damaging. Fear surrounding HIV can mean that individuals choose to keep their condition secret, having a negative impact on their health. For example:

**HYPNet adherence questionnaire:**
A medication adherence questionnaire designed by multidisciplinary health professionals and voluntary sector professionals (members of the HYPNet group) was piloted by two HIV positive young people, gained ethical approval and was distributed to 28 hospitals and voluntary sector sites across the UK between September 2009 and March 2010. Participation was anonymous, voluntary and inclusion criteria included: age 12-24 years, HIV infected (any route of transmission) and aware of status, currently on antiretroviral therapy.

Among the results the 138 adolescents, identified factors as supporting adherence: reminders from family/carers (45%), peer support (45%), memory aids (35%), regular routine (27%) and health benefits (20%).
Barriers to adherence included: forgetting (46%), too busy with other activities (28%), keeping HAART secret from friends/family (17%), side effects (14%), pill fatigue (14%) and a daily reminder of HIV (9%).

http://www.hypnet.org.uk/

2. HIV related stigma can also discourage people from coming forward to get tested. As 27% of people living with HIV in the UK are still unaware of their condition we cannot underestimate the effect that stigma is having on public health, the likelihood of onward transmission and the cost of future treatment. This is especially pertinent in light of the fact that in 2009 there were 6,630 new HIV diagnoses in the UK. While this number is a reduction on previous years which is good news, it is clear much more need to be done to adequately tackle the issue.

3. Stigma can also affect HIV Positive children in schools and their families. This can mean that children and young people experience avoidable barriers to learning. The vast majority of them are already adversely affected by poverty and illness, an additional compounding factor such as stigma means their life chances are affected negatively even further.

**Case Study Example:** A mother who access services at Body & Soul has a six year old child who is HIV Positive. Over the last two years he has had to miss school numerous times due to illness and while at school his performance is often poor and he is often tired due to the effects of his medication. The school has started to ask questions about this, however, his mother is scared to disclose his illness as she is worried about how the school will react. As a result the school cannot fully support her child and his mother is constantly worried about the situation.

4. There is evidence to show that children living with HIV experience discrimination from schools, this is despite the fact that this is unlawful. The Children’s HIV Association (CHIVA) has produced guidelines for schools to follow but our experience is that schools are not always aware of their obligations. This should also apply to young people in college or other educational settings.

b. Where are problems of stigmatisation most acute?

1. In 2009 867 people living with HIV were interviewed by their peers as part of a piece of research. The research was carried out by The People Living with HIV Stigma Index and showed significant experiences of stigmatisation within a healthcare setting. 17% of people interviewed reported had been denied health services within the last 12 months because of their HIV services. Individuals reported experiences the worst problems with dentists.

2. Individuals living with HIV have also reported experiencing stigma in their communities, within employment and accessing services. Body & Soul members who

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47 In 2007 an investigation by NAT (National AIDS Trust) revealed that children living with HIV were facing discrimination in schools. Discrimination uncovered included children as young as five being refused school places, and young people being treated differently and unfairly, all because of their HIV status. http://www.nat.org.uk/Our-thinking/Public-understanding/Schools.aspx


49 Supported by a two year grant from the UK Department for International Development, the International Planned Parenthood Federation (IPPF) in partnership with UNAIDS, the Global Network of People Living with HIV (GNP+) and the International Community of Women living with HIV (ICW) has developed an index that will be used worldwide to measure the stigma experienced by people living with HIV. ([http://www.stigmaindex.org/31/partnership/partnership.html](http://www.stigmaindex.org/31/partnership/partnership.html))
identify as religious have often expressed not being able to disclose to their religious leaders, with those from a Muslim background reporting slightly higher levels of stigma than those from a Christian background.


c. What measures are currently taken to tackle HIV stigmatisation? What more should be done?

1. In 2010 Body & Soul commissioned the Office for Public Management (OPM)\(^50\), an independent public interest company, to do primary research with young people aged 12 to 18 in London in order to gauge current attitudes to HIV. The research included a questionnaire survey of 508 young people and six focus groups with young people aged 13 to 15. Among the findings it was clear that the majority of the country’s young people understand that facts about how HIV is transmitted the research revealed that their behaviour often contradicts their knowledge:

- 81 per cent of young people know that HIV could not be transmitted by **sharing a cup**, but only 27 per cent would drink from the same cup as someone who they knew was HIV positive.
- 69 per cent know they could not get HIV by **kissing**, but only 24 per cent would kiss someone who they knew was HIV positive.
- Many respondents also noted the emotional strain and negative peer perception of having a relationship with someone who is HIV Positive.
- The statistics also indicated that HIV-related stigma starts at an **early age**.

However, young people say they want to learn more about HIV, and schools and teachers were identified as the most trustworthy source of information. Therefore, there is the opportunity to educate youth, and teachers have an important role to play.

THE ROLE OF THE CAMPAIGN

4. The ultimate goal of *Life in my Shoes* is to teach youth the realities of HIV in a language they understand. *Life in my Shoes* will help dispel common myths and stigma about HIV by engaging young people in a creative learning platform.

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\(^{50}\) [http://www.opm.co.uk/resources/33585/](http://www.opm.co.uk/resources/33585/)

\(^{51}\) [http://www.lifeinmyshoes.org](http://www.lifeinmyshoes.org)
By telling the real stories of young people living with the disease, the film will promote a new perspective on life with HIV, and its human element. The in-school component of Life in my Shoes will promote open discussions amongst youth in classrooms and other venues.

5. At Body & Soul we believe that the government also has a key role to play in challenging HIV related stigma, particularly in relation to young people. In November 2010 the Government White Paper ‘Healthy Lives, Healthy People’ said the following: Good schools will be active promoters of health in childhood and adolescence, because healthy children with high self esteem behave better in school. Within the current non-statutory personal, social, health education (PSHE) framework, schools will provide age-appropriate teaching on relationships and sexual health, substance misuse, diet, physical activity and some mental health issues. The Department for Education (DfE) will conduct an internal review to determine how they can support schools to improve the quality of all PSHE teaching, including giving teachers the flexibility to use their judgement on how best to deliver PSHE education.

6. Body & Soul would argue that this does not go far enough to addressing HIV related stigma in the classroom. In light of the findings in our research and the experiences of members of all ages who attend Body & Soul we are calling on the government to look within the current statutory framework to ensure these issues are addressed. Within the Citizenship curriculum HIV related stigma could be considered and discussed alongside racism, homophobia, sexism and other examples of prejudice. We urge the Government to consider revising the current guidance.

7. In addition to the work of Body & Soul leading HIV campaigning charities such as the Terrence Higgins Trust and the National AIDS Trust are also working hard to combat HIV related stigma. See their websites for further information about current campaigns.

February 2011
Supplementary Memorandum by Annemarie Byrne and Body & Soul (HAUK 87)

We have heard about the need for greater awareness and education amongst the population to reduce the spread of HIV. From your experience, should the focus be on targeting high-prevalence groups such as men who have sex with men, or on broader campaigns, including those in schools?

Due to the complexity of health promotion, it is difficult for us to give a simple answer to this question. There are epidemiological models of disease burden which public health professionals employ to determine whether to target information dissemination or provide mass campaigns, and these models are important to determine approach. Notwithstanding, it is imperative that the greater public receive clear messages around HIV. This is true for several reasons. First, the behaviours that prevent transmission of HIV (such as consistent condom use and avoiding IV drugs or using clean injecting equipment) are very basic health promotion behaviours. The UK has one of Western Europe’s highest rates of STIs (sexually transmitted infections) and teen pregnancy, which is a clear indicator that young people are either not getting or not internalizing messages about healthy sexual expression. Education about HIV prevention should occur in a greater context of promoting health, especially sexual health.

Second, broader campaigns can address population-wide issues such as stigma and discrimination towards HIV+ persons. They also can highlight the fact that HIV is still very real in the UK.

Finally, there is a dire need to utilize existing resources more effectively to promote healthy sexual practices. For example, any time a person who is sexually active or considering becoming sexually active attends a consultation with a GP or another health or social services professional, it should be considered an opportunity to educate on risk reduction strategies (such as condom use). Additionally, by expanding HIV testing, the NHS would create additional venues and opportunities for discussing healthy sexual practices. Given the immense toll that risky sexual activity has on society, it is imperative that professionals have capacity to openly address these issues. We would recommend a review of HIV training needs for healthcare staff such as GPs as essential to achieving this capacity.

All campaigns must be appropriately conveyed to target their primary audience, regardless of who that audience is. For example, a message targeting MSM communities should be appropriate for that community. Similarly, a message targeting a school-aged population should be appropriately constructed.

Vitally, all awareness and education campaigns (like other health initiatives) should do no harm. Harm caused by offensive, discriminatory HIV awareness campaigns may further deter target populations from testing, getting treatment, or accessing support services.

In your experience, do you feel that people living with HIV get enough help in understanding how to prevent onward transmission of the infection? Should those involved in HIV treatment and care do more to help people with HIV from passing on their virus?
In order to prevent onward transmission of HIV, HIV+ persons must be given support and skills in areas such as condom negotiation, condom use, serodiscordant relationships, and disclosure. For many people with the virus, disclosing status to family, friends, and even partners can be extremely challenging due to the stigma attached to the diagnosis. Since high levels of medical adherence relates to lower viral load, HIV+ individuals must also learn strategies and techniques to adhere to medication regimes.

While we believe it is essential for HIV+ persons to receive information about reducing onward transmission risk from their clinics, the necessary skills cannot always be adequately covered in a clinical appointment with a doctor, nurse, or health advisor.

These skills are often most effectively taught in a supportive, encouraging environment, such as in an HIV expert voluntary organization. Voluntary organizations that work specifically with communities living with and affected by HIV are crucial in preventing onward transmission. For many people, being able to successfully negotiate partner condom use or disclosure goes beyond “just using a condom”. Cultural perceptions, gender power, and self-efficacy may also need to be addressed in order to empower someone to be capable of making healthy sexual decisions. For example, if a woman is in an abusive relationship and is newly diagnosed HIV+, it is unlikely that she will be able to negotiate condom use or safely disclose to her partner. In this all-too-common scenario, the woman would have multiple needs, including needing legal help, help finding safe housing, counseling, and social support. It is highly unlikely that these diverse needs could be (or would be) met in a clinical context, which is why voluntary organizations prove so priceless.

The responsibility is not just on people who are HIV positive to promote safe sex, it’s on everyone. Undiagnosed HIV+ people are four times more likely to spread HIV than people who know their status. Since the number of UK-acquired HIV has nearly doubled in the last decade, it is clear that people who are HIV+ (whether aware of their status or not) and people who are not HIV+ are all engaging in risky sexual practices. High national rates of sexually transmitted infections and unplanned pregnancy reinforce this assertion.

The Health Protection Agency told us that optimism about the effectiveness of HIV treatment, combined with a lack of knowledge about HIV amongst younger generations, has increased the level of behaviours that put people at risk of contracting HIV. Would this tally with your experiences? What can be done to address this?

As with our other answers, we believe more work must be done around educating the general population about health promotion and protection measures in both the broader context of healthy sexual decision making and specifically related to HIV.

Young people are not receiving timely, accurate information about HIV, so do not know that there is still a risk of HIV acquisition in the UK. A recent survey by the Sex Education Forum showed that 1 in 5 young people reported that they had not learnt anything about HIV/AIDS in school. When Body & Soul surveyed teens accessing services, of whom over two-thirds are HIV+ and the majority are from London’s most deprived boroughs, it found that 48% had been taught about HIV in school or college. Statistics showing stigma around HIV illustrate that the general public is, on the contrary, NOT optimistic about HIV,
however their beliefs are tempered by the fact that they are unaware that they could still catch HIV from unprotected sex.

Certain health messages like “as easy as it is to catch the infection, it is just as easy to treat” (www.gettested.org.uk), a message about Chlamydia, do nothing to promote proactive health protection measures beyond treatment. In this example, the advertisement conveys the message that rather than wearing a condom you can just take a couple of pills. If that was the only sexual health message a young person received, then he or she would have no incentive to protect their health. There is also a need to link messages. For example, rather than target one isolated sexual health issue (like teen pregnancy), well-crafted campaigns would motivate the types of behaviour change (including abstinence and safer sex) that could prevent multiple complications of risky sexual practice.

This lack of awareness is not limited to younger generations. The alarmingly high increase in over-50s acquiring HIV during the last decade demonstrates the urgent need for effective health education in this vulnerable population as well.

While the prognosis of living with HIV has improved drastically over the last three decades, HIV is still a serious virus. While medication is exponentially better, there are still long term side effects.

During the session, the acquisition of HIV among the prison population was discussed. Do you have any additional information concerning the numbers of those acquiring HIV in prison, the means by which HIV is transmitted, and the measures taken to prevent such transmission?

While Body & Soul regularly provides support to HIV+ and affected individuals who are incarcerated, ex-offenders, or have family members involved in the criminal justice system, we do not consider ourselves experts on the epidemiology of HIV in prisons. Certain prison realities (such as drug use, sexual expression and/or assault, poor access to clean injecting equipment, poor access to condoms or lubrication, and even overcrowding) exacerbate HIV transmission risk, and this risk elevation has been shown in prison health studies worldwide. In the US, rates of HIV amongst prisoners is roughly quintuple the risk of HIV in the general population. (http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5515a1.htm)

Prison intake presents an excellent opportunity for basic health screening, including HIV and STI testing. Additionally, health promotion programmes (such as basic health education campaigns) could and should be utilized in a prison context since they have the potential to target extremely vulnerable populations who may not otherwise access health services. These programmes must liaise with HIV support services in the community to ensure they are delivered in a manner that respects the client’s needs and dignity.

Several higher-quality resources addressing prison health that the Committee might find helpful can be found through the following links:

World Health Organization Prison Health Information:

New England Journal of Medicine (gives a succinct overview of the problem and presents some reduction interventions)
Supplementary Memorandum by Annemarie Byrne and Body & Soul (HAUK 87)


30 March 2011
Memorandum by Mr David Bridle, Managing Director of Boyz magazine (HAUK 13)

Boyz magazine is London’s longest running weekly gay magazine distributed in Soho and Greater London to gay venues and businesses. Boyz was launched in 1991 at the height of the AIDS epidemic. The magazine has been at the forefront of giving messages about safer sex and preventing HIV to younger gay men who are the majority of our readers.

In 2010, the Prime Minister David Cameron wrote a letter for World AIDS Day to our readers emphasising the importance of HIV prevention and testing (Image 1, David Cameron letter in Boyz, 25 Nov 2010).

Personally, I was diagnosed with AIDS in 1994 and I have been on successful HIV combination therapy since 1996. I am writing to the Committee in an individual capacity.

My evidence addresses these Committee questions as they impact on gay men or MSM:

Is government policy sufficiently focused on prevention?
Have the right groups been targeted in recent campaigns?
What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?

Summary of evidence

1. HIV infection rates have risen over the last decade and there is on-going unsafe sexual behaviour by gay men.

2. There have been few persistent campaigns aimed at gay men about safer sex and the absolute importance of using condoms, regardless of your HIV status, in recent years.

3. Bareback sex - that is sex without condoms - has become normalised in the gay community. There are more than 180 gay porn DVDs certificated as R18 with the words "bareback" or "raw" in the title currently listed on the British Board of Film Classification’s website and available in UK gay sex shops.

4. HIV prevention charities like the Terrence Higgins Trust and GMFA have shifted their attitudes to embrace sex without condoms. The Assumptions campaign (Image 2 THT Assumptions Campaign, Sept 2009) by the Trust promotes the normalisation of bareback sex by positive men with the catchline: "No point in using condoms. All the lads here are positive".

5. The structure of the HIV charity sector creates a monopoly of thinking around HIV prevention for gay men. The result is that all too often harder-hitting, safer sex campaigns are rejected out of hand and the harsh reality of living with HIV and the side-effects of combination therapy drug treatments are hardly mentioned.

6. The HIV charity sector’s focus on stigma gets in the way of strong prevention messages and the normalisation of testing. We need to start convincing both younger and older gay men of the reasons why they are better off not becoming HIV positive.
From the Prime Minister

23 November 2010

As someone who grew up in the 1980s, I will never forget the government’s iconic HIV/AIDS campaign. There was a poster which showed a giant gravestone inscribed with “AIDS”, with a strap-line “Don’t Die of Ignorance.” It was hard-hitting and thought-provoking. And yes, at times, it made uncomfortable viewing. But that was the point. It had such a positive effect on waking up my generation to the dangers of AIDS.

More than twenty years on and we have come far. Prejudice is falling – though we still have to fight it. And increasingly effective medical treatments have been found – though there is still no cure and no one should be complacent, treatments are complex and have side-effects.

However, one area where progress has not been good enough is infection rates. Over the last ten years, they have actually increased. Of course, some of that is down to improved testing. But still, there are an estimated 83,500 people living with HIV in the UK and around a quarter of people don’t know they’re infected – which increases the risk they’ll infect their partners. Gay men are still one of the groups most at risk of catching the virus and London has the highest infection rates in the country.

That’s why, for this World AIDS Day, I am encouraging everyone reading this to make sure you know what your HIV status is. It’s simple: if you don’t know, you can’t seek the treatment you may need and you risk your health and the health of your partners. And it’s vital that if you’re negative you protect that status. Late diagnosis is the single most important factor associated with HIV morbidity and mortality so early diagnosis is crucial... So if you’re in Old Compton Street, Soho on 1st December take advantage of the testing bus organised by Boyz and 56 Dean Street.

The gay community led the way twenty years ago. You made sure information was available to all gay men about safer sex and the vital use of condoms. You created support organisations. You challenged prejudice. And now, rightly, it is illegal to discriminate against somebody, in areas like health care and employment, because they have HIV. I congratulate and thank you for the work you’ve done and continue to do.

But this is a fight that is still far from won. You need to support each other in avoiding the virus. You still need to practice safe sex. You need to test and to know your HIV status. And as a society we need to continue to fight prejudice and stigma, especially as they can be a barrier to testing and treatment.

I talk a lot about responsibility when it comes to my politics. And this World AIDS Day it’s important everyone thinks about the responsibility they have towards themselves, their partners and the wider community. Only together can we fight and then beat HIV and AIDS.

The Rt Hon. David Cameron MP
1. HIV INFECTION RATES HAVE RISEN AND THERE IS ON-GOING UNSAFE SEXUAL BEHAVIOUR BY GAY MEN.

1.1 The gay community has been failed by government policies for HIV prevention. A new approach is urgently needed if the number of new infections in gay men is going to be significantly reduced. The Labour government’s target in its National Strategy for Sexual Health and HIV in 2001 was to reduce the number of newly acquired HIV infections by 25% by the end of 2007. This reduction didn’t happen. In fact the number of new infections in gay men nearly doubled over this period from 1568 in 2000 to 2950 by 2007.

1.2 The Committee will know that the number of new infections in gay men has stayed resolutely high. The latest figures for 2009 show 2760 gay men were diagnosed with HIV. Based on Health Protection Agency (HPA) figures, the lifetime treatment and care costs to the NHS of the gay men diagnosed in 2009 will be around £855 million. The HPA’s new Recent Infection Testing Algorithm test shows that 1 in 6 of the new infections in gay men in 2009 - nearly 460 men - occurred in the 6 months prior to the men being diagnosed.

1.3 In other words, these 460 cases are not gay men infected some time ago who are only now choosing to test but are gay men who have been infected during some of the most recent prevention campaigns. These recent infections are irrefutable evidence of on-going, unsafe sexual behaviour by gay men.

1.4 15 years after the AIDS epidemic reached its peak in the numbers of deaths of gay men, it is a terrible indictment of the current HIV prevention system that gay men are still getting infected in such high numbers.

2. CURRENT GAY HIV PREVENTION CAMPAIGNS ARE WEAK AND INEFFECTUAL.

2.1 The Committee may be surprised how weak and ineffectual gay men's HIV prevention campaigns and messages are today. There have been no persistent and strong campaign messages aimed at gay men about safer sex and the vital importance of using condoms, regardless of your HIV status, in recent years. Gay men are currently being targeted by so-called niche prevention campaigns but the messages they are receiving are sometimes unclear and contradictory.

2.2 I have attached a number of recent campaigns run in 2009, 2010 and 2011 by the Terrence Higgins Trust and funded by the Department of Health or the Pan London HIV Prevention Programme (Images 3. THT Proximity, 4. THT Rapid Testing, 5. I've Just Tested HIV, What Next?, 6. THIVK You’re Still Negative?, 7. I Did It For Love, 8. Internet Chat). The Committee will note that the words safer sex are rarely used and there are virtually no references to using condoms. It was the gay community’s success in communicating what safer sex is which saved so many lives at the height of the AIDS epidemic. This shared community knowledge about condom use and safer sex is being lost.
2.3 The majority of the campaigns funded by the Department of Health in the last year are about increasing the number of gay men who test for HIV and not about preventing gay men becoming infected with HIV in the first place.

2.4 As the HIV charities and the Department of Health shifted their focus from the prime importance of safer sex to HIV testing it has been increasingly difficult to maintain messages about safer sex in gay community magazines like Boyz. It feels like we are going out on a limb to even mention the importance of condoms in editorial these days unlike the early part of the epidemic when we regularly ran Safer Sex special editions.
Image 3
THT, Proximity

1 in 7 gay men on the London gay scene has HIV.

LONDON GAY SCENE

For more information visit www.gmif.org.uk/1in7 or call THT Direct 0860 1131 200

You won’t always be told. You won’t know by looking. And he may not know himself.

*Source: The Marylebone Sex Survey 2004 in a study carried out by University College London Health Protection Agency. Supported by the Nice London AIDS Prevention Programme.
Image 4
THT, Rapid Testing

Think HIV testing takes too long? Some clinics offer “rapid tests” with results in 20 mins.

THIVK
TEST. TAKE CONTROL.

To find a clinic or get advice call THT Direct 0844 12 21 288 or visit www.thinkHIV.co.uk
THIVK
YOU'RE STILL NEGATIVE?
THOUSANDS OF GAY MEN HAVE HIV FOR YEARS WITHOUT KNOWING

Image 6
THT, THIVK You’re Still Negative?
Show him you care by taking an HIV test.

Find out why others do it and share your HIV testing stories today at I DID IT
Image 8
THT, Internet Chat

I’ve hooked up with some cute guys this year. So I just had a SexCheck.

Nice one! How did it go?

😊 All clear this time!

You won’t always notice symptoms, so have a SexCheck for all infections, including HIV, at least once a year. Find your nearest free and confidential clinic at www.gmfa.org.uk/stis or call THT Direct 0845 12 21 200.
3. BAREBACK SEX HAS BEEN NORMALISED IN THE GAY COMMUNITY.

3.1 The Committee may be shocked to discover that bareback sex - that is sex without condoms - has become normalised in the gay community. On gay dating websites individual gay men's profiles will often say "no condoms" or "bareback only" and there are many bareback internet chatrooms available for men to make contact. Gay men who use sex on premises venues like saunas or outside cruising grounds report more and more condom-free sexual activity. Clearly, the risk of HIV infection in bareback sex is very high.

3.2 Bareback gay porn DVDs are now prominently displayed in gay retail shops. Over the last five years the wide availability of bareback gay porn films featuring models in their teens and early 20s has become shocking proof of the normalisation of non-condom sex in the gay community. (Image 9, sexually explicit UK produced gay bareback DVDs)

3.3 Many younger gay men get their first knowledge and experience of gay sex watching gay porn films on DVD or the internet. The emphasis in these titles on youth means younger gay men watching them inevitably see bareback sex as a desire worth pursuing even with the risks to their health. They identify with the titles and the young models. This is particularly the case if HIV safer sex campaigns targeted at younger gay men are weak and unclear.

3.4 The numbers of bareback DVDs for sale in the UK has increased dramatically in recent years. A walk into any gay shop will see many shelves of such titles all being given official certification by the British Board of Film Classification (BBFC). This judgement by the BBFC directly affects public health.

3.5 There are more than 180 gay porn DVDs certificated as R18 with the words "bareback" or "raw" in the title currently listed on the BBFC's official website and therefore available in UK gay sex shops. In 2010, the BBFC certificated over 50 gay porn DVDs with the words bareback or raw in the title. It's almost double the amount certified in 2009. The BBFC receives between £700-£1000 for certificating each bareback film.

3.6 Some of the most recently certificated titles are "More Bareback Threesomes" (January 2011), "Deep Inside Bareback" (January 2011), "Bareback My Boy Butt" (December 2010) and "Bareback Football Orgy" (November 2010). The majority of bareback DVDs are produced overseas but a small number are produced in the UK using British gay performers.

3.7 Within the last five years the BBFC have certificated the following R18 gay films which mostly involve and target younger gay men, some made in the UK with British gay actors:

- Bareback Boys Club Orgy (January 2010)
- Bareback Soccer Sluts (November 2010)
- Bareback Emo Boys (June 2009)
- First Time Bareback (June 2009)
- Brit Lads Bareback – The Boyz From England (November 2007)
- Brit Lads Bareback – London Lads (November 2007)
- London Lads Do It Bareback (October 2006)
- Manchester Lads Do It Bareback (February 2007)
- Brighton Lads Do It Bareback (September 2007)
- Bareback Youth Hostel (June 2007)
- Bareback Skate Mates (October 2007)
Dawson’s 20 Load Weekend - which is a shocking US film of one man having multiple unsafe partners (October 2006)

3.8 The Terrence Higgins Trust has made no public statement condemning the production and availability of bareback gay porn films in the UK. The Trust held a seminar on bareback films in 2008 but no policy paper or action resulted. This is unlike its American counterpart the AIDS Healthcare Foundation which is currently taking legal action against porn companies for not making their actors use condoms on the grounds of health and safety and the American AIDS charity have also picketed porn studios on the issue.

3.9 Boyz magazine broke the story in 2008 of how three young gay men, aged 18-23, who appeared in a British bareback porn movie were infected with HIV on the film shoot. BBC2’s Newsnight followed up the story and at least one of the young men infected is already on combination therapy. The Newsnight film interview with one of the porn performers on the BBC website demonstrates the fatalistic attitude to HIV some younger gay men now have:

http://news.bbc.co.uk/1/hi/programmes/newsnight/7277000.stm

3.10 Some in the gay community, like myself, would like to see a complete ban on bareback porn films produced, sold and certificated in the UK both because of the risks to health to the performers and as a clear message to gay men here - and around Europe - about the importance of safer sex.

3.11 The BBFC has refused to make any change in its policies claiming it is following equality and anti-discrimination laws as most heterosexual DVDs are also produced without condoms. However, the risk of HIV to gay performers is many times higher than to heterosexual ones. Conservative MP Julian Brazier raised this issue on behalf of Boyz magazine in the House of Commons in a debate on the BBFC on 29th February 2008. The Commons response by the Labour Minister Margaret Hodge did not later refer to the subject.

3.12 The producers of bareback products don’t want us to talk about HIV in relation to their businesses because if we did they would be seen for what they are: promoters of HIV infection.

Image 9
Sexually explicit UK produced gay bareback DVDs
Explicit image not published. The full version of this evidence is available in the Parliamentary Archives (http://www.parliament.uk/business/publications/parliamentary-archives/).

4. BAREBACK HAS EVEN REACHED INTO HIV PREVENTION CAMPAIGNS.

4.1 Even HIV prevention charities like the Terrence Higgins Trust and GMFA have shifted their attitudes to sex without condoms. Please see the attached adverts Cum Like A Porn Star from 2005 and Assumptions from 2009. (Image 10, GMFA, Cum Like A Porn Star, Image 11 THT Assumptions).

4.2 The September 2009 Assumptions campaign by the THT promoted the normalisation of bareback sex by positive men with the catchlines: "No point in using condoms. All the lads
here are positive" and "He's not mentioned condoms. He's gotta be positive like me". The Terrence Higgins Trust’s own Hard-cell website invites gay men looking for information on bareback non-condom sex to click on a link to a US barebacking videos and contact website.

4.3 Although some HIV positive gay men do have unsafe sex with other HIV positive gay men, it remains a high risk for re-infection with multi-drug resistant virus, Hepatitis C and other sexually transmitted infections which then result in a higher chance of someone, even on treatment with a lower viral load, transmitting HIV. I believe HIV positive men need to be better targeted with prevention campaigns and the importance of safer sex.

4.4 A responsible prevention strategy needs to still promote safer sex to HIV positive gay men and not just subsume their unsafe sexual behaviour into its prevention messages. Although the shift away from condom use and the emergence of bareback porn films was driven by HIV positive men having sex with each other, not all HIV positive men bareback and that shouldn’t be the message HIV prevention charities are sending out.

Image 10
GMFA, Cum Like A Porn Star
Explicit image not published. The full version of this evidence is available in the Parliamentary Archives (http://www.parliament.uk/business/publications/parliamentary-archives/).

Image 11
THT Assumptions
Explicit image not published. The full version of this evidence is available in the Parliamentary Archives (http://www.parliament.uk/business/publications/parliamentary-archives/).

5. THERE IS A MONOPOLY OF THINKING ON HIV PREVENTION FOR GAY MEN.

5.1 The structure of the HIV charity sector has created a monopoly of thinking around HIV prevention for gay men. Over the last decade the Department of Health under the Labour government took a very hands-off approach to the implementation of HIV prevention despite ever increasing numbers of new infections in gay men in the UK.

5.2 Before 1996, the Department's Health Education Authority was directly responsible for HIV prevention campaigns including Lord Fowler's ground-breaking 1987 campaign: "AIDS: Don't Die of Ignorance". Later the Health Education Authority ran a number of campaigns aimed at gay men in the gay press but was criticised by the gay community for not describing which sexual behaviour was safe and which was unsafe for the transmission of HIV.

5.3 To answer this criticism, the Department set up a structure whereby all national government funding for HIV prevention for gay men was given to one HIV charity, the Terrence Higgins Trust. The Trust was then charged with handing out funds to select members of its CHAPS Partnership.

5.4 In 2001, the Department of Health asked the THT and CHAPS partners to work under the policy model devised by the SIGMA research team based at the University of
Portsmouth. This resulted in the same prevention policy approach being applied across the board by all the THT and CHAPS agencies regardless of where they are based. Sigma Research is more a policymaker than an evaluator despite previous evidence to the Committee by the Department of Health.

5.5 In effect, there is now a monopoly of thinking around HIV prevention. But local areas have different needs. Gay men in Manchester or Leeds may need a different message about safer sex compared with the cosmopolitan gay male population in London with its bigger range of venues and meeting places. There is a need for local distinct prevention approaches especially in working with local GPs and GUM clinics.

5.6 Sigma Research promotes risk minimisation across the CHAPS partnership as the HIV prevention approach they should all follow across the country. This approach does not place the reduction of new HIV infections at the core of its purpose; instead it places the "best sex with the least harm" at the centre of the prevention strategy. The most recent evidence of this is in the new draft for the fourth edition of Making It Count, the SIGMA strategy document that all CHAPS partners sign up to. The 2010 document is titled:

"Making It Count: Working towards the best sex with the least harm for gay men and bisexual men in England."

Making It Count states the CHAPS' strategy as: "the overall goal of our programmes is for MSM (Men who have sex with men) to have the best sex with the least harm. For some men the best sex will mean little or no sex; for others a sexual relationship with one man; for others it will mean a lot of sex with many partners. The best sex with the least harm may or may not include anal sex and if it does it may or may not include a condom." (Image 13, National Gay Men's Sex Survey, 2010)

5.7 This misguided strategy places the rights of HIV positive gay men to have sex without condoms above the rights of HIV negative gay men to be protected from the virus.

5.8 The impact of this risk minimisation strategy is that all too often harder-hitting, safer sex campaigns are rejected out of hand, the harsh reality of living with HIV and the side-effects of combination therapy drug treatments are hardly mentioned whilst bareback non-condom sex is promoted and normalised in the gay community without major criticism or comment from THT, the CHAPS partners, Sigma Research or the Department of Health.

5.9 The Department of Health has asked the Terrence Higgins Trust to fulfil two central aims:

a. Preventing as many people as possible from becoming infected with HIV.

b. Caring for and supporting people who are living with the virus.

These two aims create a contradictory position for the charity. The Trust seem unwilling to tell HIV negative gay men that they need to avoid the virus at all costs for fear of upsetting and distressing the people living with HIV who they are also charged with caring for. According to the charity’s mission statement, one of its aims is to "empower everyone living with the virus". I am not sure whether telling gay men directly why they need to avoid HIV
accords with this principle. The HIV charity sector's approach to stigma lies at the heart of this unwillingness to explain why gay men need to avoid HIV.
Everyone has the right to the best sex with the least harm.

It's a thin line between good sex and bad sex. Choices you make can tip the balance between the two. See inside what you've been doing...
6. THE HIV CHARITIES’ FOCUS ON STIGMA GETS IN THE WAY OF TOUGH PREVENTION MESSAGES AND THE NORMALISATION OF TESTING.

6.1 Although stigma is without a doubt a huge issue in the black community with its faith base and often traditional moral approach; in the gay community evidence for stigma is much less proven.

6.2 I, like many of my friends, have lived with HIV for almost two decades. The new life saving treatments have completely shifted both society’s and other gay men's views of HIV. I believe that this needs to continue and we need to focus on normalising HIV infection as a regular disease and not a “special case” disease.

6.3 Currently we remain in this vicious circle of the HIV charities claiming stigma is getting in the way of people testing and getting treatment and as a result they are not willing to give the tough prevention messages required to reduce infection for fear of upsetting people with HIV and exacerbating the stigma.

6.4 But can stigma about HIV really exist at the level which is claimed for the gay community when gay porn films and websites are allowed to promote the wilful infection of HIV between gay men as normal, accepted behaviour - as the “real thing” - without comment from most of the HIV charities or the Department of Health? The shift in attitude away from safer sex shows how HIV is now a normal part of gay life - and therefore needs to be treated as such. However, the core message from the HIV charities and government does need to urgently change. The message must be: HIV infection is not inevitable for gay men.

6.5 We need to start convincing both younger and older gay men the reasons why they are better off not becoming HIV positive. This needs strong leadership, an unwavering belief that we can reduce new infections through wise interventions and media messages and by shifting the community norms around bareback non-condom sex.

6.6 Sigma Research’s guiding principle that “Everyone has the right to the best sex with the least harm” must be abandoned if we are to persuade gay men they need to avoid HIV. Using condoms isn’t always the best sex but they will keep you from a lifetime of daily combination therapy and longer-term health problems including heart disease, increased risk of some cancers and senile dementia; also there are risks of treatment drug resistance and relationship, sexual and mental health problems for HIV positive gay men.

6.7 A new responsibility-driven approach to HIV is urgently needed but, in my view, it must be set and determined by the Department of Health and the government. The HIV charities and policymakers like Sigma Research have failed to give sufficient focus to stopping a new generation of gay men from becoming infected with HIV.

6.8 The Conservative government under Mrs Thatcher led the world with Lord Fowler's "AIDS: Don’t Die of Ignorance" campaign. I believe it is time for the Coalition government to pursue a harder-hitting HIV prevention approach. The gay community doesn’t want more gay men to be infected with HIV. This is why the Committee’s report is very welcome as an opportunity for the aims and judgements of HIV charities, Sigma Research and the Department of Health to be properly scrutinised.
David Bridle Biography

My partner Kelvin Sollis and I launched the weekly Boyz magazine in 1991 after having run the Pink Paper for two years. I worked for the BBC at Television Centre and Broadcasting House from 1982 to 1989. I had a number of short reports broadcast on Woman’s Hour and other programmes about AIDS and gay history. I was the original editor of Boyz in 1991, before becoming Managing Editor of all the company’s titles including Positive Times, the first mainstream magazine for HIV positive gay men in 1996. I became Managing Director and owner of Boyz after Kelvin’s retirement in 2004.

16 February 2011
1. Introduction

1.1 Bristol-Myers Squibb (BMS) welcomes the opportunity to respond to the House of Lords Ad Hoc Committee on HIV and AIDS’ call for evidence for its inquiry into the current situation on HIV and AIDS including monitoring, testing, treatment, prevention and stigma.

1.2 BMS’s response is informed by a programme of work launched in March last year that relates solely to our virology portfolio. This programme has comprised extensive stakeholder outreach to clinicians, commissioners, patient groups, and other healthcare organisations, and has given us a clear idea both of the general public health challenges facing the NHS and those pertaining most directly to patients with HIV. It has also provided a unique insight into the commissioning of HIV services, how different service providers currently work together to deliver care to patients, and what further improvements need to be made to help achieve first-class outcomes for HIV patients.

1.3 The first part of BMS’s consultation response outlines general views on the Government’s direction of travel regarding public health reform. The second part provides answers to the specific questions posed by the select committee.

1.4 BMS would welcome the opportunity to answer any questions about the submission in greater detail. Relevant contact details are provided at the end of this document.

2. General principles

2.1 BMS agrees with the Government that a radical shift in how it tackles public health is required. BMS regularly sees examples of innovation in public health, and frequently meets committed Healthcare Professionals (HCPs) in the course of our activities. While this should be consistent throughout the NHS, the Health Service will have to play a greater, more proactive, and more focused role in the promotion of public health. While BMS supports the movement to a leaner structure, this should focus on prevention, and then identify those at greatest risk, detect instances of poor health quickly, and deliver genuine improvements in patient care. BMS agrees that the NHS must be ambitious and determined in their plans for public health reform.

2.2 BMS is keen to work with all stakeholders in public health, including the DH, NHS, local authorities, clinicians and commissioners. It is hoped that the Government’s current programme of reform will result in a Health Service in which joint-working and seamless service integration are the norm, rather than the exception. To this end, BMS looks forward to the imminent publication of the DH’s Sexual Health Strategy. We hope that this will put forward a vision of a comprehensive, integrated, readily accessible, confidential, non-judgemental sexual health service across England, that look across the patient pathway, from prevention, through to diagnosis and treatment, and then management. It should also align with other strategies the Government is publishing that have a focus on sexual health.

2.3 The patient should be squarely at the centre of the Government’s reforms to the NHS: improvements in the quality of their care, and in their quality of life, should be the universal objective of all changes to the Health Service. BMS is therefore supportive of the
principle of using outcome measures to encourage improvements in the delivery of care. These outcomes should be ambitious and unambiguous, and should be based on the outcomes that patients value, as well as those that reflect the particular nature of the conditions they have.

2.4 Over the next four years, the NHS will undergo unprecedented changes to its structure and methods of operation. Between now and the full transition to the new architecture, standards of care must continue to improve, and the NHS must prevent the expertise and organisational memory of public health professionals from fragmenting and dissipating. The Government must also ensure that rising healthcare inflation does not systematically erode the ring-fenced funding promised by the Government. BMS would welcome any clarification the DH can provide about how it will continue to protect public health spending, both nationally and locally, within this challenging economic context. This is important in the field of sexual health, where evidence has been found in the past (Disturbing Symptoms, Terrence Higgins Trust, BHIVA, BASHH) of money being diverted away from sexual health to meet NHS deficits in other areas.

3. **Specific areas for clarification**

3.1 As outlined above, BMS is broadly supportive of the general intention of the Government’s reforms to public health.

However, we do have specific areas of concern around the changes to the commissioning structure, how to ensure a focus on prevention and where responsibility for testing will sit.

We deal with these key areas of concern in the context of the specific questions posed by the House of Lords Select Committee and attempt to provide answers to the following questions:

1) **Monitoring and data:** How robust is the current system for monitoring people with HIV in England? Could anything be done to improve monitoring?

2) **Prevention and testing:** Is the Government significantly focused on HIV prevention? Have the right groups been targeted? Are current testing policies adequate and could more be done to increase take-up rates?

3) **NHS Reform:** How can the NHS best commission and deliver HIV treatment? How will proposed commissioning reforms impact on HIV treatment?

3.2 How robust is the current system for monitoring people with HIV in England? Could anything be done to improve monitoring?

3.2.1 Across the board, our interaction with stakeholders identified poor integration between clinical and social care. They also noted that in many areas, the infrastructure of HIV services did not adequately reflect the complexity of monitoring the condition (particularly with regard to co-morbidities). To improve monitoring GPs should be responsible for coordinating a patient’s care as they progress down the pathway, but there should be clear, automatic referral routes to specialists for urgent and complex cases. All patients should be registered at an HIV centre.

3.2.2 BMS recognises that the provision of high quality care is, to an extent, dependent on the quality of data – about disease prevalence, the effectiveness and cost-effectiveness of
various interventions, and about patients themselves. It is logical that poor quality data can
have a negative impact on the treatment of people with particular conditions. For example,
cohesive information covering the number of patients that have been diagnosed, referred,
initiated on treatment, and/or have stopped their treatment does not exist. The DH must
address these knowledge gaps if NHS reform is to deliver improved patient care, and BMS
seeks Public Health England’s commitment to quality and transparency in its approach to
evidence.

3.2.3 BMS supports the Government’s plans to establish a new National Institute for
Health Research (NIHR) School for Public Health Research and a Policy Unit on Behaviour
and Health. All public health interventions should be evidence-based, and it is hoped that
these two new organisations will elicit the views of those with frontline experience of
treating patients, to

ensure real-life experience informs their interpretation of the data they collect and the
recommendations they make.

3.2.4 Over the next year, the DH has committed itself to developing a specialist
workforce to gather information and intelligence on public health. In many areas, this will
involve merging currently separate bodies, such as the Public Health Observatories and
Health Protection Agency. BMS would welcome further clarification about the potential
impact this transition period could have on the surveillance of complex conditions such as
HIV. Public Health England’s desire to use the reform process to strengthen monitoring,
surveillance and data mining is to be encouraged, but BMS would like reassurance that the
vital role played by the HPA in monitoring HIV prevalence and diagnosis rates will not be
compromised in the next few years. Indeed, this capacity should be enhanced in the future,
as part of the assessment of performance against any new outcomes measures.

Is the Government significantly focused on HIV prevention? Have the right
groups been targeted?

3.3.1 BMS supports the establishment of a national Public Health Service (Public Health
England), and the recognition that public health requires a more proactive, preventative style
of medicine. It is hoped that Public Health England will adopt a robust approach to
minimising the impacts of poor physical fitness and nutrition, as well as actively tackling
conditions such as HIV, that often have cultural or behavioural roots.

3.3.2 Even within a cash-constrained NHS, it will be important that Public Health England
has sufficient resources to educate people about healthier living and healthy behaviours.
However, there is already evidence that financial pressures on the NHS has led to the
abolition of prevention programmes and key advisory/data collection services (i.e. HPA, Aids
Support Grant etc).

3.3.3 Notwithstanding the important role of Public Health England, BMS believes that GPs
and GP practices will continue to play a vitally important role in identifying current and
future public health challenges, and providing advice about the most effective interventions.
They are the gatekeepers to the NHS, and should be incentivised to work actively with local
authorities and with their local Directors of Public Health to ensure their patients’ needs
are being addressed in a targeted and effective manner.
3.3.4 The new public health system will need to develop the right levers and mechanisms to encourage GPs to play an active role in prevention. The White Paper proposes that one of the primary mechanisms for this should be through the Quality and Outcomes Framework (QOF), with a sum equivalent to at least 15% of its current value being devoted to evidence-based public health and primary prevention indicators from 2013. BMS supports the DH’s plans to develop robust and meaningful levers to incentivise GP activism in public health. Amendments to the QOF must also be accompanied by concerted efforts to educate and support GPs to better understand public health conditions, whether they be services related to obesity and smoking, or complex conditions like HIV. BMS has observed that GP knowledge of, and familiarity with, these diseases is poor in some areas – it will take more than changes to the QOF to address this problem.

3.4 Are current testing policies adequate and could more be done to increase take-up rates?

3.4.1 The coping stone of the entire system for treating HIV should be a robust, primary-based testing infrastructure comprising a national screening programme for at-risk groups; monitoring of areas where late diagnosis routinely occurs, and continued liaison with those who test ‘negative’ to better understand public and individual attitudes to sexual health. Specialist clinicians should be responsible for instigating this new testing regime, and be compensated for it under a revised contract.

3.4.2 BMS welcomed the updated NICE guidance on increasing HIV testing among men who have sex with men and black Africans in England, which recommends that healthcare professionals offer regular, routine testing to all men and black Africans in high prevalence areas. However, we believe that there are further measures that can be made to normalise testing for HIV, by bringing testing into a more open environment. For example, in one London PCT, the Deputy Director of Public Health, has developed a PCT initiative testing for HIV, hepatitis B and C, in community pharmacies vs. GP practices; this has helped to remove the stigma for testing for HIV, by bringing testing into a more open environment. It has also proven to be more cost effective due to pharmacies’ longer opening hours and greater foot flow.

3.4.3 It is BMS’s view that further detail on where responsibility for testing for HIV will sit within the new commissioning structure is needed. The Healthy Lives, Healthy People consultation on the Funding and Commissioning Routes for Public Health states that local authorities will be responsible for commissioning testing of STIs, although the NHS Commissioning Board will also be involved in commissioning services where efficiencies can be made by procuring at scale (e.g. drugs procurement). At present, therefore, it seems that testing would fall within the remit of local health and wellbeing boards in community settings and sexual health clinics. There is scepticism, particularly among the patient group community, that local authorities possess the skills, capacity or resource to commission an effective infrastructure for prevention and detection.

3.4.4 There are also questions about who will commission testing in a primary setting. BMS would welcome reassurance that localising responsibility for these services will not lead to a damaging fragmentation in the DH’s understanding of how infection rates are changing, and what measures work best in preventing the onward transmission of both
diseases. BMS would also welcome certainty from the DH that separating the commissioning of HIV between the NHS Commissioning Board and local authorities will not hinder the delivery of joined-up services for patients with these conditions.

3.4.5 While we recognise that the QOF can be a powerful instrument for change, there are examples where provision of testing facilities have not required changes to the QOF, but have still used financial levers to promote greater GP and community engagement in HIV. For example, a Public Health Manager at a London PCT is working on a targeted approach to HIV testing for hard-to-reach communities who can be at higher risk of HIV infection, e.g. black Africans. An HIV testing pilot has been implemented in one locality, which provides financial incentives to the GP for each positive result. The pilot, which started in October 2010, is provided by 12 GPs and three community pharmacies.

3.4.6 These initiatives show that the QOF is not the only instrument that can be used to encourage greater activity from GPs in primary health, and they demonstrate how much can be achieved when different stakeholders in a local health economy work together. It is hoped that the Government’s final proposals for the future form of public health services promotes greater coordination across all organisation levels and all interested parties in public health delivery.

3.4.7 The emphasis on reducing avoidable mortality as an outcome should lead to a renewed focus on testing. This is particularly important for HIV, which is currently excluded from the Outcomes Framework and therefore risks competition for ring-fenced public funding with issues like obesity and smoking, which are better understood and more familiar in a local setting. BMS therefore endorses the position of the National AIDS Trust, that the ‘proportion of persons presenting with HIV at a late stage of infection’ should be developed as an indicator of improved clinical management within the Public Health Outcomes Framework. There are compelling arguments in favour of its inclusion. Late diagnosis accounts for at least a quarter of HIV related deaths in the UK (British HIV Association (BHIVA) mortality audit, 2006); in 2009, 52% of people with HIV were diagnosed late. The continuing failure to diagnose patients early increases the rate of onward transmission of HIV, and recent models have suggested that the majority of HIV transmissions are from the undiagnosed (see NAM, 2009). Reducing onward transmission rates also brings with it an unquestionable economic logic. According to the HPA’s 2010 HIV Annual Report, if all the 3,780 UK-acquired infections diagnosed in 2010 had been prevented, over £32 million annually or £1.2 billion over a lifetime in costs would have been saved.

3.4.8 It is hoped that success in achieving these outcome measures will be judged within an appropriate time-frame. While BMS can see the political desirability (both nationally and locally) of measuring outcomes on an annual basis, improvements in clinical management are often only apparent within a longer, two-to-three year period. A sole focus on the short-term should not be allowed to compromise genuine improvements in the standard of care, and risk demotivating HCPs and patients alike.
3.5 How can the NHS best commission and deliver HIV treatment? How will proposed commissioning reforms impact on HIV treatment?

3.5.1 In the last year, BMS has undertaken a significant body of work with stakeholders in public health, the NHS, clinical and commissioner communities, and patient groups to understand their views on commissioning reform, and how it should be undertaken in relation to their particular therapy area.

3.5.2 In September last year, BMS convened stakeholders with an interest in HIV, including clinicians in primary and secondary care, commissioners and patient groups. The purpose was to ask how HIV services should be commissioned and delivered in the post-2014 NHS landscape, and how the transition to this end-point should be undertaken. The group’s overall view was that while it was definitely desirable in future for GPs and community-based providers to play a greater role in supporting people to manage their condition, it was unrealistic and inappropriate for HIV services to be commissioned by consortia in the short term. This viewpoint has since been endorsed by the DH, and BMS welcomes the confirmation that the NHS Commissioning Board (NCB) will be responsible for HIV outpatient services, for the short-term at least. It is BMS’s view that it makes sense that specialised high-cost, low volume services should not be commissioned and carried out by individual consortia, and that expertise and financial risk for complex conditions should be pooled.

3.5.3 GPs will continue to play a key role in ensuring that patients are staying on their treatment pathways, helping patients to manage their condition and acting as advocates for local patient populations. BMS would expect that the establishment of commissioning consortia will place GPs in a much broader context than their surgery and immediate local environment, and will encourage them to develop broader networks of contacts, both horizontally (with other public health stakeholders in their community) and vertically (with secondary care clinicians). It will be incumbent for GPs to continue working with stakeholders such as patient groups, social workers, drug and rehabilitation councillors, and GUM clinics, to ensure that patients, no matter where or how they access the NHS, are staying on their treatment pathway.

3.5.4 BMS also support GPs playing a more active role in the Joint Strategic Needs Assessment (JSNA) process, and the Government’s plans to make GP consortia responsible for preparing the JSNA in collaboration with local authorities. However, at present, this process largely ignores conditions that do not have a vocal and active patient population. Improved communication between GPs and patients and patient group and professional body involvement is therefore vital.

3.5.5 The capacity of local authorities to commission sexual health services is open to debate. However, BMS seeks reassurance from the Government that devolving sexual health services to local authorities will not result in the politicisation of conditions like HIV, which is often stigmatised and misunderstood in the broader community. Local authorities have only limited experience in public health and none in commissioning. They will need to be supported to represent the needs of marginalised and excluded groups, many of whom are at particular risk of contracting conditions like HIV.
3.5.6 In light of the issues noted above, BMS would endorse the development of a sub-national level of commissioning for areas such as London, Birmingham, Manchester and Brighton, where concentrations of HIV are highest. These sub-national (or ‘supra-local’) arrangements would provide a compromise between a centralised approach which might seem remote from patients, and an overly parochial system, which lacks the expertise, resource and freedom from financial risk to commission suitable services. In such areas, BMS recommend that individual consortia pool the commissioning of their HIV services, working in partnership with a network of their Public Health Directors and Health and Wellbeing Boards to ensure any specific local issues are taken into consideration. There are already examples of successful joint commissioning of HIV services in the UK, such as the pan-London arrangements which are generally viewed as having improved the standard of commissioning in the capital. BMS would like to see this model refined and replace the current assumed division of commissioning between the NHS Commissioning Board and local authorities.

3.5.7 Alongside the structural arrangements that will need to be made for sub-national commissioning to occur, it will be important to ensure funding for HIV services reside at this level as well. This will be essential to make commissioners accountable for the services they plan and deliver.

27 May 2011
Memorandum by British Association for Sexual Health and HIV (BASHH) and the Royal College of Physicians (HAUK 55)

Executive Summary

HIV places a significant burden on the NHS and society. Due to enormous advancements in antiretroviral drugs since the 1990s, HIV positive patients can lead near normal lives if they are diagnosed promptly and have prompt access to treatment.

Early diagnoses and prompt access to treatment are also both essential in preventing the further spread of infection and halting progression, in turn delivering significant cost savings for the NHS. BASHH therefore welcomes the proposed outcome measure for a reduction in the proportion of undiagnosed cases of HIV.

Increased testing for HIV will help detect undiagnosed cases, and improve rates of early diagnoses. There are a number of pilot studies from high prevalence areas, and HIV testing guidelines that promote strategies to reduce undiagnosed HIV and prevent onward transmission. The rollout and implementation of opt out testing and targeted testing in a wider variety of non traditional testing sites is the essential next step in HIV testing.

However, BASHH also urge the committee to be aware that over half of all HIV diagnoses are made in GU settings. BASHH are concerned that the proposed removal of the rapid 48 hours GU access target in March 2011 will lead to delays in access to testing and treatment services for patients (particularly for those that may not wish to see their GP). Maintaining barrier free, rapid access to HIV services is as vital as further expansion of opt out and targeted testing.

BASHH welcomes the timely opportunity to submit written evidence to the HIV select committee, given the forthcoming changes to the NHS. HIV care is a rapidly changing area of medicine and is high cost, low volume to treat which is the principal reason BASHH supports proposals within the White Paper that recommend HIV services are commissioned by the NHS Commissioning Board. This structure also has the ability to save the NHS money through ‘economies of scale’ of drug and service procurement and ensure that treatment centres are linked up and working together to deliver seamless models of care. The National Commissioning Board is also best placed to engage GPs in the treatment of patients where appropriate, by ensuring there are no conflicts of interest. BASHH primary concern with the reforms is that they do not undermine good work that is ongoing such as the development of a national tariff for the provision of HIV services.

Finally, as the current provider of epidemiological information on HIV, the Health Protection Agency [HPA] provides a highly respected national and international service. BASHH welcomes the commitment to health protection in the NHS reforms, but has concerns that proposed reforms may have a negative impact on the ability to provide robust monitoring and surveillance, and independent policy advice.
About BASHH

1. The British Association for Sexual Health and HIV - BASHH - was formed in 2003 through the merger of the Medical Society for the Study of Venereal Diseases (MSSVD; established 1922) and the Association for Genitourinary Medicine (AGUM; established 1992).

2. BASHH has a membership of over 1,000 medical practitioners, health advisers, nurses, scientists and other healthcare workers. Our objectives are:

   - To promote, encourage and improve the study and practice of the art and science of diagnosing and treating sexually transmitted diseases including all sexually transmitted infections, HIV and other sexual health problems.
   - To advance public health so far as it is affected by sexually transmitted diseases and to promote and encourage the study of the public aspects of sexually transmitted diseases including all sexually transmitted infections, HIV and other sexual health problems.
   - To advance the education of the public in all matters concerning the medical specialty of Genitourinary Medicine (hereinafter referred to as 'the Specialty'), to include the management of HIV infections and the broader aspects of sexual health.
   - To promote a high standard in the medical specialty of Genitourinary Medicine to include the management of HIV infection and the broader aspects of sexual health.

Monitoring

How robust is the current system?

3. The HPA is the current provider of epidemiological information [1] on the number of people with HIV in the UK. They provide a highly respected national and international service. The data collection and analysis methodology has been refined over many years and there are systems in place to ensure that the data is robust, avoids duplication and that there is widespread dissemination of analysis both on their website and in peer reviewed journals. Further evidence that the data is robust is that it is used by the London HIV Specialist commissioners (LSCG) to calculate funding for the 24 HIV services within the London HIV Consortium.

4. In addition the HPA plays a key role in the following:

   - **Sexually transmitted Infections (STI):** It has been key in providing data and support to the monitoring and investigation of STI outbreaks such as Lymphogranuloma Venereum (LGV) and Hepatitis C in the HIV positive population.
   - **Mother to child transmission:** It is the only central forum for submitting and discussing maternal/neonatal transmission data. This data has contributed to the development of many of the interventions which are now standard of care in the UK with Mother to child transmission (MTCT) rates at an all time low of <1%.
   - **International HIV surveillance data:** The HPA provides a highly respected national and international service. For example, the HPA plays a valuable role as a crucial international partner with the European Centre for Disease Control and Surveillance based in Stockholm, as well as the WHO and UNAIDS globally.
Will the proposed public health reforms impact on this system?

5. It is difficult to be certain what impact public health reforms will have as there is uncertainty about the details of the changes. It is important that any changes do not have a negative impact on the ability for such an agency to provide robust monitoring and surveillance. However, depending on the outcome, it could be an opportunity to further enhance the excellent work that the HPA does.

6. There is a great deal of useful data that is supplied to the HPA which is not currently analysed as other key data is prioritised. There is a concern that any reduction in personnel or resources may lead to a reduction in key epidemiological analysis and a reduction in the ability to respond quickly to requests for data analysis in outbreak situations.

7. It should be noted that Scotland has robust systems for monitoring patients diagnosed HIV positive and also collects national data on HIV viral load and CD4 count to allow ongoing assessment of effectiveness of treatment. It is unlikely to be affected by public health reforms.

8. The public health White Paper - *Healthy Lives, Healthy People* - sets out the plans to integrate and strengthen existing public health functions. As part of this, Public Health England (PHE) will encompass all the current functions of the HPA and BASHH welcomes this commitment to health protection. Furthermore, with prevention as a key focus of the public health reforms, this may encourage further research on and analysis of the impact of preventative measures for HIV on HIV diagnoses.

9. However, some concern has been raised about the potential loss of independence, credibility and trust that could arise out of such a move. Independence of the functions of the HPA is critical in terms of retaining credibility and the trust and confidence of the public, health professionals and others working in the field of health protection - locally, nationally and internationally. If the integrity of advice provision were to be eroded, or perceived to be so, this would impact on the HPA’s ability to influence, protect and improve public health. Therefore, steps must be taken to preserve its independence.

Could anything be done to improve reporting?

10. Currently, HIV services voluntarily report a variety of data to the HPA. There are some key elements regarding data submission that can impact on data accuracy:

- Data is pseudoanonymised to protect patient confidentiality. The anonymisation process is based on patient name and not NHS number.
- Data is supplied to 4 different datasets. These include HIV/AIDS reporting, Survey of Prevalent HIV Infections Diagnosed (SOPHID), CD4 surveillance and Genitourinary Medicine Clinic Activity Dataset (GUMCAD). There are robust data sharing policies.
- Patients diagnosed outside of reporting centres who do not access HIV care at a treatment centre may not be reported to the HPA.

11. Matching data between data sets is complex and due to use of patient identifiers, as opposed to NHS number, may impact on accurate case matching. Reconsideration of the anonymised data rules for HIV patients may permit improved and streamlined data analysis. Accurate data matching between CD4 surveillance and SOPHID would permit assessment of average
HIV viral load in populations which may prove to be a useful marker for HIV prevention research.

12. Standardised electronic patient records, whilst costly, may enhance data collection.

13. Whilst it is very much welcomed that HIV testing is expanded outside of GUM services, we need to strengthen the relationship between national surveillance and HIV testing by enhancing local HIV reporting procedures in order to maintain high quality national surveillance.

14. Additionally, unlinked anonymous HIV prevalence surveys could be expanded outside of traditional settings.

**What groups in particular are at risk from HIV?**

15. Predominantly HIV is transmitted among two major groups:

- Men who have sex with men (MSM)
- Black-Africans (BA)

16. Injecting drug users and mother to child transmission account for a small minority of new infections but surveillance continues to be important to identify emerging trends of transmission.

**Prevention**

**Is Government policy sufficiently focused on HIV prevention?**  
**Have the right groups been targeted in recent prevention campaigns?**

17. HIV places a significant burden on the NHS and society:

- According to the latest statistics, the number of people currently living with HIV in the UK has reached an estimated 86,500
- A quarter of these people are unaware of their infection, and over 50% of them were diagnosed late
- During 2009, a total of 6,630 people were newly diagnosed as HIV-infected.[2]

18. However, preventing the further spread of infection can deliver significant cost savings. It is well publicised that:

- It is estimated that the prevention of one new HIV infection would save the public purse between £280,000 and £360,000 in direct lifetime healthcare costs.[3]
- If all patients diagnosed HIV+ in 2008 had been diagnosed earlier, and prevented from transmitting HIV to one additional person through effective treatment, then the annual saving would be in excess of £50 million.

19. This data suggest that, whatever prevention activity is in place currently, more should be done. Emphasis should be on implementing what is known to be beneficial and funding more
UK based research into prevention. The role of well thought out non-stigmatising campaigns should be considered.

20. Prevention of cases of HIV can be achieved through the prevention of onward transmission, the activities of which are three-fold:
   - **Increased and timely access to testing services**: more routine and accessible testing ensures both early diagnosis and reduces undiagnosed cases of HIV.
   - **Early diagnoses**: Earlier diagnosis ensures that patients can receive timely treatment. Additionally, awareness of HIV diagnosis has been shown to result in a reduction in risky sexual behaviour.[4]
   - **Prompt access to treatments**: Effective (prompt) treatment significantly reduces viral load and infectiousness, and thus the likelihood of transmitting HIV.

21. With early diagnosis and access to prompt treatments, the viral load is reduced, and this reduces the likelihood of transmitting HIV. Prompt diagnosis and effective (prompt) treatment can reduce, almost halt, onward transmission in an individual.

22. Currently, an estimated 53% of all diagnoses are made in GU settings. GUM clinics are ‘Open Access’ and are currently underpinned by the 48 hour access to GUM clinics (‘guaranteed access to a GUM clinic within 48 hours of contacting a service’.) In recent years, sexual health services in England have worked together to improve health outcomes through meeting and sustaining the very challenging 48 hours target.

23. When someone makes that decision to get a test, we need to make sure that there are as few barriers as possible. Having the ability to offer open access, free and immediate/same day testing to those who are worried about HIV ensures that they both get tested and find out their status. Introducing barriers and delays, such as appointments with long waiting times, may result in that moment to test becoming lost. In order to reduce the number of people who are unaware they have HIV, to ensure early diagnosis and access to treatment, and ultimately, help prevent the further spread of HIV, rapid access to HIV services (within 48 hours) must be maintained.

24. Barriers to testing may also be divided into: those affecting the individual, those affecting the healthcare provider and those affecting the healthcare professional. For the individual, barriers include perceived stigma and fear of a lack of confidentiality, for the healthcare professional these include; a reluctance to test, and for the provider, barriers include a lack of systems in place to promote and/or provide immediate HIV testing. Through open access and confidential services with a 48 hour target to see patients, GU clinics already have in place many measures to reduce well known barriers to HIV testing.

25. HIV testing guidelines that promote strategies to reduce undiagnosed HIV and prevent onward transmission were published by BHIVA and BASHH in 2008.[5] These Guidelines recommend more routine HIV testing in healthcare settings in PCT areas with an HIV prevalence of more than 2 per thousand population. Widespread implementation of the guidelines would help to increase the uptake of HIV testing and reduce the proportion of individuals that are not aware of their HIV status.

26. In December, the Time to Test meeting supported by BHIVA and BASHH presented data on expanded testing outside of traditional settings. The data showed that expanded testing
in a variety of healthcare settings successfully identified many previously undiagnosed HIV positive patients and that more routine testing was very acceptable to patients (see 11).[6]

27. Currently, there is a relative paucity of practical prevention intervention research in the UK. International research has suggested that lowering community HIV viral load, pre and post exposure prophylaxis following exposure to HIV and early HIV diagnosis may all impact on onward HIV transmission. Further funding should be made available for high quality large research projects in the UK.

28. The right groups need to be targeted for HIV testing and the draft NICE guidance of HIV testing men who have sex with men (MSM) and black Africans go a long way to helping this to happen.[7][8]

29. In Scotland there is a clear focus on HIV prevention and an HIV action plan from 2010-2013 together with development of Quality Improvement Scotland HIV Care Standards which include considerable emphasis on prevention activities. A similar review should take place for the rest of the UK.

To what extent have prevention initiatives targeted at injecting drug users been successful?

30. Injecting drug users (IDUs) account for a minority of all new infections. Sharing needles is a very efficient way of transmitting HIV infection. Needle exchange has been shown to be very effective in reducing transmission.

31. Whilst government policy is supportive of needle exchange its use has declined in recent years with many users continuing to share. The implementation of needle exchange in prison settings is complicated by security concerns and stigma within the prison environment.

32. A recent HPA report stated that the prevalence of HIV among current injectors has increased from 0.7% to 1.5% over the past decade, and is now similar to the level found in the early 1990s. In addition, there is regional variation with the prevalence ranging from 0.6% in Scotland to 4.1% in London.[9]

33. However, the uptake of HIV testing amongst IDUs is improving, with three-quarters now reporting that they have had a test; however, almost a third of IDUs with HIV remain unaware of their infection.[9]

How could prevention initiatives be better delivered and evaluated?

34. HIV prevention should be a priority of both the NHS and the new Public Health Service. It is unclear how the government’s proposed reforms will impact on HIV prevention. Currently HIV prevention and HIV treatment and care are commissioned separately. This separation leads to lack of clarity as to the where the responsibility lies in driving some prevention programmes especially as funding for treatment and care declines.

35. Incentives should be put in place to encourage local healthcare providers and Directors of Public Health to increase their focus on HIV prevention, increase testing, deliver appropriate services, and evaluate the impact of these measures. The use of effective commissioning
using tools such as CQUINS, QOFs and QIPPS (Quality, Innovation, prevention and productivity) would be a valuable lever to promote testing and prompt HIV diagnosis in specific settings.

36. HIV and HIV prevention should be a priority of both the NHS and the new Public Health England. Public Health England should play a leading role in the coordination and evaluation of prevention initiatives.

37. The NHS and Public Health England should give HIV the appropriate priority on the ground by requiring that it is systematically considered in health needs assessments and other relevant local health planning processes.

38. Implementation BHIVA/BASHH HIV testing guidance and the upcoming National Institute for Health and Clinical Excellence (NICE) public health guidance on HIV testing will further enable the improvement of HIV prevention efforts.\[5\][7][8]

39. Additionally, funding of high quality research programmes in the UK will help to identify what works.

Testing

Are current testing policies adequate across the country? What can be done to increase take-up rates?

40. According to the latest statistics, the number of people currently living with HIV in the UK has reached an estimated 86,500. A quarter of these people are unaware of their infection, and over 50% of them were diagnosed late. During 2009, a total of 6,630 people were newly diagnosed as HIV-infected.\[2\]

41. In order to meet the Government’s outcome of reducing the proportion of persons presenting with HIV at a late stage of infection as set out in *Healthy Lives, Healthy People: Transparency in Outcomes*, it is essential that more widespread testing is carried out.

42. Increased testing, which leads to earlier diagnosis, will also reduce unnecessary death and long term morbidity due to AIDS and enable treatment to reduce HIV viral load and the risk of onward HIV transmission.

43. Opt out testing and targeted testing in a wider variety of non traditional testing sites is essential to identify those unaware of their HIV status. National BASHH BHIVA HIV Testing guidelines have been available since 2008 and the draft NICE public health guidance on HIV testing further adds support to increased and more routine HIV testing as recommended in this document.\[5\][7][8]

44. Regular testing should be offered in high prevalence areas. Such testing should be open access for those at risk and routine in new GP registrants. This is a recommendation of the 2008 British HIV Association, the British Association for Sexual Health and HIV and the British Infection Society National Testing Guidelines.\[5\]

45. In order to increase HIV testing, policies that translate national guidance into clinical practice are urgently required and provision of adequate resources and incentives, and the
use of effective commissioning tools should be used as leverage to ensure high uptake of policies.

46. Finally, in consideration of this, it should be noted that some interventions have been more successful than others in leading to an increase in HIV testing. For example, the letter in 2007 from the Chief Medical Officer to healthcare professionals, including GPs, urging them to offer and recommend HIV tests to their patients (if it was thought that they may have been at risk of or exposed to HIV infection), demonstrated very little impact on, or increase in, HIV testing practices.

47. However, a national awareness campaign which ran in the early years of HIV infection, had a significant impact. Whilst BASHH recommends that consideration should be given to further national awareness campaigns, we urge that care should be taken in designing the campaign to avoid stigmatisation of persons who fall into high risk categories.

Treatment

How can the NHS best commission and deliver HIV treatment? What impact might the proposed new commissioning reforms have on HIV treatment?

48. There is a need for a commissioning process that is able to deliver high quality care, ensure patients have ease of access to care, and that care is equitable nationally. As such, BASHH welcomes the proposal, as set out in Healthy Lives, Healthy People: consultation on the funding and commissioning routes for public health, for Public Health England to work with the NHS Commissioning Board to provide more specialised commissioning for HIV treatment and care, and where efficiencies can be made from procuring drugs and services at scale.

49. HIV care is a rapidly changing area of medicine due to introduction of newer treatments, emerging toxicities and co-morbidity in an ageing cohort. Given the high cost, low volume nature of the HIV specialty, national/ regional drug procurement strategies including therapeutic tendering approaches, as proposed to take place through the National Commissioning Board (NCB), have the ability to save the NHS significant amounts of money. The NCB should also ensure that there are treatment centres working together or in a network to help achieve this outcome.

50. The changing needs of patients and the continuing rise in patient numbers puts pressure on a commissioning process to be sufficiently intelligent to be able to adapt to the evolving needs of patients and be cost effective in reviewing service delivery whilst maintaining high quality care.

51. BASHH is concerned that reforms do not undermine much good work that is ongoing such as the development of a national tariff for the provision of HIV services.

In what setting can treatment most effectively be delivered?

52. Current HIV services are delivered via medical specialities such as GUM or Infectious diseases (ID). They have demonstrated excellent treatment outcomes for patients started on antiretroviral therapy despite many patients presenting late.
Memorandum by British Association for Sexual Health and HIV (BASHH) and the Royal College of Physicians (HAUK 55)

53. Furthermore, as patient numbers have continued to rise alongside an ageing cohort and fewer opportunistic infections, HIV services have adapted to the many changes required of them.

54. There are no published studies evaluating alternative strategies for delivering HIV care in the UK and research into different models of care is urgently needed to ensure that any proposed changes are appropriately evaluated and shown to be of similar or improved quality as well as cost effective.

55. Any small reduction in quality of care may lead to adverse treatment or patient outcomes such as an increase in HIV drug resistance or onward HIV transmission, both of which would have a significant impact on overall treatment and management cost.

56. With an increasing ageing cohort of HIV positive out-patients, engagement of GPs in managing the treatment of this group will undoubtedly be required. The NHS Commissioning board is well placed to manage any transition of the care pathway, engaging with GPs and ensuring that appropriate support is given to evaluating and implementing changes to the delivery of HIV care to patients. Furthermore, any changes to the treatment care pathway will necessitate patient involvement ("no decision about me, without me"). Understanding the risks, benefits and barriers to engagement of HIV positive patients with primary care will be key.

57. Finally, consideration should be given to the provision of free prescriptions for HIV as a long term condition and addressing patient fears of stigma regarding disclosure of their HIV status to primary care professionals.

58. HIV inpatient care is best delivered by units with a specialist expertise in HIV inpatient care. Whilst earlier diagnosis will hopefully reduce late presentation, there will be a need to review the most cost effective models of inpatient care. Collaboration with BASHH, BHIVA and BIS would be required for any evaluation.

Cost

Have cost considerations been satisfactorily balanced with public health imperatives in HIV:

59. HIV is costly to treat and manage and the cost of providing HIV treatment and care to an increasing cohort of HIV patients continues to rise:
   • The annual cost of drug therapy alone is in excess of £50 million; this does not include the additional costs of provision of HIV alongside care for long term co-morbidity (e.g. cancer, lymphoma, and disability following opportunistic disease), social care, time off work and cost of benefits.
   • It is estimated that the prevention of one new HIV infection would save the public purse between £280,000 and £360,000 in direct lifetime healthcare costs[^3].
   • If all patients diagnosed HIV+ in 2008 had been diagnosed earlier and prevented from transmitting HIV to one additional person through effective treatment then the annual saving would be in excess of £50 million.
Memorandum by British Association for Sexual Health and HIV (BASHH) and the Royal College of Physicians (HAUK 55)

60. Prompt diagnosis and effective treatment can reduce (almost halt) onward transmission in an individual and we now have testing guidelines that promote strategies to reduce undiagnosed HIV and prevent onward transmission. These statistics suggest that further investments in research and the delivery of known interventions to prevent new HIV infections have the potential to save money in the long term.

Stigma

What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?

61. At an individual level, stigma against HIV can result in those at risk of HIV infection being reluctant to get tested and/or to go to current settings where HIV testing is offered. There is also a problem of “othering” the epidemic, belief in the idea that it’s “someone else/those people” that get HIV and not “people like me”.

62. Research shows that routine opt out testing in less stigmatised services will improve uptake of testing at a population level and reduce undiagnosed HIV infection.[7]

63. Well recognised problems in those individuals diagnosed with HIV infection include:
   - fear of rejection,
   - fear of stigma and discrimination,
   - fear of disclosure,
   - perceiving themselves as “unclean” and “not whole”,
   - social isolation, and;
   - low self esteem.

64. This can result in reluctance to access care, a reluctance to disclose HIV status, mental health problems, and unwillingness to access emotional support and information.

65. Fear of stigma can also prevent HIV positive individuals from utilising appropriate services and could be a barrier to changing the current model of care. Due to perceived stigma, many patients continue to fear disclosure of their HIV status and sexuality in primary care settings.

66. At a national level, the prevalence of stigma can means that there is a reluctance to carry out campaigns which target high risk groups, venues and activities, due to a fear of increasing stigmatisation and other sensitivity considerations. As such, public health campaigns can be poorly targeted, and poorly taken up.

67. BASHH welcomes the draft NICE guidance on testing of MSM and BA.

Where are problems of stigmatisation most acute?

68. Stigma is most acute in those groups and individuals already stigmatised by racial and sexual orientation characteristics.

69. From a public health and effective provision of care perspective, stigma and fear of stigma can result in non-disclosure of HIV status by patients in medical settings where:
Memorandum by British Association for Sexual Health and HIV (BASHH) and the Royal College of Physicians (HAUK 55)

- HIV is not commonly encountered and/or;
- Where training is not thorough and up to date regarding HIV and the importance of adhering to GMC guidance on confidentiality and good medical practice.

70. In addition stigma and fear of stigma impacts on the process of disclosure to prospective and previous sexual partners which may result in a failure to identify other persons with HIV infection.

**What measures are currently taken to tackle HIV stigmatisation? What more should be done?**

71. Empowerment and education of persons living with HIV infection: provision of training, help and support to HIV positive persons to aid them to have a secure understanding of transmission risks and the self-confidence to express them and feel confident in medical settings that they will not be stigmatised, should be increased.

72.  Stigmatisation (and reasons promoting patient fear of stigmatisation) in medical settings should be reduced through engagement of key stakeholders and implementation of education programmes and policies.

73.  Normalise HIV testing: HIV testing should be normalised through the Implementation of the forthcoming National Institute for Health and Clinical Excellence (NICE) public health guidance on HIV testing. This should be achieved by encouraging the development and implementation of local strategies to increase HIV testing (e.g. testing for new GP registrants in high prevalence areas).

74.  Raising awareness and reducing stigma: thoughtful and sensitive public health campaigns should be developed to promote education and awareness of HIV and to reduce stigma.

Notes

[1] Information provided: Estimated number of people living with HIV, New HIV diagnoses, Recently acquired HIV infections, Late diagnosis, AIDS and deaths among HIV-infected individuals, People in HIV care, HIV among adults aged 50 years and over, Prevalence of undiagnosed HIV infection in STI clinic attendees, Pregnant women and children, HIV testing, HIV and tuberculosis co-infection, Monitoring HIV care in London

http://www.hpa.org.uk/Publications/InfectiousDiseases/HIVAndSTIs/1011HIVUK2010Report

http://www.hpa.org.uk/Publications/InfectiousDiseases/HIVAndSTIs/0911HIVUK2009Report


[5] BHIVA/BASHH HIV testing guidelines  

[6] Time to Test  
www.hpa.org.uk/Publications/InfectiousDiseases/HIVAndSTIs/1011TimetotestHIVtesting
Memorandum by British Association for Sexual Health and HIV (BASHH) and the Royal College of Physicians (HAUK 55)

[7] NICE draft guidelines – Increasing up take of HIV testing amongst MSM
[8] NICE draft guidance – increasing uptake of HIV testing amongst black African communities
http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1287143384395

February 2011
Supplementary Memorandum by Dr Keith Radcliffe, President of British Association for Sexual Health and HIV (BASHH) and Chair of the Joint Specialty Committee (JSC) for Genitourinary Medicine at the Royal College of Physicians (RCP) (HAUK 73)

1. **A HIV outpatient funding tariff is being developed by the Department of Health, with the involvement of many clinicians within the HIV community. Can you explain how this will work and what advantages it will bring?**
   
   I believe that the development of an HIV outpatient tariff will be beneficial to services. In the speciality of GU medicine we have had a number of years of experience of a national tariff for general GU medicine services (but not HIV). This is known as “payment by results”.
   
   This has been very beneficial for the service in that it sets a government approved and national rate for the job, so to speak, so that it has largely removed the endless debates with commissioners over whether the services are over- or under-funded, as it gives a national benchmark to refer to. As I say, we have found this to be extremely positive in general GUM services, so my expectation is that this would be true for HIV treatment and care services also.

2. **How confident are you, following reforms to bodies such as the Independent Advisory Group on Sexual Health and HIV, that there will be sufficient channels in place to provide independent advice on HIV to the Government?**
   
   Reforms to advisory bodies – previously there were two advisory bodies. I sit on one of them in an individual capacity, known as EAGA (Expert Advisory Group on AIDS). EAGA has been re-categorised as a different entity, but appears to be continuing to carry out its functions as previously, so I am very pleased that this is the case as it obviously provides high-quality advice to the Department of Health on this subject.
   
   The other body was the Independent Advisory Group on Sexual Health, chaired by Baroness Gould. This has been stepped down, but we have been informed that a new stakeholder body is going to be set up to advise the DH on sexual health matters. I have not yet received any details of that, and it is obviously important that a suitable such body is set up. If this does indeed happen then I would be satisfied that with two such advisory bodies to the Department of Health then needs have been adequately met in this area.

   a. **What contribution could organisations such as yours make to HIV and AIDS policy development? How involved are you at present?**
   
   I believe that organisations such as the British Association for Sexual Health and HIV (BASHH) have a very valuable role to play in developing HIV / AIDS policy. At the moment this is done through *ad hoc* meetings with relevant civil servants in the Department of Health, plus responding to policy consultation documents sent out from the DH. As mentioned in 2 above, I have been led to believe that BASHH will
be asked to nominate a representative to sit on the proposed new sexual health stakeholder group by the DH and this would obviously be very welcome.

3. **What do you think should be the conclusion of the review, announced by the Government, into the ban on those with HIV working in “exposure-prone” fields of medicine?**

Healthcare workers and exposure-procedures – this was recently discussed at a meeting of EAGA (see above). In my opinion restrictions on healthcare workers in these fields should be relaxed subject to certain safeguards such as occupational health monitoring, taking antiretroviral drugs, and having a suppressed HIV viral load on testing.

4. **Do you have any specific examples of cases where those infected with HIV were not tested in a timely fashion, leading to expensive inpatient treatment at a later stage of their infection?**

   **Case 1**: a white heterosexual man in his forties. A successful businessman with a long-term female partner. He was thought to be depressed and was struggling at work. After a 12 month decline in memory, thinking and behaviour he lost his business and was admitted to hospital with a diagnosis of early onset Alzheimer’s disease. After a prolonged admission he developed difficulty in swallowing and was noted to have thrush (candida) in his mouth and probably also in his oesophagus (gullet). A diagnosis of oesophageal candida was made, which is a diagnosis highly suggestive of AIDS. He was tested for HIV infection and found to be positive. The diagnosis of Alzheimer’s was reviewed and it was felt that, in hindsight, he had had HIV-associated dementia. He was transferred to an HIV inpatient unit where he received HIV treatment via a nasogastric tube as he refused to swallow HIV tablets. He remained an inpatient for over 3 months and was then transferred to a nursing home for long term care. He has regained some mental function but has been unable to work and is unlikely ever to be able to work again, although his physical health is good. He requires a long term care package. Thankfully his female partner tested HIV negative despite significant risk whilst unaware of his HIV status.

   **Case 2**: a Zimbabwean woman in her thirties was ill for 12 months with weight loss, night sweats and a persistent cough. She was admitted to hospital unable to move or feel her legs. A diagnosis of spinal TB resulting in paraplegia was made. Due to her TB diagnosis she was tested for HIV infection and found to be HIV positive. She was noted to be severely immunosuppressed. She has recovered from TB infection and her HIV is now well-controlled. However, her paraplegia is permanent which means that she is permanently wheelchair-bound requiring a life-long package of care.

   **Case 3**: Zambian lady in her forties and in full-time employment. Her known medical problems included non-insulin dependent diabetes with diabetic eye disease resulting in blindness in one eye. Her health declined over 2 years with multiple visits to her GP and her local hospital. Eventually, after a 3-week inpatient stay for investigation of weight loss and sweats an HIV test was performed and found to be positive. She was transferred to an HIV unit and noted to have a serious viral infection (cytomegalovirus, CMV) in her remaining functioning eye and brain. She required hospitalisation for many months as the treatment for her eye and brain infection was complicated by kidney failure, infections and bone marrow problems. Her HIV
Supplementary Memorandum by Dr Keith Radcliffe, President of British Association for Sexual Health and HIV (BASHH) and Chair of the Joint Specialty Committee (JSC) for Genitourinary Medicine at the Royal College of Physicians (RCP) (HAUK 73)

treatment was started and her HIV infection came under control. She is now registered blind and is not working. Her husband is her main carer.

February 2011
Memorandum by The British HIV Association (BHIVA) (HAUK 53)

1. Monitoring

Please also refer to the evidence submission by the ‘Halve It Campaign’ of which BHIVA is a member.

We wish to emphasise the following points:

i) The quality of HIV surveillance in the UK provided by the Health Protection agency (HPA) is high and internationally recognised. The HPA provides information on the epidemiology of HIV infection across different populations and localities. Reporting of HIV surveillance data is voluntary, but both participation and reporting is high.

ii) Under the proposed public health reforms it is important the quality and extent of the current surveillance provided by the HPA is maintained and enhanced. It is vital sufficient resources are made available, and that fragmentation of surveillance and monitoring systems does not occur.

iii) The development of clinical outcome indicators by the HPA in collaboration with the London specialist commissioning group has been a significant initiative in the monitoring of treatment and care outcomes and will help inform the commissioning of services.

iv) We would welcome the development of a common HIV clinical data set and patient registry for use by HIV treatment centres, to enable better planning, commissioning and monitoring of HIV treatment and care services. A move to electronic patient records and development of HIV specific IT services and programmes would be of benefit in this regard as well as improving individual clinical case management.

2. Prevention

Please also refer to the evidence submission by the ‘Halve It Campaign’ of which BHIVA is a member.

HIV prevention, both primary (preventing new infections) and secondary (preventing significant mortality and morbidity of HIV disease) should be a priority for both NHS and public health services.

2.1 Rationale

The rationale for this includes:

i) The number of people living with HIV infection in the UK continues to increase. As a consequence the total population annual cost of HIV care is projected to rise and is estimated will be between £721 to £758 million by 2013. (1)

ii) It has been estimated that preventing one new HIV infection would save the public purse between £280,000 and £360,000 in direct lifetime health care costs.

iii) Late diagnosis is common and associated with increased mortality and reduced life expectancy. In 2009, 52% of all adults newly diagnosed with HIV infection had a CD4 count at presentation of <350 x 10⁶/l, the level at which starting
antiretroviral therapy (ART) is recommended (2). Data from the UK CHIC research collaboration involving an observational cohort of more than 17,500 HIV positive people, reported that individuals starting ART late and with severe immunosuppression (CD4 count $<200 \times 10^6/l$) have an estimated life expectancy 10 years lower than Individuals who start ART earlier (3).

iv) **On ART the HIV viral load in blood falls to undetectable levels resulting in a marked decrease in infectiousness and risk of onward transmission.** In a meta-analysis of 11 cohorts reporting on over 5,000 discordant heterosexual couples, the risk of HIV transmission to the uninfected partner by treating the infected partner with ART was reduced by 92%, from a transmission rate of 5.46 to 0.46 per 100 person years (4). Other studies have recently reported similar reductions in the risk of transmission. There is more limited observational data in studies of MSM, but similar reductions in transmission with ART is likely to occur.

v) **The number of new diagnoses per year in MSM remains high and has increased over the last 10 years.** It is estimated 83% acquired their infection in the UK and that 1 in 6 within the previous 4-5 months of testing. This suggests that current prevention efforts in this group need to be more effective.

vi) UK acquired HIV infection now accounts for 27% of all new diagnoses in heterosexuals. Even among black Africans, who account for the majority of all new diagnoses in heterosexuals, 13% are estimated to have acquired their infection in the UK (2). However a recent study has suggested this figure may be as high as 25-30% (5).

### 2.2 Response

In response we wish to make the following comments:

i) **Enhanced prevention efforts are urgently required**, particularly amongst MSM but also amongst black Africans and the general population at large. Prevention programmes need to deliver a combination of prevention interventions involving multiple stake holders (including community behavioural interventions, increased testing, health promotion, STI services, condom promotion and provision). There is a need for a national prevention strategy, with national and local leadership.

ii) There is a need for formal evaluation of the effectiveness of prevention programmes to include both outcomes and outputs, to better inform commissioning. We would also welcome the creation of a national HIV prevention research committee to develop and co-ordinate the UK’s strategy for world-class research into HIV prevention.

iii) **Integration of sexual health and HIV treatment services is vital to allow the provision of effective positive prevention and testing programmes.** The proposed new commissioning arrangements for HIV treatment, sexual health and HIV testing services must not result in the fragmentation of these services. As such there needs to be close liaison between the national commissioning board, the local authorities and public health England to ensure integrated HIV and STI services.

iv) **There is an urgent need to reduce the number of people with undiagnosed infection and the number diagnosed in late disease**, through increased testing, allowing individuals to access and start treatment earlier in line with treatment guidelines. This will result in reduced mortality, improved life
expectancy, reduce annual treatment costs and increase opportunities for positive prevention.

3. Testing

Please also see submission by the ‘Halve It campaign; of which BHIVA is a member.

The current testing policies across the UK are inadequate.

3.1 Evidence

This is evidenced by:

i) The number of adults diagnosed with late HIV disease is high. In 2009, 52% of all adults newly diagnosed with HIV infection had a CD4 count at presentation of <350 x 10^6/l, the level at which starting antiretroviral therapy (ART) is recommended (2)

ii) The estimated number of people with undiagnosed HIV infection has not changed significantly over the last 10 years and is about one quarter of all people living with HIV infection (2)

iii) Several studies suggest that many individuals diagnosed late have been seen for health care in both primary and secondary care settings in the 12 months prior to diagnosis suggesting opportunities for earlier diagnosis had been missed.

iv) There has been a significant increase in the number and rate of testing in GUM clinics over the last 10 years which is welcomed. However 80% of all HIV tests occur in GUM clinics, which suggests a need to increase testing in non GUM health care and community settings (2)

v) The number of MSM ever tested has increased but the number undertaking annual tests is low.

BHIVA undertook a national audit of all newly diagnosed patients first seen for care between August to October 2010 at 132 participating clinical centres throughout the UK. Preliminary findings show of the 1112 individuals, 28% had acquired infection since 2008, 54% were diagnosed in GUM clinics and 10% in general practice.

Increasing testing in non GUM settings has been shown to be feasible and acceptable to patients.

3.2 Response

We strongly support the following:

i) The wider implementation of the UK national testing guidelines (2008) (6)

ii) A strategy of universal (opt out) HIV testing of individuals attending specified settings, this means that individuals are offered and recommended a HIV test as part of routine care, but the individual has the option of refusing a test. Published research suggests that uptake is increased where universal routine testing strategies are adopted. This is the current practice in antenatal and GUM clinics with over 95% of pregnant women in the UK accepting a routine antenatal HIV test. Universal
routine testing should be extended to the health care settings and patient populations as recommended in the UK national testing guidelines (2008)

iii) BHIVA welcomes the NICE public health guidance to increase the uptake of HIV testing in MSM and black African communities to reduce undiagnosed HIV infection and prevent transmission.

iv) In the proposed public health reforms it is vitally important that local authorities prioritise local HIV testing programmes in a variety of health care and community settings other than GUM and antenatal clinics and they develop the expertise to both commission and monitor the effectiveness of these programmes in line with the NICE recommendations and guidance. This should apply irrespective of local HIV prevalence. It is important sufficient resources are made available by local authorities for these programmes and that they show strong local leadership.

v) There needs to be increased education and awareness amongst health care professionals other than GUM specialists of HIV testing guidelines, including general practitioners, secondary care medical specialists and non medical health care professionals.

vi) The use of 4th generation HIV diagnostic tests should be standard as this allows for diagnosis of primary HV infection.

4. Treatment

Current HIV treatment and care services in the UK are of a high standard.

Treatment outcomes in the UK are very good and comparable to other European countries. Life expectancy has improved significantly over the last few years, with HIV positive individuals currently starting ART at recommended CD4 counts, having similar projected life expectancy to that of the general population (3)

4.1 Commissioning:

i) There are very good examples of the commissioning process in England particularly in areas of high prevalence such as London, Brighton and Manchester. Pan-London commissioning of HIV treatment and care services has had significant benefits including equity of access to care, reduction in drug procurement costs and effective engagement with both clinicians and patients in the commissioning process. It is important that the national commissioning board imports this expertise and adopts best commissioning practice.

ii) The arrangements for the national commissioning board have yet to be finalised, as such there is uncertainty that they will be effective in commissioning and maintaining quality services across all areas of England

iii) The commissioning of HIV treatment and care services by the national board however does offer potential opportunities and these include: the promotion of service networks with centres for complex care and locally accessible services, ensuring equity of access to quality services in both areas of high and low prevalence, cost reduction with drug procurement programmes and the development of service specifications, quality standards and outcomes and integrated patient pathways.

iv) Clarification concerning the operational framework and procedures of the national commissioning board is needed to determine: how the board will commission services from multiple providers through out England and how they will liaise with public health England, local authorities and GP consortia to ensure integrated
services and patient pathways for all aspects of care. Currently the London SCG commissions services from 23 providers in London alone. How patients are also engaged with the commissioning process also needs to be clarified.

4.2 Provision of care and standards

The model of care for HIV is centred in secondary care specialist centres and historically there has been limited involvement by primary care services. Treatment and care services need to evolve to meet the changing care and services needs of people living with HIV. The rationale for this includes:

- HIV has become long term chronic condition
- The number of people living with HIV and accessing care continues to increase year on year.
- The number living with HIV over the age of 50 years has and will continue to increase.
- Patients living with HIV are of increased risk of non-AIDS co-morbidities such as cardiovascular and renal disease.
- Care of patients with HIV is often complex and requires multidisciplinary care.

We wish the following to be considered:

i) **There needs to be a greater involvement of GP services to include promotion of HIV testing, the prevention and treatment of certain co-morbidities and the provision of primary care.** Patient and professional barriers to the involvement of primary care services need to be addressed.

ii) Development of integrated care pathways between primary care, community services, hospital based specialist services and HIV specialist treatment services is essential to meet the evolving and often complex care needs of people with HIV. Innovative services need to be developed to meet these needs, such as joint clinics within secondary and primary care.

iii) **BHIVA has been responsible for setting best practice guidelines in the UK which are internationally recognised. BHIVA wishes to be involved with the development of national quality standards and outcomes to inform commissioning and provision of integrated HIV treatment and care services.**

iv) Provision of mental health and psychological services is an extremely important aspect of HIV service provision. It is vital there is equity of access, quality standards are developed and integrated mental health services provided.

v) The clinical pathology of HIV disease is difficult, and many infected ill patients have uncertain HIV-related (and often non-HIV-related) processes going on. We need to maximise the clinical information we have on all HIV positive patients, so that future patients can be diagnosed and treated even better. This requires autopsy examinations when patients die, especially when the underlying disease processes are unclear. There should be encouragement of regional pathology expertise in the area of HIV and other infectious diseases to facilitate these examinations. Clinicians should request more consented hospital autopsies. The data from the autopsies should feed into regular clinic-pathological audit and research. Specific examples
where such an approach is vital, in the HIV arena, are brain disease and lymphoproliferative disorders.

4.3 Access to care

i) **We strongly support changes to the overseas regulations to allow access to free treatment and care services for HIV positive migrants who do not have ordinary residency status.** There is public health benefit in terms of cost saving and reduction of HIV transmission. The current situation deters migrants from testing which is not compatible with a national strategy to reduce the number with undiagnosed infection and encourage earlier testing. We do not believe a change in the regulations will encourage health tourism.

4.4 Research

Please also see attached supplementary evidence

i) The UK is a significant player in the overall funding of AIDS research particularly internationally. It devotes a significant amount of its research budget into areas which can be classified as international HIV research. The MRC which is the major funder devotes a very large proportion (one third) of its HIV budget to overseas commitments.

ii) The UK has made significant contributions in more mechanistic, proof-of-principle type studies investigating immune responses to HIV and correlates of protection and these different types of vaccine research (large field efficacy studies versus small mechanistic studies) need to be distinguished. Despite very substantial investment, progress on vaccine development has been frustratingly slow and difficult. By contrast enormous strides have been taken in understanding the virus itself and the immuno-pathology of HIV infection; a substantial contribution has been made in this area by UK scientists. A significant proportion of these have been made within the UK but it is notable that some of the highest profile work in the field has been done by UK scientists working in other countries, notably the USA. Availability of funding is likely to have been an incentive for such researchers to move from the UK.

iii) The other area of quite astonishing progress in the HIV field has been the development of a whole panoply of therapeutic drugs which have transformed the prognosis of those infected with the virus. The UK has made an extremely powerful contribution to this through the co-ordinated activities of centres with large population of HIV-infected patients particularly in London but also Edinburgh, Brighton and Manchester. The role of the MRC Clinical Trials Unit should also be acknowledged in this work.

iv) HIV is a multifaceted condition with biomedical, political and social causes and consequences. This means that research questions frequently cross academic disciplines and intellectual boundaries. Research funding structures in the UK are poorly equipped to deal with this overlap and important HIV related questions remain unfunded. Increasing work on disciplinary and intellectual overlap and collaboration between the various research councils would be useful in taking this forward.
5. Stigma

Please refer to the evidence submission by the ‘Halve It Campaign’ of which BHIVA is a member.

Please refer to the evidence submission by the National AIDS Trust which BHIVA supports.

Stigma remains a significant concern for both HIV prevention and HIV treatment and care services. Stigma remains a barrier to HIV testing and access to treatment services and continues to be a significant barrier to disclosure. Reduction in stigma is an important priority and BHIVA supports measures which address and reduce stigma.

References

2. HIV infection in the United Kingdom 2010 report: Health protection Agency
3. May M, Gompels M, Sabin C for the UK Collaborative HIV Cohort study. Impact of late diagnosis and treatment of HIV-1 infected individuals in a large UK Cohort. 10TH Inter Congress on drug therapy in HIV infection, Glasgow November 2010 Abs O27
6. UK National testing guidelines 2008: British HIV Association, British Association of Sexual Health and HIV, British Infection Society

This written evidence is submitted on behalf of the British HIV Association by Dr Ian Williams, the current Chair of the Association.

21 February 2011
I am writing on behalf of the General Practitioners Committee of the BMA to offer some general comments on the key issues identified by your Committee from the perspective of general practice. Dr Bill Beeby will be able to elaborate on these points during his oral evidence session on 29 March. We do not have any particular expertise in the field of HIV/AIDS, so the focus of these comments is largely on the potential impact of the reforms to the NHS outlined in the current Health and Social Care Bill, and in particular, how clinician-led commissioning might affect the way in which HIV/AIDS is dealt with in primary care. The impact of public health reforms is also briefly considered.

In relation to the possible impact of the proposed public health/commissioning reforms, it is clear that currently, the majority of HIV tests are not provided through general practice but rather through NHS clinics and that often, the GP does not have a central role in the treatment of HIV. The reasons for this have been rehearsed before. GPs do, however, play a key role in managing patients with long-term and chronic conditions, partly through the Quality and Outcomes Framework and the structuring of the rest of the GP contract. They are in a strong position to understand the needs of their own patients and mobilise health resources in support of these. Inevitably, there is some local variation in the way in which this is approached.

With the advent of commissioning consortia, there may be an opportunity to commission these services more effectively; for instance, clinicians should be involved in setting out specifications and standards for services that will achieve the clinical and other outcomes sought. In theory, successful commissioning should improve services in HIV/AIDS by: involving an appropriate range of people in establishing what is needed; assessing the value of different interventions; and developing care pathways that clearly support an improvement in patient outcomes. This, of course, depends on the appropriate resources being available. There is considerable emphasis in the proposed legislation on the importance of patient involvement in this process, and we strongly support this.

There has been some suggestion that patients in a practice should routinely be asked about HIV and potentially offered testing. We do not feel this is entirely practicable, partly due to the time constraints within GP appointments. The question also arises as to where this testing should take place, and more importantly, what support would be available when the result was known. Many GPs do not have appropriate training to undertake this sort of activity. As with other conditions, there would need to be a consistent national approach with a clearly defined, evidence-based process, and appropriate resources both for the GP and the patient. The commissioning of such a service, as with other specialties and care pathways, will in future be done by commissioning consortia but, as outlined below, significant additional advice would be needed.

Questions have also been raised about the reasons why potentially HIV positive patients do not generally choose to investigate this through their GP. Concerns (real or imagined) about the confidentiality of information in general practice are thought to be a factor, so working to address these concerns may make it more likely that the focus of initial diagnosis would shift to primary care.

Published and emerging evidence from the National Institute for Health and Clinical Excellence (NICE) also strengthens the case for whole system approaches to tackling issues
such as this in a coherent and structured fashion. In some areas, there is already evidence of effective ‘joined up’ commissioning across a geographic population to deliver a structured clinical pathway, delivering interventions from prevention to tier four treatment in a cost-effective manner. The coverage of individual consortia may actually inhibit that kind of supra-consortia development, though in many areas it is not yet clear what populations will be covered by consortia.

GP s already play a role in delivering public health improvements although there are external factors that constrain this aspect of their work (as previously mentioned, limitations on consultation times and the difficulty, in some areas, of finding appropriate support for patients). In the new world of clinician-led commissioning, improvements in primary care in relation to HIV/AIDS are most likely to come from the commissioning consortia themselves, working with public health colleagues to ensure that their commissioning decisions are evidence-based and properly resourced. This will require appropriate input from public health doctors in the commissioning process and Primary Care Trust clusters should now be considering how best to achieve that. This will also require adequate numbers of public health specialists and ensuring that they are working within an appropriate framework.

In terms of the proposed reorganisation of public health, there is real concern across the public health community that the future structure of the public health service envisioned by the Government, by sending different elements of public health into different organisations, will potentially lead to fragmentation and this can only be detrimental to health protection, health improvement, and identification and monitoring of conditions generally. Unfortunately there is inadequate reference to public health support for commissioning in the Health White Papers that have been published on this issue. The BMA responses to these consultations reflect our concerns about this.

Furthermore, the proposed abolition of the Health Protection Agency (HPA) may also impact on the effectiveness of national monitoring and it is vital that these functions are continued by whatever body replaces the HPA.

I hope these general comments are helpful but would be happy to provide any further information, or respond to specific additional questions.

25 March 2011
Thank you for the opportunity for Dr Bill Beeby to appear as a witness for the Committee’s general practice session on 29 March. I hope that you found his contribution useful.

We recall from the session that the Committee requested further information on the Public Health Outcomes Framework. The Committee noted that only one indicator related to HIV – the proportion of persons presenting with HIV at a late stage of infection – and was interested in our thoughts on whether this will act as a driver to improve HIV services and whether this single indicator is sufficient.

Late diagnosis is the single most important factor associated with HIV-related morbidity and mortality in the UK. Late diagnosis is defined as a CD4 count of less than 350 mm$^3$ within three months of diagnosis. The sooner a person with HIV is diagnosed, the sooner they can benefit from effective treatment when indicated and make any behavioural changes to prevent further HIV transmission.

Gathering information is therefore of central importance and this currently is obtained by the Health Protection Agency (HPA), but in future would be through local authorities, ‘national areas’, and ‘output numbers’ (presumably from hospital statistics). Our concerns about the impact of the proposed abolition of the HPA was raised in our previous submission to the Committee – it appears to us that these future proposals do suggest that if national prevalence is to be known, robust mechanisms would need to be in place to ensure that local figures were still collected in some way at national level.

Furthermore, we believe that it does seem inadequate that HIV/AIDS is only mentioned once in the Public Health Outcomes Framework and this only in the context of preventing morbidity and mortality of people at a late stage of infection. There is nothing to address prevention at an earlier stage, nor anything about the role primary care can potentially play.

I hope that you find this useful.

13 June 2011
Memorandum by the Sexual Health/HIV Faculty of the British Psychological Society (HAUK 12)

Introduction

This response to the call by the Select Committee of the House of Lords for evidence was compiled by Dr Tomás Campbell, Consultant Clinical Psychologist on behalf of the Sexual Health/HIV Faculty of the British Psychological Society.

The response contains collated statements from:

Dr Stuart Gibson, Clinical Psychologist and Chair, Sexual Health/HIV Faculty of the British Psychological Society.

Dr Alexander Margetts, Clinical Psychologist, Chelsea & Westminster Hospital, London

Dr Louise Mozo Dutton, Clinical Psychologist, North Manchester General Hospital, Manchester

Dr Tomás Campbell, Consultant Clinical Psychologist, Head of Clinical Health Psychology, East London foundation Trust, London

What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?

From a psychological understanding there are at least three forms of stigma; there is enacted stigma where negative group/community/societal beliefs and given some form of concrete expression. This may take the form of expressing disparaging opinions about working with, sharing food with or sharing space with people with HIV. Courtesy stigma occurs when the stigma about a disease is transmitted to family members, associates or those health care workers working with the targeted group. Internalised stigma occurs when an affected individual is aware of, and believes the negative associations of the disease and feels ashamed of themselves. Commonly, this results in secrecy, lack of engagement in services, difficulty in adhering to anti-retroviral medication and disclosure of status to others.

Unfortunately it is society’s fear and condemnation of HIV that contributes to its unremitting spread across the world. Many people who contract HIV will feel shame and rejection because it is a disease that is often associated with certain activities that many people don’t approve of. The fear of rejection, condemnation and even punishment can be corrosive and hurtful to those who already feel marginalised. It is under these circumstances when individuals may begin to engage in risky activities as a way of managing or coping with their emotional pain. They may begin to drink alcohol excessively, misuse recreational drugs and/or engage in unprotected sex as a means of escaping from their pain. And it is these kinds of risky activities that contribute to the onward transmission of HIV.

From clinical experience, the effect of stigma can impact upon individuals in a variety of ways but most notably, it can affect a person’s confidence to disclose their HIV status to others. Fear relating to how well another person might react to the information that a person is
HIV positive or what they may do with that information once disclosed can mean that disclosure is anything but a simple act, but rather a process and one that on each occasion needs careful consideration.

Feeling unable to disclose can carry implications for social support. There have been a number of studies that have highlighted the importance of social support for mental health but unfortunately, feeling unable to disclose your status to those important to you can often leave a person feeling alone and isolated. Disclosure of a positive status also carries with it the potential to reveal other information that a person may prefer to keep secret or that may give rise to double stigma that may also impact upon the level of support received. For example, it may disclose a person’s sexuality, an extra marital affair, the use substances or that a person’s parents are also positive. With the later of these examples, disclosure can become doubly complicated in that whose information is it to disclose? The young person’s or the adults?

Disclosure can also be difficult within the work place. Individuals living with HIV often need to attend regular health care appointments. Often and depending upon the work a person is employed to do, it can be important that disclosure occurs at least to a senior staff member. Unfortunately, we are aware of many clients who have disclosed to find their information is no longer private and work colleagues changed in the way they approached them.

Disclosure within intimate relationships is particularly difficult and a person can often struggle to know when might be a good time as well as how best to do it. Worries around fear of rejection and again how the person might use this information can make this difficult. Moreover, recent prosecutions around HIV transmissions can add to this fear. Fears around disclosure to potential sexual partner’s also carries implications for addressing HIV as a public health problem. For example, an individual who struggles to disclose may also struggle to negotiate safe sex.

For a large number of people, disclosure is often a surprisingly positive experience. Unfortunately, occasions still occur where people have reacted angrily to the information, been unsupportive or informed others of the person’s status. Health professionals are not excluded from this group and again, several clients have reported unhelpful and at times discriminatory behaviour that has occurred once a person’s status has become known.

One of the contributors to this statement (TC) has studied the impact of stigma in HIV+ African people on emotional wellbeing. The study was conducted with a group of African HIV+ people with Lipodystrophy (LDS: a collection of body fat changes as a result of anti-retroviral medication) and a control group of HIV+ African people who did not have LDS. Both groups received measures of anxiety, depression and stigma. The results indicated that contrary to the studies’ hypotheses that those participants with LDS would feel MORE stigmatised because they carry the embodied effects of HIV treatment with them and these side effects are well known in African communities, stigma was experienced at high levels by ALL participants regardless of whether or not they had visible effects of HIV treatment.

These results indicate that HIV+ Africans in this study feel highly stigmatised by their status irrespective of how well controlled their HIV status is. These results are available to the committee if required.
Where are problems of stigmatisation most acute?

Communities that are already marginalised feel the impact of stigmatisation most acutely. In the UK, immigrants from regions of the world already ravaged by HIV and men who have sex with men are two such groups. However that is not to say that anyone with HIV can feel the condemnation and rejection by others. For example a white heterosexual man with HIV can become very isolated and withdrawn from others out of fears of rejection and condemnation. And it is these conditions that place an individual at risk for not looking after themselves and others.

African people report that there are high levels of stigmatising behaviours in their communities. Pastors preach that AIDS (HIV and AIDS are often not distinguished) is punishment from God and can be cured. We have direct experience of working with people who have stopped their anti-retroviral medication because they have been “cured”. Obviously, this is not the case but indicates how stigmatised they have felt with their HIV status and the relief they have felt to be “forgiven”.

Young people with HIV may often have a double whammy of stigma. They have inherited and witnessed a context in which they have been told to keep their HIV status secret. Their parents do not talk about HIV to them because they are afraid that the child might disclose to the community or to other family members (TC has written about the effects of this on they way in which young HIV+ people cope with their status and this evidence is available on request). Young people grow up and develop in a context in which secrecy affects the way in which they become aware of their sexual feelings. They emerge afraid that they will never be able to have “normal” sexual relationships because they will have to disclose their status to their partner and run the risk of not only being rejected but that the secret will become common knowledge.

From a clinical perspective we feel that many of the mental health problems experienced by HIV+ people are underpinned by a fear of if not an experience of enacted stigma. People with HIV have high rates of mental health problems in comparison with the rest of the population and to some extent this reflects the stigma attached to their illness which makes it more difficult to cope with. People have expressed to that they would rather have cancer than HIV because at least one can talk about having cancer and expect a level of sympathy and understanding from others.

What measures are currently taken to tackle HIV stigmatisation? What more should be done?

Protection from discrimination for people living with HIV has been has been written into various legislation over the past decade in the UK. No doubt this has been a positive development for human rights. However it is difficult to say how much impact it has had for an HIV-positive individual who fears rejection and condemnation from family members and friends. Tackling this more personal form of stigmatisation is more difficult as it can be more insidious and subtle. Public health campaigns for treating people with HIV with more respect, acceptance and understanding might be a good place to start. This may be considered an obvious recommendation for some but it is still needed.
Twenty years ago there was a considerable effort put into HIV awareness training and education in the health and social care sectors. However this has become almost nonexistent today despite the fact that many, if not most, of these people are no longer working. Therefore a renewed effort for training and education is also warranted.

Angry or fearful reactions often appear to relate to worries around the threat of onward transmission either to themselves or to important others (e.g. their children). The public awareness campaign of the 1990’s particularly the image of the falling tombstone continues to stay with people and many remain unaware of the advances in HIV medication, still perceiving it as a death sentence. We wonder whether a large scale public health initiative might be helpful, one that aims to provide up to date information about HIV, how it can be transmitted, how it can be prevented, what’s available for people who are positive as well as information about where to access support if needed.

At a more individual clinical level it is worth considering building an anti-stigma component into every mental health intervention. This might take the form of explicitly asking the extent to which an HIV+ individual feels stigmatised, the form they feel it takes in their lives and the impact they consider it has had on their mental health, relationships and family functioning. TC has had some experience of running an anti-stigma intervention with a group of African HIV+ parents modelled on a published intervention designed for people with long term mental health problems. The response was moving. Participants reported that they had never been able to express their feelings of being stigmatised previously. The intervention helped them to focus on the forms stigma had taken in their individual lives and the strategies they might be able to employ to more effectively cope with such situations in the future.

February 2011
Supplementary Memorandum by Dr Stuart Gibson, Chair, Faculty for HIV & Sexual Health, British Psychological Society (HAUK 90)

1. We have heard evidence that “some very good things” have been achieved within HIV treatment in recent years, and that care must be taken to maintain them in a time of extensive reform. What elements of existing HIV treatment and care do you think most need to be protected?

As a psychologist, I would say that one thing that needs to be maintained is easy and quick access to specialised services, such as HIV mental health services. We all know how depression and other psychological problems can place people living with HIV at risk for self-neglect. This self neglect includes failing to attend clinic appointments and stopping anti-retroviral medications. It can also include substance misuse and other risky activities, including unsafe sexual activity. There is no point in providing access to effective medical treatment if we don’t address and support the psychological and social concerns that people living with HIV have.

The Faculty for HIV & Sexual Health in the British Psychological Society is working in conjunction with BHIVA to draft some standards for psychological support for adults living with HIV. One of the drivers for such a big task is the recognition that access to effective and appropriate mental health services is patchy across the UK. We fear this is only going to get worse in the near future. One of the things that we are calling for are some basic competencies that mental health providers should have in working in this highly specialised field. One of these competencies includes an awareness of the diversity of needs that people living with HIV may have - especially men who have sex with men, those from minority ethnic communities, women and substance misusers. Another competency includes an understanding of HIV disease, including disease progression, how symptoms impact on daily living, and the complications of treatment regimens. Another competency is an understanding of issues pertaining to confidentiality and disclosure, which includes the ethical and legal issues relating to HIV transmission. There are more. But the point I’m trying to make is that this remains a highly specialised area which requires considerable training and support for effective and appropriate care.

I can appreciate and I do support the proposal to shift many aspects of treatment and care of healthy and stable HIV-positive patients to general services such as GP surgeries. However I am worried about similar proposals to dismantle and de-commission other specialised (expensive?) services such as HIV mental health teams in the hope that it can be done just as well in general primary and secondary mental health care sectors. If this happens, they will need substantial education, training and support to provide such care. The very long waiting times to access psychological therapy in the general community could also place many HIV-positive people who are struggling with depression or anxiety at risk.
2. What can health professionals do to help their HIV-positive patients understand and reduce their risk of infecting others?

Developing a safe and trusting therapeutic relationship with an HIV-positive patient is absolutely necessary. It is very important for health care providers to convey an accepting and non-judgemental stance towards their patients when discussing potentially awkward and uncomfortable topics, such as self-disclosure of HIV to sexual partners. In such discussions, patients need to explore the potential barriers of self-disclosure and/or condom use. It is one thing to inform clients that they are obliged to tell their sexual partners about their HIV status and that they should use condoms all of the time. However it requires some sensitivity and skill to explore why this doesn't always happen. In the end, I'm not sure how effective a new locum medical doctor in a GP surgery will be in a 8 minute consultation with a new patient. I know I may be exaggerating my point in this example. But what I am trying to convey is that this type of work requires patience, with multiple conversations with patients about safer sex and disclosure.

3. Given the continuing spread of HIV, do you believe that the right balance is being struck in the work that you do between treatment and prevention?

This is such a BIG question!

But I'll try my best to address it succinctly. In my opinion effective and appropriate treatment includes some attention and time dedicated to education and discussing issues such as safer sex, disclosure and other prevention topics. However this means that these ‘treatment sessions’ or clinic visits will take some time. The health care provider also needs to assess and review a patient’s psychological and social functioning. What I am trying to say is that effective treatment in the HIV clinic involves more than looking up blood test results and checking for drug interactions should medications need to be changed. Identifying, acknowledging and addressing the psychological and social needs of patients will help them to look after themselves and others (and help prevent onwards transmission of HIV).

4. Migrants who do not have the right to remain in UK have to be charged for their HIV treatment and care, yet they can be treated for free for other infectious diseases such as TB. What impact do these rules have on efforts to tackle HIV, from both an individual and public health point of view?

My understanding is that many HIV positive migrants who do not have the right to remain in the UK are still receiving care in most outpatient settings across the country. I encourage the Committee to read the following article by aidsmap on this issue:

http://www.aidsmapcom/Secondary-care/page/1503058/

13 May 2011
1 About Brook

1.1 Brook is the country’s leading sexual health organisation for young people under 25 offering young women and men free and confidential sexual health services and advice from a network of Centres throughout the UK and Jersey. Brook has over 45 years’ experience of providing services through specially trained doctors, nurses, counsellors, and outreach and education workers to over 260,000 young people each year.

2 Introduction

2.1 Brook believes that young people need to be well informed about the risks of sexually transmitted infections, including HIV, so that when they choose to become sexually active they are able to protect their sexual health.

2.2 The continuing increase in diagnoses of sexually transmitted infections show that there is clearly a need to improve education and prevention programmes in order to reduce sexually transmitted infections amongst young people. Around 12% of annual HIV diagnoses in the UK are in young people under the age of 25.52

2.3 Brook believes that improving sex and relationships education by making it a statutory part of the national curriculum and providing services that are accessible, well publicised and that young people are reassured are confidential are the keys to improving young people’s sexual health.

2.4 Brook believes that sexual health information, education and services need to be relevant to people’s everyday experience of sex and relationships. Messages need to be integrated to link unwanted pregnancy, STIs and HIV together and put them in the context of young people’s lives.

3 Sex and relationships education

3.1 Brook believes that the most effective way to ensure that young people are enabled to make informed choices about their sexual health and protect themselves from sexually transmitted infections, including HIV, is to make Sex and Relationships Education a statutory entitlement for all children within the PSHE curriculum.

3.2 For too long children and young people have been saying that the sex education they receive is too little, too late and too biological because schools are only required to teach what is in the science curriculum. They report too little discussion of social and emotional issues, including real life dilemmas, and that what little information they are given about sexually transmitted infections is not relevant to their lives. A survey of almost 22,000 children and young people53 found that 40% of respondents thought their SRE was either

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52 Health Protection Agency Centre for Infections, Health Protection Scotland and UCL Institute of Child Health. Unpublished HIV Diagnoses Surveillance Tables 01:2010 Table 6

53 UK Youth Parliament. SRE – Are you getting it?, June 2007
poor or very poor and a further 33% thought it was average. 43% said they had not been taught about personal relationships at school.

3.3 There have been welcome improvements in SRE but consistency and quality would be further improved by a statutory curriculum instead of leaving it to the discretion of individual schools to define within their SRE policy what, if anything, is taught in addition to the requirements of the science curriculum.

3.4 A parliamentary briefing written by Brook’s team of young campaign volunteers is attached with this evidence to give young people’s perspective on why SRE should be made a statutory part of the curriculum.

3.5 SRE should be age-appropriate and start by teaching children and young people about friendships, feelings and boundaries, names of the body parts and preparing them for puberty. In secondary school it teaches children and young people about relationships, as well as the biological aspects of sex, and the links with alcohol, risk-taking and personal safety.

3.6 Any curriculum should not just focus on information-giving but should help children and young people to develop the skills to act on the information they have been given and help them clarify their values and attitudes. Children and young people need to be specifically helped to develop the ability to recognise and resist pressure so that they can delay intercourse until they are ready for it; to develop healthy relationships; and to negotiate and practise safer sex.

3.7 Young people themselves say that sex education at school must be bolder in approach. The link between unprotected sex and the consequences of both pregnancy and sexually transmitted infections must be strongly highlighted and STIs should feature more prominently. Pupils should be informed about local young people’s services, including their addresses and telephone numbers. Homosexuality should be discussed, rather than ‘swept under the carpet’ in an effort to tackle discrimination.54

3.8 The needs of young people who attend school irregularly or who are excluded from schools should not be forgotten. It is all too easy for these particularly vulnerable young people to miss out on SRE altogether. Brook has found that outreach education work in youth and community centres, peer education and detached work are all effective methods of reaching young people. Youth workers, with appropriate training, would be in an ideal position to deliver sex and relationships education to young people who may not have received education in mainstream settings. SRE must also be delivered within Pupil Referral Units.

3.9 There should be strong links between schools and clinical services. International research has shown that good and comprehensive sex education combined with easy access to contraceptive services leads young people to delay first intercourse and results in them being more likely to use contraception when they do become sexually active.55, 56

54 Brook on behalf of the Department of Health, Consultation with Young People on the National Strategy for Sexual Health and HIV, 2001
55 NHS Centre for Reviews and Dissemination (CRD). Effective Healthcare Bulletin 3 (1) Preventing and reducing the adverse effects of unintended teenage pregnancies, 1997;
4 Clinical and support services

4.1 Young people need easy access to young people friendly sexual health services in order to support them to protect their sexual health.

4.2 We are very concerned that local areas could lose their focus on what has been proved to improve young people’s sexual health as a result of the NHS reorganisation and public sector funding cuts. This could reverse the progress that has been made as a result of the teenage pregnancy and sexual health strategies.

4.3 The drive to make efficiency savings and reduce management costs must not result in disinvestment in sexual health services which are often regarded as easy targets. There is significant evidence in fact that in many areas sexual health services were reduced or even closed when the NHS was under pressure to balance budgets during 2006/07, despite the commitment of substantial additional funding to sexual health at that time. Brook services are already experiencing funding cuts in some areas and our service in Stockton on Tees is under threat of complete closure.

4.4 It is crucial that the provision of separate young people’s contraception and sexual health services continues. Young people need support from easily accessible, well publicised and confidential services in order to make safe, informed choices about their sexual health. We know that young people worry about encountering judgemental attitudes and are concerned that their confidentiality will not be respected in mainstream services.

4.5 Brook believes that clinical and support services should be delivered both in central locations and taken out to young people in community venues that they feel confident using.

4.6 Brook believes it is crucial to provide integrated contraceptive and STI services in the Centre and in community settings to reduce stigma and make services more accessible to young people.

4.7 Young people say that services must be confidential and free, open at times convenient to them, in locations they can easily reach, provided by friendly, non-judgemental staff and well publicised.57

4.8 Young people should be involved in the development and evaluation of services so that services are built around their needs.

4.9 Outreach and education work with marginalised communities and satellite provision in acceptable and easily accessible locations is crucial to engage with groups who find it difficult to use mainstream services.

4.10 The provision of services in schools is welcome, particularly in light of the research evidence which shows that combining sex and relationships education with access to services delays first intercourse and makes young people more likely to use contraception.

57 Brook, Someone with a smile would be your best bet, 1998
when they do become sexually active. However, the needs of young people who are excluded from school or would be reluctant to use services based in schools must not be forgotten. Services must continue to be provided in other locations that they would be comfortable to use.

Appendix 1
we are not just a bunch of statistics
we are real people

Every school should have SRE - and teachers who are trained to teach it properly. Making SRE compulsory will make this happen.

Giving out information about sex, contraception, STIs and relationships is not going to promote sexual activity. It simply allows us to make smart decisions and handle difficult situations with confidence & knowledge. It's about making decisions based on the right reasons—and knowing what these reasons look like.

VOTE FOR COMPULSORY SRE
... encourage others to do the same

The sex education we do get isn't enough, and is too late. We are missing out on learning about real life, emotions and relationships - Science lessons are science lessons - and will never give us what we need when we come face to face with real situations.

When going through life, no one can tell where it's going to go. Who you fall in love with, what experiences you'll have, and what issues you may have to face. But knowing where to go for advice makes us feel safe and in control. That's why we think every young person should be signposted by their school/college on where their local sexual health clinic is. Making SRE compulsory will give schools a platform for this to happen.

February 2011
I Introduction

1.1 As Lead Commissioner for HIV services in South London I feel I am well placed to make this submission to respond to the following questions of the select committee:

- How could prevention initiatives be better delivered and evaluated?
- How can the NHS best commission and deliver HIV treatment?

1.2 In what follows I show how prevention and treatment can be better delivered and evaluated and how good commissioning practice can deliver HIV treatment. The good commissioning practice should be maintained and rolled out and the bad should be reviewed and reformed.

1.3 To respond to these questions I will compare and contrast the results of two cross-London programmes running for the last three years, which involved new commissioning models and initiatives intended to modernise the responses to the HIV/AIDS epidemic:

- The South London HIV Partnership (SLHP), is a programme of integrated community services for people with HIV, intended to complement and add value to their clinical treatment;
- The Pan London HIV Prevention Programme (PLHPP) combines three separate strands of work to deliver HIV prevention across the whole of London to African communities and to gay men, and to deliver treatments information to people with HIV.

1.4 When commissioners designed these new programmes in 2006/07 the explicitly stated key drivers of this modernisation were:

- concern about increasing incidence and prevalence of HIV
- value for money with increased efficiencies and reduced duplication
- a shift from historically contingent service provision towards outcome-based commissioning and delivery
- service design based on needs assessment and best practice identified in the scientific literature
- a shift of emphasis from broadcast media services, towards interactive services, intended to achieve relevant and appropriate behaviour change with those individuals most at risk
- a robust approach to monitoring and evaluation, with the development of robust datasets of clients’ needs and the outcomes achieved for them
- laying the foundations for tariffs and payment by results.

1.5 The select committee have rightly and repeatedly raised the issue of what evaluation is available of the outcomes of programmes. This submission hopes to directly answer that question. Both of these programmes have commissioned independent monitoring and evaluation as an integral element from the onset and delivered a
series of evaluation reports which can be made available to support this summary paper.

1.6 I believe the learning from the evaluation of these programmes is particularly relevant and transferable in reforming the national response to HIV and AIDS for a number of reasons. Both models

- bring together large numbers of commissioners to develop cross-cutting efficiencies and economies of scale
- set out to modernise services
- aim for a clear focus on outcomes and value for money
- are intended to serve a large proportion of the populations most at risk: the remit of the SLHP covers approximately a third of people diagnosed with HIV in the UK; the PLHPP covering the whole of London, responds to more than half of the incidence and prevalence in the UK epidemic.
- include independent monitoring and evaluation from the start.

2 Comparison of London regional programmes

2.1 The key features of the SLHP are:

- a model of service provision for people with HIV which jointly addresses both their health and social care needs
- joint commissioning by PCTs and Local Authorities across South London
- an outcomes focused commissioning model
- 7 core services with an integrated data collection network
- an annual budget of approximately £1.4 million.

2.2 The key features of the PLHPP are:

- 3 strands of service provision covering: HIV prevention for African communities, HIV prevention for gay men and Treatment information for people with HIV
- collaborative commissioning across all 33 PCTs in London
- 18 workstreams with separate data collection by each workstream
- an annual budget of over £2.5 million.

2.3 Both programmes have had a significant number of changes in personnel in commissioners and providers over the last three years. One has largely achieved its original vision, whilst the other has not.

2.4 The following table summarises the most important similarities and differences between the governance, planning and implementation of the two programmes, which explain this differential performance.
### Similarities

| A formal tendering process and a 3 year commissioning cycle. | ▪ SLHP has a lead commissioning function, clearly defined governance, a performance management framework and clear accountability arrangements  
▪ PLHPP does not. |
| Both are collaborative commissioning programmes | ▪ SLHP has used the evidence from its programme to take informed commissioning decisions e.g. decommissioning, retendering and new service development.  
▪ By contrast although robust data has been available within the PLHPP this has not been used to make commissioning decisions |
| In the absence of clear national direction both programmes are directed by local needs and priorities | ▪ SLHPP developed detailed and comprehensive Commissioning Intentions and Service Specifications in advance of launching the programme, which set out the rationale for the reconfiguration of services (with explicit linkage to needs assessment, and literature and policy review) and specified each provider’s roles and quality standards in advance.  
▪ The PLHPP did not. |
| Both aim to address the modernisation of HIV services | ▪ SLHP have developed and tested care pathways in South London and there is clear evidence of purposeful joint working.  
▪ This has not happen in the PLHPP. |
| Change management was needed in both programmes of Third Sector providers | ▪ SLHP had a formal 3-month start up process and devoted significant resources to change management  
▪ This did not happen in the PLHPP |
| Both programmes are committed to integral evaluation of outcomes achieved for clients and impact on populations | ▪ SLHP has developed agreed data sets to measure outputs and outcomes (pre and post measures) and can demonstrate per capita costs and value for money.  
▪ By contrast PLHPP cannot, because, although it has defined data sets to measure outputs and outcomes, in most cases there is no evidence to suggest that this data has been collected diligently across the programme. |
| Both programmes aspired to interact with large numbers of clients in order to demonstrate a significant impact on their target populations | ▪ Towards a third of people with HIV resident in South London have already been registered as clients on the SLHP data network. Independently collected client satisfaction data shows high ratings for SLHP services and client needs met in approximately 85% of cases.  
▪ By contrast there is limited output as well as outcomes data for the PLHPP and no sense of the reach of services to the client groups most in need. |
| Both programmes are accountable to a large number of stakeholders | ▪ SLHP has developed systematic communications and stakeholder engagement, including formal events and one annual report completed and one almost in press. |
3 A summary of the evaluation of the PLHPP

3.1 This section presents shortened extracts from the executive summary of the final Evaluation Report on the Pan London HIV Prevention Programme.

3.2 The brief for this final PLHPP report was to present a literature review of new prevention methodologies, lessons learnt from the evaluation, an analysis of successes and challenges within and across initiatives, and a recommendation of which current or new prevention methodologies merit further support through future commissioning.

3.3 Key learning points from the brief HIV prevention literature review are:

- There is good evidence for interactive and assessment-based project and programme methodologies.
- There is no evidence that literature review has informed the construction of the current programme or of the methods used by most of the prevention workstreams (as opposed to the treatment information workstreams).
- The literature review does not support a number of key assumptions that constrained the methodological approaches of workstreams.

3.4 Key learning points about the programme as a whole are:

- Original Commissioning Intentions were well aligned with world class commissioning and the scientific literature. Revised Commissioning Intentions were an incomplete and internally inconsistent amalgam.
- The Revised Intentions joined three disparate types of work (African and gay men’s HIV prevention and treatment information) without any rationale for doing so.
- The tendering framework and processes were incomplete and inconsistent.
- There was insufficient provision for change management.
- Development time for start up never occurred, with the result that each individual workstream started from a different place and the programme became operational before there was a shared understanding of purpose.
- Throughout the life of the programme, governance and decision-making was unsystematic, contradictory, and lacked clarity.
- Standard programme management principles were not applied, and as a result, there was little understanding or agreement of the purposes of the programme and of individual workstreams’ roles.
- Standard performance management principles were not implemented.
- Recovery planning failed as a result of the issues outlined above.
- Funding for this programme is unlikely to be sustainable without a fundamental shift to a focus on the target populations’ needs, methodological rigour, and outcomes.
3.5 In relation to the performance of individual workstreams of the PLHPP:

- 11 workstreams red-flagged after 18 months merit no further investment.
- 4 amber-flagged workstreams require fundamental re-structuring.
- 2 green-flagged workstreams merit continued commissioning.
- Because output-delivery by most workstreams was substantially less than contracted, programme attention was focused on this underperformance at the expense of addressing shortcomings in project planning or demonstrating and achieving outcomes and impact.
- With one or two exceptions most prevention workstreams were unable to articulate a clear theory of action explaining how what they were doing would lead to HIV prevention. The assumption that providers “knew best” by virtue of their long experience in the field was often articulated. However, standard project planning and quality assurance systems were largely absent or token in most of the HIV prevention workstreams, and overall there was little evidence of quality or capability in the methods used in practice.
- Because of the disconnect between custom and practice in HIV prevention and the scientific literature, quality control measures need to be integrated into every level of commissioning of the new prevention programmes.
- By contrast, the treatments information workstreams were able to articulate a theory of action, and demonstrate effective project planning and quality assurance, which contributed to their higher level of performance.

3.6 Overall, there is little compelling evidence that the present construction of the PLHPP is in the main positively contributing to HIV prevention for gay and bisexual men or African Communities. As such, commissioners might wish to carefully consider the appropriateness of “rolling over” the programme for a further year.

3.7 Because of the disconnect between custom and practice in HIV prevention and the scientific literature, quality control measures need to be integrated into every level of commissioning of the new prevention programmes covering: an explicit Theory of Action detailing how the programme will achieve HIV prevention outcomes; behaviour-change as the benchmark used to design and evaluate interventions; segmentation of target audiences; pre-testing of proposed intervention elements; good care pathways to and from clinical services; ‘media-industry standard’ best practice to monitor the reach, impact and effectiveness of publications; integral and ongoing evaluative research to test effectiveness and to make recommendations for filling gaps and changing methods and/or advice as appropriate; and a clear framework for contract monitoring to support a Monitoring & Evaluation provider to be able to make constructive but challenging observations and criticisms.

3.8 With this in mind it seems that there might be two not entirely mutually exclusive options for the next year:

- To decommission PLHPP and use some of these resources to undertake a needs assessment in relation to gay & bisexual men and African communities to establish the bedrock of future service provision. This might occur in parallel with a revisit of the original Commissioning Intentions so that the needs assessments and the corresponding vision, principles and structures are set out in advance of future tendering processes.
• Pilot a much reduced targeted programme using the original Commissioning Intentions and involving current “green flagged” workstreams to provide current services and develop capacity to innovate and bid for some of the essential services outlined in the original Commissioning Intentions. Commissioners might decide to incorporate “amber flagged” workstreams provided they evidence the significant and demonstrable restructuring required as outlined in M & E reports.

4 A summary of the evaluation of the SLHP

4.1 By contrast, I conclude with some shortened extracts from The Bigger Picture, the first annual report of the SLHP, published and launched at a national conference in 2010. This report provides evidence about approaches to commissioning and provision of HIV services that need to be maintained and rolled out.

4.2 The South London HIV Partnership is managed by a lead commissioning function from NHS Croydon and a Commissioning Executive, with representatives from all funding organisations from the NHS and Local Authorities in South London. Funders have committed in principle to extend the partnership in its current format to 2012, extending the original commissioning intentions from a 3-year to a 5-year cycle.

4.3 The is a collaborative commissioning arrangement to complement clinical services delivering health and social care services for people living with HIV in South London. It is a partnership of third-sector HIV provider organisations, private sector companies and both NHS and local authority commissioners.

4.4 The partnership carefully structured with five core services to complement rather than duplicate clinical services:

• First Point which assesses people with HIV, helps them understand what is available, refers or signposts them to all relevant services, and tracks their outcomes, stepping in to assist where there are problems in access.

• Advice and Advocacy which provides information, advice and support about housing, immigration, finance, employment, discrimination, and benefits.

• Counselling for individuals and couples to manage the emotional effects of living with HIV.

• Peer support which provides a place for individuals to meet other people with HIV, share experiences and build networks of support.

• HIV Health Support Service designed to complement the work of healthcare teams by helping clients increase their level of health and treatments knowledge, thus strengthening self management, supporting adherence, and developing expert patients.

4.5 The Partnership also runs a monitoring, verification and evaluation workstream, a data network, and a strategic support function.

4.6 But services could not be provided without the involvement of NHS clinics and healthcare teams; and community-based nurses; support from statutory and social services including asylum and immigration services; as well as statutory and non-governmental agencies outside the partnership, together enabling us to truly see the bigger picture for service users.
4.7 As commissioners we put a lot of work into research processes before we even started developing invitations to tender. We did as much as we could to research trends in outcome-based commissioning, in mapping potential provider organisations and in consulting with service users (and people living with HIV who were not using services) to find out why they were or were not using existing services.

4.8 Even before that, because a large and disparate group of people were coming together to commission jointly in a way that had not happened before, we offered strategic support to confirm what we were agreeing to commission and to help us work well together as commissioners. We did not underestimate the work that just setting up a partnership was going to take, from a commissioning perspective.

4.9 We also knew, before we issued invitations to tender, that as a disparate group of commissioners we needed to be of one mind before we went out to the market. It felt like a lot of work before we even had a single service commissioned but this advance agreement saved time and money and eliminated significant amounts of conflict that could have tainted the Partnership’s early days.

4.10 Once we were ready with our new service model and were clear what overarching outcomes we wanted to achieve, then putting the original service specifications to work was our first task. Issuing our service specifications was a fairly standard process but we did feel better prepared for the difficult task of assessing bids and inviting potential providers to interview because we had planned right through this process, not just up to it. This needed a combination of intense follow through and doggedness in pursuing results through to their conclusion which takes a tremendous amount of focus and persistence but brought us far better results. Knowing and understanding your market adds significant value to the tendering process.

17 February 2011
Memorandum by The Children’s HIV Association (CHIVA) for the UK and Ireland (HAUK 10)

Endorsed by: The National Children’s Bureau and the British HIV Association

Authors: Magda Conway, CHIVA Manager and Marthe Le Prevoste, CHIVA Health Lead

PREVENTION

1. We are deeply concerned about the lack of provision of infant formula milk to prevent Mother-To-Child Transmission (MTCT) of HIV, where the mother has no recourse to public funds.

2. The British HIV Association (BHIVA) and the Children’s HIV Association (CHIVA) guidelines for the management of HIV infection in pregnant women (2008) stipulate the following interventions in reducing/preventing MTCT:
   - To stabilise maternal viral load to undetectable by specialist HIV services
   - To effectively manage vaginal delivery or caesarean section
   - To avoid breast feeding and promote infant formula feeding

Without any intervention, the transmission of HIV from mother to child is around 30% and just under half of this risk relates to breast-feeding. Based on this risk the guidance specifies, infant formula as an integral part of the Preventing MTCT Program, and as important as the provision of anti-retroviral therapy.

3. HIV infected women with established immigration status or UK citizens who are resident in the UK are able to get infant formula milk and feeding equipment:
   - If they have sufficient income
   - As part of their benefit package

HIV infected mothers with no recourse to public funds have no established immigration status and therefore no rights to be in the country (except special circumstances). This means they have no legal access to any of the above.

4. Under current legislation, HIV infected pregnant women with no recourse to public funds are provided with full obstetric and HIV care without hesitation in order to prevent transmission to the baby (although the woman may be charged postnatally). Yet once the infant is born, no support is provided to ensure the final intervention required to prevent MTCT is available.

5. Once born, the infant is entitled to provision under Section 17 of the Children Act 1989 regardless of immigration status. A baby at risk of HIV infection should be considered ‘in need’, as section 17 (10) states "a child shall be taken to be in need if - he is unlikely to achieve or maintain ....a reasonable standard of health or development without the provision of services .....and (b) his health or development is likely to be significantly impaired without the provision of services"

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58 BHIVA and CHIVA guidelines for the management of HIV infection in pregnant women, 2008
6. Yet some local authorities refuse to provide infant formula milk for infants in families where there is no recourse to public funds. Health practitioners have reported this being ‘like a lottery system’ and dependant on individuals in the local authority rather than the need of the infant.

7. There are currently no data on the number of pregnant HIV positive women with no recourse to public funds. The National Study of HIV in Pregnancy and Childhood (NCHPC) data shows between 2006 and 2009 approximately 1200-1300 infants a year were born in the UK to diagnosed HIV-positive women, (the data for 2010 is currently incomplete). CHIVA conducted a survey amongst its members in the first week of February 2011 to try to gauge the number of HIV positive women with no recourse to public funds who gave birth last year. 457 births were reported of which, 72 (16%) were believed to have no recourse of public funds. If birth data continues as above, we estimate that between 210-230 infants each year will need support in accessing infant formula milk to prevent MTCT of HIV.

8. A child acquiring HIV due to the mother’s and health care provider’s inability to provide infant formula milk presents economic, moral, ethical and legal issues, as well as being a Public Health concern.

9. The economic impact to the NHS, over a lifetime, of an infant acquiring HIV is estimated at £350,000-£500,000 per child. The provision of the appropriate equipment (a steriliser and bottles), and a year of infant formula milk come to just £500. Even if a family is soon to be deported, the provision of infant formula makes complete financial sense, in comparison to the quite possible general paediatric or intensive care admission costs (of around £2000 a day) for an infected infant. Working on the estimate detailed in point 7, the total yearly requirement of infant formula and equipment to all infants born to HIV positive mothers with no recourse to public funds amounts to between £105,000-£115,000 per annum.

10. In public health terms, an HIV positive mother not being supported to access infant formula milk when required is the equivalent to not giving a known HIV positive intravenous drug user disposable needles.

11. We do not feel we need to state the moral reasons for ensuring all the interventions are in place to prevent a child acquiring HIV.

12. The Human Rights Act 1998 (implemented in 2000) article 2 (the right to life) places on state authorities a positive obligation to protect a person’s life, whatever their age. By not providing infant formula milk where the mother is financially unable to, these infants are potentially being exposed to a chronic condition that even with medical intervention, will limit their life.

13. We ask that the Committee consider that Primary Care Trusts (or the National Commissioning Board) have a duty of care to provide infant formula milk to infants of HIV positive mothers with no recourse to public funds, as part of the package to prevent MTCT. We request that funding is made available for infant formula milk and equipment to be distributed by the health care workers providing the specialised HIV care, a system currently running in some hospitals. Although the local authority has a legal obligation, we

59 Geographical area covered England and Wales.
feel that as the other MTCT interventions are monitored and administered in this setting, this is the most appropriate place for this intervention to be properly managed.

**TESTING**

14. Undiagnosed HIV is a well-recognised problem in the UK among adults and is associated with late presentation and increased morbidity and mortality. It is less well understood in children. Two years ago a conference, *Don’t Forget the Children*, was held after the death of a 10-year-old child from AIDS related illnesses. This child had remained untested for HIV, even though both parents were known to be HIV infected and accessing care.

15. Testing of all individuals at risk of HIV is crucial to allow them to be linked into services and to access effective treatment as early as needed. However, testing children of HIV positive parents presents unique problems in comparison to testing adults at risk of HIV. Untested children born to parents with HIV, will have no understanding of their own risk factors and therefore due to lack of knowledge or understanding (dependant on age), cannot safeguard themselves against potential ill health, death or onward transmission.

16. An audit in the UK and Ireland undertaken by the HIV Young People’s Network (HYPNet) found 42 cases where young people with vertically acquired HIV had survived childhood without anti-retroviral therapy and were diagnosed at age 13 years and above.60

17. All health care professionals have a duty to ensure the safety of children. HIV testing of children is clearly in the medical interests of the child. In some cases testing can raise complex issues for the parents, relating to consent and disclosure, yet it is critical to ensure the well-being of these children.

18. We are asking that this issue be included in all policy and guidance relating to HIV testing. For example, the current NICE guidance on increasing uptake of HIV testing among black Africans in England does not address the testing of children at all and this is the primary target group in relation to testing children of HIV positive parents, as 80% of HIV positive children are of Black African origin.

19. Additionally, we would like the Committee to stipulate that all HIV services should have protocols and procedures in place for the testing of children of HIV positive parents in line with the guidance developed by BHIVA and CHIVA.61 This needs to include services ‘looking back’ to establish the HIV status of any child whose HIV positive parents attend that service.

**TREATMENT**

20. Within treatment, we want to bring to the Committee’s attention the CHIVA Standards of Care for Infants, Children, and Young People with HIV, (including infants born to mothers with HIV) (2009)62 which has been produced by a national association of Paediatric HIV Health Practitioners.

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62 http://www.chiva.org.uk/health/guidelines/standards
21. The cohort of HIV infected children is ageing with the current mean age being 14 years. Adolescents living with HIV have additional complex medical and psychological stressors, such as growth and neuro-cognitive vulnerabilities, coping with a family health condition, isolation and stigmatising attitudes, many of which are not typically seen in other chronic diseases of childhood. These stressors have the potential to impact throughout transition and into adult care. Therefore the provision of transitional care for this group is critical in ensuring they continue to engage with HIV health providers and get support around issues such as adherence to their complex drug regimens, management of side effects, relationships, disclosure and sexual health.

22. Additionally to the above, we ask the Committee to consider that the commissioning of HIV services needs to include MTCT prevention and ensure specialist multidisciplinary care for women in pregnancy. The need for specialist paediatric involvement in the care of pregnancies, and follow up of infants, especially those where there may be child protection issues or drug resistant virus, is essential is supporting the best outcome for the infant or child.

STIGMA

23. For children and young people living with HIV the impact of stigma cannot be underestimated. As stated in the testing section, this stigma stops parents from testing their children for HIV, even though establishing the diagnosis may save the child's life.

24. The stigma also means that children diagnosed with HIV are often not told the name of their condition until they are well into their teens. Having learnt their diagnosis, the HIV positive young person is advised not to share this information with anyone. Coming to terms with living with a stigmatised chronic illness and being unable to share this with their peers, has been shown to impact on young people's mental health and well-being and peer interaction.

25. Young people are warned that due to the criminalisation of the onward transmission of HIV, they should tell any sexual partner they have about their diagnosis. In one case in the UK, a young man reported having his sexual debut with a young woman, after which he presented at a police station, as he had not used a condom. Being born with a stigmatised sexually transmitted infection, where onward transmission can be deemed a criminal offence, presents a huge pressure on this group. Therefore we ask the Committee to at the very least engage with the Crown Prosecution Service to discuss the complexity of HIV prosecution relating to young people and the stigma they face.

26. The management of anti-retroviral therapy, with considerable side effects, is difficult for all people with HIV. For young people, hiding treatment from their peer group and school, impacts heavily on their adherence to treatment. 95% adherence is necessary for this medication to be effective. Without this, the virus can develop resistance to the medication, and since there are only a limited number of drug combinations available, a reduced life expectancy. Poor adherence and its complex interaction with stigma, combined with poor psychosocial support, can have major impacts on the health outcomes for this group of people.

63 Data from the National Study of HIV in Pregnancy and Childhood (NSHPC) www.nshpc.ucl.ac.uk and the Collaborative HIV Paediatric Study (CHIPS) www.chipscohort.ac.uk
64 Transition from paediatric to adult services: experiences of HIV-positive adolescents. AIDS Care 2004;16(3):305-14. Miles K, Edwards S, Clapson M.
children and young people.

27. Parents/carers on the whole, choose not to tell schools or other services, and therefore the child and family may not receive the pastoral care and other support they need. This may lead to both HIV infected and affected (those living in a family where there is HIV) children struggling at school, both educationally and pastorally, and unable to access appropriate help.

28. Recent calculations from the Children With AIDS Charity (CWAC) estimate the number of HIV affected young people under 18 year in the UK at between 24-35,000\(^65\). In 2007 there were just over 25,000 schools in England and so we can presume that a large proportion of schools have at least one HIV affected pupil, demonstrating this is an issue for all schools.

29. There is often much emphasis on the need for better education being available in schools and colleges relating to HIV prevention. We strongly agree with this and would stress how HIV needs to be discussed sensitively to acknowledge there may be young people or adults present who are infected or affected by HIV. As well as a prevention message, teacher needs to understand the different ways HIV is transmitted, that advances in treatments have resulted in HIV being a treatable chronic condition and those living with HIV deserve the equal respect and care given to all in the community.

30. We want to stress the huge importance that schools, colleges and other settings for young people need to be ‘HIV friendly’. In these places the next generation is being educated and these are therefore places where stigma should be eradicated. Normalising HIV within these settings, whilst acknowledging the need for confidentiality for individuals living with HIV, will begin to establish a culture where HIV is demystified and accepted as a chronic health condition.

31. We ask the Committee to recommend that HIV be seen as distinct within the context of school policy and protocol. Currently, if HIV is found in school policy, it is as part of generic disability agenda. Stigma makes HIV distinct from other disabilities at all levels of society. We ask the committee to endorse or promote the guidance produced by the National Children’s Bureau\(^66\) that sets out simple ways schools and child/youth settings can within their policies and protocols address institutional prejudice and enable families to engage and the children get the support they need.

This evidence has been submitted on behalf of the CHIVA Executive Committee, and CHIVA members.

15 February 2011

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\(^{66}\) HIV in Schools (NCB, 2005)
Memorandum by Carol Waudby, Assistant Director, Primary Care, City Healthcare Partnership Hull (HAUK 15)

**Monitoring:**

a) How robust is the current system for monitoring the number of people with HIV in the UK

Generally, where the patient has a definite diagnosis, the monitoring of the number of clients living with HIV is adequate. There are also measures in place to quantify the number of clients living with HIV who are unaware of their diagnosis. However this work is currently managed by the HPA and I am concerned as to how this work will continue when the HPA ceases to exist.

b) Will the proposed public health reforms impact on this system?

Yes with the loss of the HPA and the fact that prevention and treatment will be uncoupled will cause fragmentation.

c) Could anything be done to improve monitoring

Yes a national central database that services could input onto. One organisation for monitoring how much testing and prevention work is going on and number of positives.

d) What groups are at particular risk of HIV?

Those living in social deprivation, BME, asylum applicants, gay men, commercial sex workers.

**Prevention**

a) Is Government Policy sufficiently focussed on HIV Prevention?

No there is very little emphasis on HIV prevention - no dedicated funding, no national campaigns, no local funding.

b) Have appropriate groups been targeted in recent prevention campaigns?

Not aware of any campaigns nationally. Locally we had non recurrent funding for a HIV prevention post, this was very successful in delivering locally relevant messages and included peer ed training for high risk groups. Disappointingly funding was not made recurrent and so we lost this valuable resource. Our budget does not include HIV prevention funding now.

c) To what extent have prevention initiatives targeting at injecting users been successful?

Not aware of this initiative and not as relevant to our clients as vast majority of HIV is sexually transmitted. Focussing on condom use would be more beneficial.

d) How could prevention initiatives be better delivered and evaluated?

With the provision of local funding and local schemes with messages tailored to the local at risk groups. If national campaign should be around condom use and give positive messages as well re treatment options – many people refuse a test because they are not aware of
benefits of early diagnosis. Other initiatives should include more joined up working with TB teams and HIV specialists re screening and educating asylum applicants/new entrants from high risk areas.

**Testing:**

a) Are current testing policies adequate across the country?

There are good evidence based policies available but implementation of the policy is patchy. For example not enough emphasis is placed on screening of high risk people by their GP – in many cases the GP’s do not even ask about risk factors.

b) What can be done to increase take-up rates?

Dedicated funding for HIV prevention officer roles. Include need to assess and test in primary care via the QOF or NES. More public facing education around the benefits of early diagnosis.

**Treatment:**

a) How best can the NHS commission and deliver HIV treatment?

Currently all aspects of HIV care are commissioned by the local PCT and this is closely linked to sexual health and GUM medicine. Local commissioning allows flexibility based on patient need and demographics. In Hull and the East Riding of Yorkshire where I work, our service offers a community based (over 17 sites) fully integrated sexual health service which includes public health promotion and HIV as well as contraception, community gynae and GUM. Under the new plans care will be very fragmented. Sexual health and HIV will be commissioned by separate organisations and so will be uncoupled. As HIV is primarily a sexually transmitted infection this is very dangerous. As an integrated provider we will in future have to deal with 3-4 commissioning bodies (council for prevention and screening, GP consortia for com gyn and ? contraception, possibly SCG for HIV treatment and ?? consortia hubs) – this will result in fragmentation and potential confusion over priorities between different organisations. Our experience of working with the SCG is that it is very hospital centric - despite the fact that 99% of clients are successfully cared for entirely within a community setting. So I think we should be commissioned by one local organisation that is also responsible for commissioning sexual health to prevent fragmentation. We should stop the backward step of hospital centric SCG commissioning for HIV services. For those reasons identified above.

b) As above, complicated, fragmented and hospital centric care.

c) Services should be commissioned in the community with a separate commissioning stream for those patients at end stage of HIV those with Aids etc – which form the minority of patients. Agree with year of care model but costings should be based on local tariff (though may be benchmarked against national indicators).

**Cost:**

2a) have cost considerations been satisfactorily balanced with public health imperatives in HIV

i) prevention policy – no very little funding or recognition for HIV prevention work
ii) treatment policy - yes but SCG commissioning too hospital centric and don’t reflect costs for community delivery.

2b) Is research funding correctly prioritised? Don’t know – have not seen any funds/bids for HIV research locally???

**Stigma:**

a) Reluctance to be tested. Fear of informing GP and family and friends of status. Reduced update of screening.

b) With BME applicants and Commercial Sex Workers and gay men.

c) Locally use of word of mouth via those clients with HIV is used with good effect. IE in promoting access to local services. Attendance at Gay Pride and peer ed projects worked very well (till funding pulled). A lot more could be done as part of school PSE education etc. and also with funding for dedicated campaigns.

February 2011
Memorandum by Dr Mario Cortina-Borja, Principal Investigator UA Thames Survey, MRC Centre of Epidemiology for Child Health, UCL Institute of Child Health (HAUK 34)

From the Unlinked Anonymous (UA) newborn anti-HIV-1 testing programme in the four former Thames regions (UA Thames Survey)

1. Summary
The Unlinked Anonymous (UA) Survey of HIV infection in pregnant women is carried out using residual neonatal dried blood spot samples routinely collected for newborn screening. The presence of HIV antibody in the newborn infant reflects maternal infection status, and most infants whose blood spot samples are HIV-positive are not themselves infected.

We are responsible for the UA Survey in the four former Thames regions, and the Health Protection Agency conducts the survey in other selected English Regions. The UA Survey enables us to obtain unbiased estimates of HIV prevalence in pregnant women. The main function of the UA Survey is to assess the extent of infection in pregnant women, and monitor how rapidly it is spreading in different sub-groups of the female population, including those born in the UK. The survey is completely anonymised, and in addition only aggregated data are reported. Our findings help to inform public health policy, and contribute to the monitoring of the spread of HIV infection in the general population. The UA Survey in the four former Thames regions (UA Thames Survey) relates directly to three of the six key issues identified by the Select Committee:

- monitoring prevalence of HIV infection in pregnant women; our record matching procedures allow us to analyse the distribution of positive cases by specific subgroups in south east England, the area with the highest concentration of HIV infections in the country
- we have been particularly successful in the development and quality control of population-based newborn HIV testing; we test neonatal dried blood spot samples from approximately 238,000 live births per year (about one third of all live births in England), and since 1999 we have maintained a 100% quality assurance record certified by the USA Centers for Disease Control and Prevention (CDC)
- the UA Thames Survey cost £163,665 (approximately £0.69/live birth) in the year April 2010-March 2011 representing excellent value for money

The graph (combined data from the Health Protection Agency (HPA) and the Institute of Child Health) shows changes in HIV prevalence since 1990 among pregnant women in England by their children’s year and region of birth. Prevalence peaked around 2005 and has been declining in inner and outer London thereafter; in the English Regions outside London there has been a sharp increase in prevalence among pregnant women since 2000.

Currently we estimate overall HIV prevalence
in the four former Thames regions to be 1 in every 374 women with live births overall, ranging from 1 in 632 women in non-metropolitan districts to 1 in 206 women in inner London. One in every 42 women from sub-Saharan Africa having their babies in the four former Thames regions are HIV-positive, compared with 1 in 2114 UK-born women.

The HIV epidemic in England reflects the strong social, migration and travel connections between the UK and countries where HIV prevalence is high.

2. Brief outline of methods
The UA newborn survey has provided information on HIV prevalence by area of maternal residence at delivery continuously since 1988. The four former Thames regions include all of inner and outer London, Bedfordshire, Hertfordshire, Essex, Kent, Sussex, and Surrey. Over 2.2 million newborn samples have been tested as part of the UA Thames Survey since 1990.

After completion of routine neonatal metabolic screening, residual dried blood spot samples are punched into microtitre plates and stored. Survey data files are then transferred to the Office for National Statistics (ONS) for matching to national birth registration records using an algorithm primarily based on NHS number and date of birth (methods published in Ades et al, AIDS 1999). Through this record matching procedure demographic information including hospital of birth, district of residence, maternal age, and parental countries of birth are added to the survey records. All patient identifiers which enabled data linkage are irreversibly deleted by the ONS before the demographic file is returned. Only then are the samples tested for HIV. It is impossible to link HIV results back to individual mother-child pairs. We collaborate with the HPA in quality assurance exercises regarding testing procedures.

3. Dissemination
We transfer data to the HPA to be combined with UA Survey data from the other English Regions for publication in their regularly updated surveillance tables and annual reports. We also publish our findings as original research papers, and participate in academic and professional study days and conferences.

4. Funding and Staff
The original UA Survey was developed at the Institute of Child Health in 1988. It was originally funded by the Medical Research Council (MRC) and from 1991 by the Department of Health which transferred responsibility for funding to the HPA in 2006. Through this continuous investment for over 20 years the programme has maintained high standards of testing and data coverage. Our current 3-year contract with the HPA (which ends on 31 March 2011) is for the collection processing and testing of the dried blood spot samples from the former Thames Regions, the analysis and interpretation of results, and the regular transfer of datasets to the HPA. The renewal of this contract is currently under negotiation; we have agreed to reduce the sum requested by over 40%, which will only support the testing of 6 months worth of samples each year. We are attempting to identify alternate additional sources of funding in order to maintain our standards of testing and data coverage.

The Principal Investigator, who manages ethics, research governance, funding, statistical support, collaboration, and dissemination, is currently funded by the Higher Education Funding Council for England (HEFCE). Epidemiological expertise is provided by two Co-Investigators who are also currently HEFCE funded. The senior biomedical scientist with responsibility for testing and curating the neonatal dried blood spot samples is currently the
only member of the team supported by HPA funding. IT and other technical support is provided through the MRC Centre of Epidemiology for Child Health, and the University College London (UCL) Institute of Child Health. Additional laboratory support is provided by the Virology Laboratory at Great Ormond Street Hospital NHS Trust.

5. Ethics
Research ethics approval was obtained from the London multi-centre research ethics committee (Reference 99/2/85) with agreement from the hospital trusts responsible for the relevant neonatal screening laboratories. Under the UK Human Tissue Act parental consent is not required for using residual blood or issue from the living as long as the research has been approved by a research ethics committee and the researcher cannot link the blood or tissue to the patient.

6. Selected papers


18 February 2011
Memorandum by Paul Clift, on behalf of UK-CAB, UK-Community Advisory Board (HAUK 80)

House of Lords Select Committee on HIV and AIDS in the UK

There are three specific questions in the section on treatment:

a. How can the NHS best commission and deliver HIV treatment?
b. What impact might the proposed new commissioning reforms have on HIV treatment?
c. In what setting can treatment most effectively be delivered?

Thanks to the success of 15 years of Highly Active Antiretroviral Therapy (HAART), or combination Antiretroviral Therapy (cART) as it is also known, people living with HIV/AIDS (PLWHA) in the UK are now surviving much longer on treatment, and are able in many cases to live full and active lives, with expected life-spans in many cases being only a few years less than the non-infected general population. However, as PLWHA survive longer on HAART, it is also becoming clear that there are long-term health implications, which need to be addressed.

There is increasing evidence to show that PLWHA are at higher risk of a range of conditions and disease – co-morbidities – including increased risk of cardiovascular disease (CVD); kidney and liver disease; a range of cancers; problems with the central nervous system (CNS), specifically cognitive dysfunction; and loss of bone mineral density (BMD). This is in addition to any issues with co-infection of other illnesses such as Hepatitis C (HCV) or tuberculosis (TB), both of which as quite often seen in PLWHA.

This means that as the HIV population in the UK ages (and already there is a significant proportion of “older” PLWHA), their treatment will become increasingly complex, with treatment required not just for HIV, but also for one or more of these co-morbidities. This will require good communication between the various disciplines, since there is a real issue with drug-drug interactions: drugs for treating an illness can have a profound impact on the efficacy of the HIV drugs being used, so before any treatment for any co-morbidly, checks with the HIV consultant will need to be made.

It is not at all clear how best this situation will be handled, in terms of who has the overall responsibility for the patient’s best interests in terms of health. Although perhaps in an idealised world, there is a role for the GP in “project managing” the patient’s health care, in reality at present there are a number of concerns about the role of the GP. Specifically:

1. Some PLWHA are reluctant to disclose their HIV status to their GP. Although clearly from a health perspective, such disclosure should be made, other factors (fear of stigma, discrimination, “leakage” of status to the local community) may prevent a patient from being willing to disclose.

2. Some PLWHA in the UK do not have access to a GP, or are not registered with a GP.

3. Many GPs are reluctant to “get involved” with HIV. This may be from a fear of lack of adequate training in the field of HIV; or concerns about the impact of the cost of care for PLWHA, or other factors.
4. From a patient perspective, it is not always clear where a patient should go for treatment. Already, there is a sense of HIV patients being “bounced around”. For example, HIV consultants can prescribe only the HIV drugs; other medication required to treat, say, the side-effects of the HIV medication such as diarrhoea or peripheral neuropathy (PN) must be obtained from the GP, even though they are being caused by the HIV drugs being prescribed. This means that the patient then needs to see the GP as well as the HIV clinician on a routine basis, and spend more time at appointments and waiting in pharmacy for drugs – time-consuming and completely unnecessary, since the drugs will need to be prescribed by someone – shuffling cost between hospital and GP is causing unnecessary problems for HIV patients.

5. If a patient feels unwell, there is always the concern and anxiety that it may be HIV related in some way, and so should the patient see the GP, the HIV clinician, or – as many people do at present – both? Indeed, many GPs also advocate seeing the HIV clinician, “just to be sure”.

Diagnosis and screening for HIV-related co-morbidities is another area for concern. For many cancers and diseases, there are risk factors and screening protocols that GPs will use. However, these will not be appropriate for PLWHA. So for example, in the mind of the GP, osteoporosis or osteopenia is normally a problem associated with older women, not middle-aged men; however, for PLWHA, increasing evidence suggests that men are at risk at a relatively early age. Similarly, many cancers which in the general population might not typically be expected to be seen until over 60 or 65 will be seen maybe a decade or more earlier in PLWHA. This means that GPs (and patients) need to be more alert to early symptoms, and not underestimate the potential severity of the issue in PLWHA. Testing protocols should also be done earlier for PLWHA than for the general population for these specific co-morbidities. This will require a significant and sustained training programme for all GPs if we are to avoid preventable illness in PLWHA.

There is a specific area of concern with regard to the mental health and emotional well-being of PLWHA. There is evidence to suggest that over half of the population of PLWHA already have mild cognitive impairment; it is not yet clear if or how quickly this might deteriorate to serious cognitive impairment requiring medical or social interventions. There is a need to monitor and plan for this eventuality, so that we are not caught unaware in 5 or 10 years if indeed cognitive decline in the long-term PLWHA population continues. Also, rates of depression are dramatically higher in PLWHA than in the general population, again an area that is not often recognised or acted upon by the GP. For many PLWHA, their local HIV organisation provides some measure of support in the area of emotional well-being, with these local groups offering peer support and the opportunity to share concerns and issues with similarly-affected individuals in a welcoming environment. More and more of these local HIV organisations are struggling to survive as funding cuts are made, with a deleterious effect on the emotional well-being of those PLWHA in that area.

24 February 2011
1. Is there any programme of mandatory screening for HIV for those joining the armed forces, or for those already part of the armed forces?

There is no routine pre-employment screening for HIV for individuals wishing to join the Armed Forces nor for serving personnel.

2. Does a positive diagnosis impact on one’s ability to join, or affect in any way the roles one is able to undertake, within the armed forces?

Should an applicant declare a history of being HIV seropositive, this would render them unfit for entry.

Service personnel diagnosed as HIV positive are managed according to their medical condition, their treatment needs and their specific role within HM Armed Forces. All cases are dealt with on an individual basis, and so it is not possible to predict the potential effect of a diagnosis of HIV.

Service policy does not discriminate against individuals with HIV infection or AIDS. Personnel diagnosed as HIV positive are therefore managed in accordance with normal downgrading and subsequent employability arrangements. However, those with AIDS are normally recommended for medical discharge.

10 May 2011
Memorandum by the Edinburgh Drug and Alcohol Partnership (HAUK 93)

What level / number of services do you provide? How many people access your services?

The level of service provision is set out in the annual report attached for 2009/10 (10/11 is currently being pulled together). This provision is in line with Scotland's framework on Injection Equipment Provision and a local Lothianwide Policy (also attached).

What level of engagement do you have with HIV / AIDS as an issue?

The provision of injecting equipment is more focussed on reducing blood borne viruses such as Hep B and Hep C as opposed to HIV. We have a Social Work Team for people who are HIV+ which is managed within the same service as the social work drug/alcohol services. They report that the majority of people they are in contact with have been injecting drug users and generally have been HIV+ for over 10 years. This may give a distorted picture of the link as those people are more likely to have chaotic lifestyles and therefore require social work input. However we are not seeing large numbers of injecting drug users testing HIV+.

What is the community / police response to the location and use of needle exchange services?

Needle exchange services are based within pharmacies as well as support services so are generally accepted within the community. There are occasional concerns about injecting equipment being discarded but these are dealt with through environmental health. The relationship with the Police is very positive and the Police vice chair Edinburgh's Alcohol and Drug Partnership (equivalent of a Drug Action Team in England). There is an understanding that access to injecting equipment is an important aspect of our partnership approach to address harm caused by drug use.

What are the current challenges facing needle exchange services? How do you see services being impacted by funding, policy or other changes over the next few years?

Addressing Blood Bourne Viruses is a priority within Scotland and we would expect to see Needle Exchange provision remain a priority for NHS Lothian. We are interested to see the outcomes of pilots in England around the provision of foil for heroin smokers, to the impact on reducing initiation to injecting.

19 May 2011
Memorandum by Professor Jonathan Elford, City University London (HAUK 29)

Submission Status: INDIVIDUAL:

PLEASE NOTE:
The views expressed here are given in a personal capacity and do not represent those of City University London

This submission relates to:
Prevention

d. How could prevention initiatives be better delivered and evaluated?

Behavioural surveillance

Summary

Behavioural surveillance programmes are important for monitoring HIV risk behaviours in hard-to-reach populations such as men who have sex with men (MSM). Trends in sexual behaviour among MSM can provide a valuable insight into corresponding trends in HIV incidence as well as providing information for evaluating prevention initiatives. In the UK, behavioural surveillance programmes have monitored changing patterns of sexual behaviour among MSM living in London, Edinburgh and Glasgow since 1998. However, there is no equivalent programme at a national level in marked contrast to other European countries such as France, Switzerland and Germany. In the UK, if national behavioural surveillance data were available for MSM, prevention initiatives could be better targeted and evaluated.

1. Behavioural surveillance

The World Health Organization (WHO) defines behavioural surveillance as “the ongoing systematic collection and analysis of behavioural data which will help us understand trends in HIV transmission” 67. Behavioural surveillance programmes are especially useful in providing information on behaviours among sub-populations who may be difficult to reach through traditional household surveys, but who may be at especially high risk for HIV such as men who have sex with men.

WHO recommends that behavioural surveillance programmes are part of an integrated surveillance system which monitors various aspects of the HIV epidemic. For example, trends in sexual behaviour over time can provide an insight into corresponding trends in HIV incidence. In addition, behavioural surveillance provides valuable information for planning and evaluating prevention initiatives.

2. **MSM**

In the UK men who have sex with men (MSM) are at increased risk for HIV. Even though there has been a rise in the number of new HIV diagnoses among heterosexual men and women in recent years, MSM still account for over two thirds of new infections that occur in this country annually.  

In the UK, epidemiological surveillance systems provide vital information about changing patterns of HIV infection among MSM at a national level. Ideally this should be complemented by a behavioural surveillance system which could monitor, at a national level, corresponding changes in sexual behaviour among MSM over time.

3. **Behavioural surveillance among MSM: London, Edinburgh and Glasgow**

According to WHO, a behavioural surveillance programme should use a consistent sampling strategy in multiple rounds of data collection over a number of years. In this way, behavioural surveillance can monitor, at a population level, changes in HIV risk behaviours over time.

Time trends in sexual behaviour have been monitored among MSM living in London by research groups based at City University London and at UCL, and among MSM in Scotland by researchers at the MRC Social and Public Health Sciences Unit. Behavioural surveys have been conducted among MSM attending gyms, bars and clubs in these cities. The projects have received funding from a variety of sources including local health authorities, Primary Care Trusts, the Medical Research Council and the Health Protection Agency. These behavioural surveillance projects have provided valuable data about trends over time in the sexual behaviour of MSM in London, Edinburgh and Glasgow.

4. **Behavioural surveillance among MSM: national**

There are no national behavioural surveillance data available for MSM in the UK.

Since 1997, the Department of Health has provided funding for annual national surveys of gay men’s sexual behaviour through the Terrence Higgins Trust and the CHAPS programme.

Although these surveys have generated a series of annual reports, the data have not been used to monitor trends in sexual behaviour over time at a national level.

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70 Dodds JP, Mercey DE, Parry JV, Johnson AM. Increasing risk behaviour and high levels of undiagnosed HIV infection in a community sample of homosexual men. Sex Transm Infect. 2004;80:236-40

As a consequence the UK currently lacks a national behavioural surveillance programme among MSM. This is in marked contrast to other Western European countries such as France\textsuperscript{73}, Switzerland\textsuperscript{74} and Germany\textsuperscript{75} which have monitored trends in sexual behaviour among MSM at a national level for many years.

5. Conclusion

In the UK, behavioural surveillance programmes have monitored changing patterns of sexual behaviour among MSM in London, Edinburgh and Glasgow. However, there is no equivalent programme at a national level, despite sustained investment by the Department of Health in the evaluation of the CHAPS programme.

If national behavioural surveillance data were available in the UK, prevention initiatives could be better targeted and evaluated.

16 February 2011

\textsuperscript{72} Gay and bisexual men, final reports. Sigma Research http://www.sigmaresearch.org.uk/go.php?reports/gay


Memorandum by the Faculty of Public Health (HAUK 38)

About the UK Faculty of Public Health

The UK Faculty of Public Health (FPH) is the standard setting body and the leading professional body for public health specialists in the UK. It aims to advance the health of the population through three key areas of work: health promotion, health protection and healthcare improvement. In addition to maintaining professional and educational standards for specialists in public health, FPH advocates on key public health issues and provides practical information and guidance for public health professionals.

We welcome the opportunity to submit evidence to the House of Lords Select Committee on HIV and AIDS in the UK.

Monitoring

a. How robust is the current system for monitoring the number of people with HIV in the United Kingdom?

The current system works well. The Health Protection Agency (HPA) is responsible for coordinating the collection and analysis of surveillance data across the UK and the nature and quality of the data available are illustrated by the HPA’s latest annual report: HIV in the UK, 2010 Report.

The strengths of the current system lie in the fact that it is based on a variety of complementary data sources (e.g. clinician reports, laboratory reports, serosurveillance data from unlinked anonymous testing), data collection, collation and analysis are managed by a single body with appropriate public health expertise, and the system is coordinated across the four UK countries.

HIV is not a statutorily notifiable condition and therefore surveillance is dependent on the willingness of clinicians to voluntarily report cases, as requested by the Chief Medical Officers. However, this has not impaired the robustness of the surveillance system and it therefore seems appropriate that this arrangement should continue.

b. Will the proposed public health reforms impact on this system?

It is intended that Public Health England incorporates all the existing functions of the HPA. It is important that this should include responsibilities for all aspects of surveillance.

One threat to this is the possibility that routine data collection might in future be managed by the NHS Information Centre (NHSIC). This would have the effect of separating data collection from data analysis and interpretation and could adversely affect the quality and validity of the information available on people with HIV.

Another issue is the independence and credibility of advice provided on HIV, both when dealing with local incidents and with aspects of national policy. There is a risk that advice provided by the new service will not be seen as independent of government unless measures are put in place to safeguard professional integrity.

At the local level, it will be important that local health protection units continue to work in close collaboration with NHS and other partners on all aspects of their work relating to
HIV including providing advice on infection control, managing local incidents, and developing local policies and programmes.

c. Could anything be done to improve monitoring?

The main area of weakness is probably the monitoring of HIV at local level. These are quite limited, particularly in primary care. All patients who access care are monitored through an annual survey – the Survey of Prevalent HIV Infection Diagnosed (SOPHID). As the prevalence of chronic HIV becomes increasingly common, these data will take on greater importance for the planning and provision of local services for prevention and care.

There is a need to ensure that the recent decision to repeal the AIDS (Control) Act 1987 does not diminish the availability of relevant local information.

d. What groups in particular are at risk from HIV?

Most HIV transmission occurs in groups with a high HIV prevalence and high levels of risk behaviour. Currently, in the UK these are men who have sex with men and heterosexuals who have acquired infection abroad.

Prompt diagnosis and rigorous contact tracing e.g. through partner notification are therefore likely to be the most potent approaches to prevent spread.

Prevention

a. Is government policy sufficiently focused on HIV prevention?

Government policy is not sufficiently focused on HIV prevention. The profile of HIV is much lower than it was in the 1980s, yet the prevalence of HIV is higher than ever before.

In the past, the focus has tended to be on prevention by reducing behavioural risk. This is still important, particularly as public awareness of HIV has fallen. It also remains an important issue among groups with high prevalence of HIV such as men who have sex with men and black Africans.

With the development of successful treatment for HIV and its dramatic impact on life expectancy, there is also a real need to give greater publicity to the availability and desirability of HIV testing. Once a person knows they have HIV, they can access appropriate care and they are more likely to take precautions to prevent spread.

b. Have the right groups been targeted in recent prevention campaigns?

Yes, current HIV prevention campaigns focus predominantly on the groups at highest risk including men who have sex with men and injecting drug users. Initiatives to promote HIV testing will also need to target these groups, but will also need to target people living in communities or areas with high HIV prevalence.
c. To what extent have prevention initiatives targeted at injecting drug users been successful?

Harm reduction programmes, particularly needle exchange schemes, have had a considerable role in preventing spread of HIV among injecting drug users. It is important to ensure that these continue to be provided in an appropriate way. Though the prevalence of HIV in injecting drug users remains low in most areas, other blood borne viruses like hepatitis B and hepatitis C remain common and there is evidence of ongoing transmission. Younger, newly started injecting drug users and prison inmates are particularly vulnerable.

d. How could prevention initiatives be better delivered and evaluated?

HIV prevention should be a priority for the NHS and public health services in all four UK countries. There should be more coordination of prevention with HIV treatment and care services and greater incentives to encourage local healthcare providers and Directors of Public Health to increase their focus on HIV prevention. All new prevention initiatives should include an evaluation plan as an integral component.

Testing

a. Are current testing policies adequate across the country?

At the moment, HIV testing is mostly carried out through genito-urinary medicine and sexual health clinics. Universal testing is recommended in this setting, though it is not always carried out and it should be more carefully monitored.

Testing needs to be made much more widely available and to become routinely offered in hospital and primary care settings.

The British HIV Association provides guidelines on a wide range of groups that are considered at higher risk of HIV and this could form the basis for promoting a more extended policy on testing.

b. What can be done to increase take-up rates?

Routinely offering HIV testing appears to be acceptable to both patients and staff. Experience with antenatal screening has shown that making HIV testing routine can dramatically increase uptake. The key is therefore to make HIV testing a national priority and to make it more widely available, ideally in a variety of healthcare settings.

NICE has issued draft guidance on increasing the uptake of HIV testing among men who have sex with men and black Africans.

Treatment

a. How can the NHS best commission and deliver HIV treatment?

Commissioning and delivery of HIV treatment should be normalised. In some ways, it is analogous to treatment for cancer where developments in combination therapy have led to rapidly improving survival rates. For HIV, there should be similar emphasis on the
importance of early diagnosis, prompt referral, access to optimal treatment, and careful monitoring of clinical outcomes.

b. What impact might the proposed new commissioning reforms have on HIV treatment?

Cost

a. Have cost considerations been satisfactorily balanced with public health imperatives in HIV:

(i) Prevention policy?

Increased testing will result in earlier diagnosis and incur greater treatment costs. These are, however, offset by a reduction in onward transmission and a reduction in the complications associated with late presentation.

The HPA’s annual report on HIV for 2009 estimated that preventing one new HIV infection would save the between £280,000 and £360,000 in lifetime costs. Preventing all UK-acquired HIV infections newly diagnosed in 2008 would have resulted in a saving of around £1.1 billion in healthcare costs.

(ii) Treatment policy?

b. Is research funding correctly prioritised?

In the 1980s and 1990s, the UK Health Departments provided funding to the MRC for a programme to tackle the spread of the HIV/AIDS epidemic. This programme initiated a large number of studies which informed national policy-making and placed the UK at the forefront of HIV/AIDS research. It included the National Survey of Sexual Attitudes and Lifestyles, unlinked anonymous testing surveys, and work on prevalence and risk behaviours among prisoners and sex workers.

Currently, however, the strategy for HIV research in the UK is much less clear without the same focus on prevention. For example, there has been little research into barriers to HIV testing and evaluation of initiative to promote testing uptake, particularly among vulnerable groups.

Stigma

a. What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?

Stigma is a barrier both to HIV prevention and care. It can, for example prevent people from coming forward for testing or to access treatment and care. It may also make staff more reluctant to offer testing as well as hindering partner notification.

Public education and awareness-raising can reduce the stigma associated with HIV. This is particularly important in groups who may also be stigmatised for reasons of race or sexuality.
b. Where are problems of stigmatisation most acute?

c. What measures are currently taken to tackle HIV stigmatisation? What more should be done?

UNAIDS (2007) have produced resources for national stakeholders entitled: ‘Reducing HIV stigma and discrimination: a critical part of national programmes’.

It requires multi-faceted action at all levels but with a clear national lead. This implies making HIV a national public health priority as well as ensuring that it is given priority by the NHS, social care, and public health services. People with HIV also need to know that they can expect full support from other agencies and services and from the legal system.

February 2011
Memorandum by FPA (HAUK 5)

1. Executive Summary

1.1 FPA is one of the UK’s leading sexual health charities. We have restricted the following comments to our areas of knowledge and expertise.

1.2 FPA believes that sex and relationships education (SRE) should be a statutory subject for all children and young people at all key stages as a way of reducing the transmission of HIV and other sexually transmitted infections (STIs).

1.3 FPA is concerned that investment in preventative services is sometimes seen as an easy target for cuts when budgets are under pressure. This can mean that prevention is not invested in, which leads to greater costs in the longer term.

1.4 The stigma and embarrassment that continue to surround HIV and other elements of sexual health are of concern as they can deter people from coming forward for the advice and treatment they need. Stigma can also mean that people are reluctant to talk about the services they need, which can therefore lead to services being more vulnerable to budget cuts.

2. About FPA

2.1 FPA is one of the UK’s leading sexual health charities, with over 80 years’ experience of providing the UK public with accurate sexual health information, advice and support services. Our mission is to help to establish a society in which everyone has positive, informed and non-judgmental attitudes to sex and relationships; where everyone can make informed choices about sex, relationships and reproduction so that they can enjoy sexual health free from prejudice and harm.

2.2 FPA provides a comprehensive sexual health information service, including a national telephone helpline and web enquiry service that respond to 45,000 enquiries a year on all aspects of sex, sexual health and relationships, as well as a library and information service for professionals. We produce a range of publications for professionals and the public on sexually transmitted infections, contraception and pregnancy choices, including abortion, as well as educational materials to support parents and schools to deliver age-appropriate sex and relationships education. FPA offers a variety of resources, including training courses, for those involved in delivering sexual health services. We also run a series of community-based sex and relationships education projects for young people, parents and people with learning disabilities. FPA represents a national voice on sexual health, working with and advocating for professionals and the public to ensure that high quality information and services are available to all who need them.

2.3 We have restricted the following comments to our areas of knowledge and expertise.
3. Education

3.1 FPA believes that everyone needs to be equipped with the knowledge and skills to develop sexual behaviour that is safe, responsible and enjoyable, including full information about STIs, including HIV.

3.2 We believe that high quality, comprehensive sex and relationships education needs to be a statutory subject for all children and young people at all key stages to ensure that they receive the information they need to protect their sexual health, and that of their partners, as they grow up.

3.3 While secondary schools are currently required to include discussions around STIs, including HIV, in their curricula, we are concerned that this does not meet young people needs. The current curriculum does not always cover the sexual health and wider social aspects of HIV to enable young people to understand that HIV is an issue in the UK as well as in the developing world.

3.4 Various surveys have demonstrated young people’s desire to have more and better quality SRE. For example, in 2006–07 the UK Youth Parliament surveyed more than 21,000 young people and found that 40 per cent of young people aged 11 to 18 thought their SRE was either poor or very poor and a further 33 per cent thought it was average. In addition, the survey found 57 per cent of girls aged 16–17 had not been shown how to use a condom and only 49 per cent of the young people surveyed knew where their local sexual health clinic was.

3.5 FPA is concerned that the non-statutory nature of the majority of the SRE curriculum means it not afforded the priority it needs within schools, which is leaving young people’s sexual health and wellbeing at risk. Many teachers who deliver SRE have not received specific training to do so and are therefore uncomfortable or embarrassed with the subject material. In addition, in some schools, SRE is not given sufficient time within the school timetable, which also has a detrimental impact on young people’s knowledge. A recent report by Ofsted into the provision of Personal, Social, Health and Economic (PSHE) education, through which much of SRE is delivered, noted that a lack of discrete curriculum time meant full programmes of study were not covered; SRE was highlighted as one of the areas that suffered as a result.

3.6 Comprehensive SRE can enable children and young people to develop the skills, knowledge and confidence they need to develop safe and healthy relationships as they grow up, including negotiating safer sex and avoiding sexually transmitted infections. High quality SRE can lead to young people starting to have sex later, especially when linked to confidential advice services. High quality school based SRE has also been found to contribute to meeting government public health priorities, such as achieving a reduction in teenage pregnancy rates and the prevalence of STIs.

3.7 FPA believes that sex and relationships education needs to be statutory to ensure that all children and young people develop the skills, knowledge and confidence they need.

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77 Ofsted, Personal, social, health and economic education in schools (Manchester: Ofsted, 2010)
to protect their sexual health. We believe that this will help to reduce the transmission of HIV in the future.

4. Prevention

4.1 FPA is concerned that funding for HIV is not sufficiently prioritised and that it is sometimes seen as an easy target for cuts when budgets are under pressure.

4.2 A review of the National Strategy for Sexual Health and HIV carried out by MedFASH commissioned by the Sexual Health Independent Advisory Group on Sexual Health and HIV highlighted issues with investment in sexual health services, particularly prevention. The review found that: 'nearly two-thirds of Choosing health money pledged by the Government for sexual health did not reach its target in 2006/7; much of it was diverted to cover PCT deficits, though the picture for 2007/8 seems to be more mixed. There also appears to have been relative disinvestment in sexual health promotion and prevention, notably HIV prevention, despite this having been shown to be cost-effective, and in many cases cost-saving'.

4.3 FPA believes there needs to be greater investment in prevention and this needs to fund both universal prevention and awareness raising campaigns and targeted campaigns for those most at risk. While it is clear that some people are at greater risk of HIV, not everyone with HIV is in one of those groups. We are concerned that investment solely in targeted campaigns could give the impression that only certain people are at risk of HIV and other people do not need to protect themselves. This could not only put people’s health and wellbeing at risk but could also increase the stigma associated with HIV.

4.4 A significant amount of time has passed since the last universal HIV awareness raising campaign. While more recent national campaigns, such as the Condom Essential Wear and Sex: Worth Talking About campaigns, included generic messages about the importance of people protecting their sexual health, there will be a significant number of young people who have not encountered specific HIV prevention messages. The improvements in the effectiveness of HIV medications and the increasing focus on HIV in the developing world could combine to imply that HIV is not a major problem in the UK.

4.5 Given that around a quarter of people with HIV are unaware of their HIV status, it is crucial that greater efforts are made to raise awareness of HIV, how it is passed on, how people can avoid it and how to access testing if people think they may be at risk. Investment in campaigns such as this could be cost saving by reducing onward transmission of HIV as more people with HIV are tested and diagnosed and more people take action to protect their sexual health.

4.6 Prevention information cannot just be provided once; there needs to be ongoing awareness raising and prevention work both targeted and universally available to ensure that each new generation of people receives the information and that it is widely accessible to all who may need it.

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5. Stigma

5.1 FPA is concerned that the stigma and embarrassment that continue to be associated with HIV and other aspects of sexual health are deterring people from coming forward for help and advice when they need it. We believe stigma also makes people reluctant to talk about their own use of sexual health services which can mean that these services are more vulnerable to budget cuts.

5.2 Although outwardly the UK can appear to be a society at ease with sexuality, this is often not the case when it comes to people’s personal relationships. Many people continue to find it difficult to talk about their sexual health, even with their partners, for fear of being judged.

5.3 This fear of being judged can deter people from accessing sexual health services, including HIV testing. People can be reluctant to be tested, even if they think they are at risk, if they think that a diagnosis will lead to them being judged or excluded by other people. This can be particularly acute where people live in small and/or close knit communities.

5.4 A survey of people living with HIV in 2007–08 found that around one in three people had experienced HIV-related discrimination in the last year, 19 per cent had experienced discrimination from a doctor or other health or care professional in the last year. Fear of discrimination such as this can lead to people not coming forward for testing.

5.5 Fear of stigma can also mean people are reluctant to talk about the services they need and it can be very difficult to get accurate feedback about sexual health services. This can mean that sexual health services become more vulnerable when budgets are under pressure as people are less likely to campaign against their closure. If services do close it can have a significant impact on people’s health and wellbeing and can actually be more costly in the longer-term as the cost of treating sexually transmitted infections, including HIV, increases.

February 2011

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Supplementary Memorandum by FPA (HAUK 83)

1. Executive summary

- FPA is one of the UK’s leading sexual health charities. Natika Halil, FPA Director of Information, appeared as a witness to the House of Lords Select Committee on HIV and AIDS in the UK on Tuesday 22 March 2011.

- FPA believes that sex and relationships education (SRE) should be a statutory subject for all children and young people at all key stages as a way of reducing the transmission of HIV and other sexually transmitted infections (STIs).

- We also believe that parents play a crucial role in giving information to their children about sex, relationships and growing up and that high quality SRE should be a joint home-school programme.

- There is a need for a national awareness raising campaign for HIV and AIDS, as there are a significant number of young people who will not have encountered specific HIV prevention messages in their lifetime.

- FPA would like to see a sexual health strategy that recognises sexual health as a key issue through all life stages and therefore services, information and support are needed by people of all ages; not just young people.

2. Parents’ role in sex and relationships education (SRE)

- FPA believes that parents play a crucial role in giving information and advice to children and young people about sex, relationships and growing up. We believe that they should be encouraged to get involved, where possible, with SRE in schools through ways such as contributing to the schools’ SRE policy. We believe that when parents and teachers work together and see SRE as a joint home-school programme it delivers high quality learning for their children.

- FPA runs a groundbreaking course, called Speakeasy, which is accredited by the Open College Network. It covers topics such as the changes that happen during puberty, looking at outside pressures on young people, contraception and learning how to respond to the needs of children around sex and relationships education. The course aims to empower parents to have the confidence and knowledge to talk to their children about all aspects of growing up towards sexual maturity. As a result, they can provide positive sex and relationships education in the home.

- Being equipped with these skills and knowledge means that parents can not only talk openly to their children about sex and relationship issues, but they can also answer difficult questions that may come up, honestly and with confidence.

3. Raising awareness

- There hasn’t been a national campaign to raise awareness of HIV and AIDS since the 1980s. Therefore FPA believes that there is a need for a national awareness raising
campaign for HIV and AIDS, as there are a significant number of young people who will not have encountered specific HIV prevention messages in their lifetime.

- We have concerns that investment solely in targeted campaigns could give the impression that only particular people are at risk of HIV and other people do not need to protect themselves. This could not only put people's health and wellbeing at risk but could also increase the stigma associated with HIV.

4. Priorities for a national sexual health strategy

- FPA would like to see a sexual health strategy that recognises sexual health as a key issue through all life stages and therefore that services, information and support are needed by people of all ages; not just young people.

- We also believe that the sexual health strategy should emphasise building on the achievements and improvements that have been made in sexual health in the past decade, for example the reduction in the rate of under 18 conceptions, and commit to continued improvements in these areas.

- In the sexual health strategy, FPA would also like to see:
  - A commitment to the proposed sexual health outcomes on under-18 conceptions, rates of chlamydia diagnosis and late diagnosis of HIV.
  - An emphasis on quality and accountability for outcomes for sexual health services and information.
  - Recognition of the need to develop the sexual health workforce and the crucial role that community contraception clinics have to play as 80 per cent of contraception training takes place in community services.
  - Emphasis on prevention and high quality information and advice enabling people to self help.
  - Recognition of the cost effectiveness and efficiency of continuing to commission some sexual health services centrally. For example the FPA helpline and information service is provided uniformly across England; because it benefits from economies of scale and significant expertise built over many years it would not be possible for this service to be replicated at a local level to such a high standard and so cost-effectively.

7 April 2011
Memorandum by Gilead Sciences Limited (HAUK 74)

Summary

- The number of people living with HIV in the UK reached an estimated 86,500 by the end of 2009. A quarter of these were unaware of their infection and over 50% of them were diagnosed late.\(^82\)
- With effective and early therapy an individual diagnosed with HIV at 35 years of age can expect an almost normal life expectancy with improved health outcomes and quality of life.\(^83\)
- Individuals on effective HIV treatment and those who are aware of their status are less likely to infect others.\(^84,85\)
- It is estimated that the prevention of one new HIV infection would save the public purse between £280,000 and £360,000 in direct lifetime healthcare costs.\(^86\)
- Gilead is committed to HIV nationally and globally: it innovates to develop and deliver antiretroviral medicines; and it is committed to supporting HIV testing, as illustrated by our ongoing support for the Gilead Fellowship Programme and our collaboration with the “Halve It” coalition. Gilead UK and Ireland was the founding member of the “Halve It” coalition and continues, along with the British HIV Association, to support the coalition. “Halve It” has submitted its own evidence to the committee, elements of which are reflected in our response.
- The ongoing NHS reconfiguration creates challenges and opportunities to improve the management of HIV:

1. We need to strengthen the relationship between national surveillance and HIV testing by enhancing local HIV reporting procedures while maintaining a world-class national surveillance capability.
2. Current professional guidelines for expanding testing to a wider range of settings beyond sexual health and antenatal clinics are well developed and endorsed. The real challenge is that these policies are not being implemented at a national or local level.
3. Expanding and normalising HIV testing beyond Sexual Health and antenatal settings could significantly reduce late and undiagnosed HIV. People who are aware of their own status and who are in care are highly unlikely to infect others.
4. There is a need to improve integration of HIV prevention and treatment commissioning to ensure smooth transition into care for those who are diagnosed.

5. There is an opportunity for service redesign to support the QIPP agenda, especially through encouraging those patients with HIV who are stable, treated and well to be managed day-to-day in the community whilst under specialist care.

**Gilead Sciences UK and Ireland**

Gilead Sciences is a biopharmaceutical company that discovers, develops and commercialises innovative therapeutics in areas of unmet medical need. The company’s mission is to advance the care of patients suffering from life-threatening diseases worldwide.

Since Gilead was founded over 20 years ago, the company’s history has been punctuated with key innovative milestones in supporting the treatment of patients with HIV both in the developed and developing world. Gilead has developed several leading therapies for HIV patients.

Thanks to combination antiretroviral therapy, the life expectancy of someone living with HIV has increased markedly over the last 15 years. Recent research\(^\text{87}\) found an individual diagnosed with HIV at 35 years of age, with prompt access to antiretroviral therapy, can expect to live to 72 years, only a few years less than a person without HIV.

Today, many people in the UK living with HIV benefit from a once-daily, single tablet regimen (STR) to treat HIV which has changed the HIV treatment paradigm. Gilead is further striving to develop new STRs to meet the new challenges in HIV treatment whilst investing in worldwide access to its medicines and prevention of HIV transmission.

Gilead is engaged with a number of key initiatives that are directly relevant to this Select Committee:

**The Gilead UK and Ireland Fellowship Programme**

The Gilead UK and Ireland Fellowship Programme aims to encourage the development, exploration and dissemination of new ideas which generate and promote best practice in the delivery of patient-centred care through innovative and practical models in the field of HIV and hepatitis B.

Since the programme’s launch in 2009, Gilead has awarded grants to over 25 locally based projects which aim to increase HIV diagnosis and links to care in the UK and Ireland across a variety of clinical and non-clinical settings. A core element of this programme is a Best Practice Sharing Event where grant recipients come together to share best practice and key learnings. Gilead has worked closely with the Department of Health and the Health Protection Agency to evaluate the cost effectiveness of these projects.

**“Halve It” coalition**

As a founding member, Gilead UK and Ireland continues to support, the “Halve It” coalition, a group of HIV and healthcare experts who are determined to tackle the continued public health challenges posed by HIV. The “Halve It” coalition calls upon all levels of government to make HIV a public health priority both locally and

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nationally. “Halve It” is working to halve the proportion of people living with undiagnosed HIV and halve the number of people diagnosed late with HIV over the next 5 years.

Gilead also recognises the urgent global need for access to HIV medications, particularly in resource-limited countries where the epidemic has hit the hardest. Since our first HIV product Viread reached the market in 2001, we have focused on expanding access to our portfolio of HIV medications. Today, approximately 1.1 million patients in the developing world are receiving Viread or Viread-containing products.

Please find overleaf the Gilead response to the call for evidence from the House of Lords Select Committee on HIV and AIDS in the UK.

Gilead UK and Ireland response

Monitoring

a. How robust is the current system for monitoring the number of people with HIV in the United Kingdom?

a.1. The current system is effective in monitoring the number of people with HIV in the UK. At present, the UK’s surveillance and monitoring process led by the Health Protection Agency is capable of publishing robust data on many indicators including numbers of new diagnoses by patient group, number of people living with HIV and in care and late diagnoses and deaths.

a.2. The Health Protection Agency’s data are reliable and widely respected as a definitive source of information. Furthermore, the Health Protection Agency plays a valuable role as a crucial international partner with the European Centre for Disease Control and Surveillance, based in Stockholm, as well as the World Health Organisation (WHO) and UNAIDS globally.

a.3. In its 2010 report on HIV, the Health Protection Agency recommended that the clinical outcome indicators recorded to assess the quality of HIV care received by patients in London should be adopted nationally.

b. Will the proposed public health reforms impact on this system?

b.1. The current approach to monitoring trends has proved to be very effective. The Health Protection Agency has adopted a comprehensive approach to understanding and communicating the changing face of HIV in the UK. It is imperative that, as accountabilities for monitoring and surveillance change under the forthcoming healthcare reforms, the positive characteristics of the Agency are retained and further enhanced.

b.2. Currently, clinicians voluntarily report data to a national centre; this is coordinated by the Health Protection Agency, which has capacity to deliver large-scale data collection, analysis and reporting. This capacity has proved a cornerstone in delivering a coordinated public health response.

b.3. The current recommendations regarding an information warehouse potentially threaten the involvement of local public health experts, who are closely involved in many aspects of surveillance and reporting and who are crucial in leading the local response to HIV.

b.4. The potential dangers of outsourcing the aggregation of data, and/or separating the responsibilities of those collecting data and those who analyse them, must be evaluated. This separation has the potential to reduce the quality of the findings on HIV trends and therefore the response to it.

c. Could anything be done to improve monitoring?

c.1. At present, HIV information systems in the NHS are quite limited, particularly in primary care. In high prevalence areas this information is especially crucial for training, increasing awareness in healthcare professionals, as well as service planning for GP consortia (in particular, expanding HIV testing or HIV long-term condition service planning). This is especially concerning as HIV is likely one of the fastest growing chronic conditions in the UK.

c.2. We need to strengthen the relationship between national surveillance and HIV testing by enhancing local HIV reporting procedures while maintaining a world-class national surveillance capability.

c.3. We need to improve the level of transparency by requiring the local public health service to report back to the public on local progress in tackling late HIV diagnosis and new levels of infection.

d. What groups in particular are at risk from HIV?

d.1. In 2009, data from the Health Protection Agency showed that the 6,630 new diagnoses were made as follows:

- Men who have sex with men (41.6%)
- Black African men (12.1%)
- Black African women (21.1%)
- Injecting drug users (2.6%)
- Other (2.1%)


d.2. In recent years there has been an increasing case load of heterosexual transmission in the UK. Given there is lower prevalence in the general population than in the populations listed above, identifying HIV among the general population can present a challenge in that HIV tests are less likely to be offered, those infected remain unaware of their own status and HIV may be diagnosed late.

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d.3. In addition, the joint British HIV Association, British Association of Sexual Health and HIV, and British Infection Society guidelines for HIV testing⁹¹ recommend offering HIV tests to the following groups, who may be regarded as being ‘at risk’ of HIV infection:

- All patients presenting for healthcare where HIV, including primary HIV infection, enters the differential diagnosis.
- All patients diagnosed with a sexually transmitted infection.
- All sexual partners of men and women known to be HIV-positive.
- All men who have disclosed sexual contact with other men.
- All female sexual contacts of men who have sex with men.
- All patients reporting a history of injecting drug use.
- All men and women known to be from a country of high HIV prevalence (>1%).
- All men and women who report sexual contact abroad or in the UK with individuals from countries of high HIV prevalence.

Prevention

a. Is government policy sufficiently focused on HIV prevention?

a.1. Government policy is not sufficiently focused on HIV prevention. There is also a problem that public awareness of the dangers of HIV has fallen and therefore unnecessary transmissions are still occurring.

a.2. HIV prevention has historically largely focused on behavioural prevention only. There is limited UK-based, formally evaluated evidence on the effectiveness of UK prevention programmes in the antiretroviral therapy era, particularly for black Africans.

a.3. There is also insufficient focus upon testing. Increasing the uptake of HIV testing raises the proportion of people who are aware of their status. Once an individual’s HIV infection has been diagnosed, they can access appropriate care. Effective treatment significantly reduces viral load and infectiousness, and thus the likelihood of transmitting HIV. Few transmissions take place when one sexual partner is HIV-positive and on antiretroviral therapy and the other is HIV-negative.

a.4. A study has shown that those living with HIV who are aware they have been infected are more likely to take precautions, such as using condoms, to prevent transmission to partners.⁹² A study of newly diagnosed HIV-positive men who have sex with men reported that 76% had eliminated the risk of onward transmission 3 months after diagnosis.⁹³

a.5. A negative HIV test, on the other hand, provides an opportunity to offer preventive education and advice and may also lead to changes in behaviour. Notification of current and former sexual partners to recommend testing and treatment is also possible following diagnosis. Treatment during pregnancy and careful management of delivery allows women

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aware that they are HIV positive to plan for HIV-free births and childcare. More widespread testing, earlier diagnosis and treatment, especially in areas of high prevalence and among groups at increased risk, provide a clear public health benefit by reducing onward transmission rates.

a.6. With a determined effort we believe it would be possible to halve the number of undiagnosed HIV cases and this is the reason for Gilead’s support of the “Halve It” campaign. This would have a profound impact on HIV transmission and hence prevention.

a.7. In the 1980s, HIV and AIDS had a very high profile – and rightly so. Patients were dying, there was no cure for the disease, and there were no drugs to treat it. That is why, as Secretary of State for Health, Lord Fowler mounted an extensive public education campaign using television, radio and poster advertising, and sent letters to all households to provide education on the prevention of HIV and AIDS.

a.8. Today the profile is nothing like as high and more people are living with HIV than ever before. The assumption is that new drugs have solved the problem and that fewer people are infected. Nothing could be further from the truth. There is still no cure and, away from the public gaze, HIV has developed into one of Britain’s fastest growing health conditions. According to the Health Protection Agency’s 2010 HIV report, the number of people living with HIV in the UK had reached an estimated 86,500 by the end of 2009. A quarter of these were unaware of their infection and over 50% were diagnosed late.94

a.9. The stigma associated with HIV has ensured that the growth of the epidemic has been silent but, each year, thousands of individuals are infected, by people who are not even aware they are living with HIV themselves. Lives are being harmed, even lost, because people are being diagnosed either late or not at all.

a.10. More than two decades after the ‘tombstone’ campaign, it is time we refocused on HIV and those most at risk of being infected. We call upon the government to increase and enhance the provision of education and information to specific vulnerable groups. In particular, black Africans and men who have sex with men are critical groups on which to focus HIV prevention services. There is, however, another important factor: the fact that living in a high prevalence area is a surrogate risk in itself and so the concept of routine testing in these areas is important and an efficient way of case-finding and reducing transmission.

b. Have the right groups been targeted in recent prevention campaigns?

b.1. Despite successful local prevention campaigns focusing on HIV prevention among men who have sex with men, among black Africans and injecting drug users, the continued high rate of late diagnosed HIV underpins the need for a broader co-ordinated campaign.

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c. To what extent have prevention initiatives targeted at injecting drug users been successful?

c.1. Injecting drug users account for only 2.6% of new HIV infections per annum.95

c.2. A recent Health Protection Agency report stated that the prevalence of HIV among current injectors remains low although it has increased from 0.7% to 1.5% (varies from 0.6% in Scotland to 4.1% in London) over the past decade, and is now similar to the level found in the early 1990s.96 Prevention strategies aimed at injecting drug users have met with mixed success.

c.3. The uptake of HIV testing is improving, with three-quarters of injecting drug users now reporting that they have had a test; however, almost a third of injecting drug users with HIV remain unaware of their infection.15 The vast majority of HIV-infected injecting drug users in contact with specialist HIV treatment services are receiving antiretroviral therapy.15

c.4. Specific settings such as prisons may be particularly appropriate for conducting testing initiatives. One such example is an inter-agency framework for blood-borne viruses screening in prisons in Dorset which was established in 2008, with a grant from the Gilead UK and Ireland Fellowship Programme. In this project, a targeted approach to testing supported by technology-based educational packs and videos for prisoners in multiple languages was adopted. The project, run by the local genito-urinary medicine service and prison staff, sourced HIV and AIDS information videos in many languages, uploaded to touch screen computers for prisoners to access in their own language to encourage screening for blood-borne viruses. In 2008/09, before the introduction of the initiative, only 27% of HIV-positive inmates, seen by the genito-urinary medicine service had been diagnosed HIV-positive. After the intervention in 2009/10, 78% of HIV-positive inmates seen by the service had already been diagnosed HIV-positive.

d. How could prevention initiatives be better delivered and evaluated?

d.1. The Public Health White Paper consultation proposes sexual health/HIV prevention and sexual health services to be commissioned locally through local authorities; HIV treatment services, however, are expected to be commissioned through the National Commissioning Board. The resulting prevention and treatment split provides few incentives for development of pathways to aid prevention through cost effective treatment.

d.2. HIV and HIV prevention should be a priority of both the NHS and the new Public Health England. Public Health England should play a leading role in the coordination and evaluation of prevention initiatives; they should also give HIV the appropriate priority on the ground by requiring that it is systematically considered in health needs assessments and other relevant local health planning processes. Public Health England should be transparent in reportage and be accountable for informing the public of both local and national progress in tackling late HIV diagnosis and levels of new infection.

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d.3. Incentives should be put in place to encourage local healthcare providers and Directors of Public Health to increase their focus on HIV prevention, deliver appropriate services and evaluate the impact of these measures.

d.4. HIV testing in the community and in specialist settings is currently being piloted by the DoH in eight sites and early data suggests that patients respond well to being offered HIV testing in a mix of settings. The Gilead UK and Ireland Fellowship Programme has shown a mix of results, with some projects not finding new patients while others have resulted in a positive rate of 2% and an approximate cost of less than £2000 per new case found; early estimations suggest that this represents a highly cost effective use of NHS funding based on the threshold that NICE use. Work is ongoing to evaluate these projects further to allow comparisons to be made with disease areas other than HIV. A publication is in draft which is aimed to be published in May this year.97

d.5. The full implementation of the upcoming National Institute for Health and Clinical Excellence (NICE) public health guidance on HIV testing will further enable the improvement of HIV prevention efforts.

Testing

a. Are current testing policies adequate across the country?

a.1. Current professional guidelines for expanding testing to a wider range of settings beyond sexual health and antenatal clinics are well developed and endorsed. The real challenge is that these policies are not being implemented at a national or local level.

a.2. In 2007, the UK Chief Medical Officer wrote to healthcare professionals, including GPs, urging them to offer and recommend a HIV test to their patients if they may have been exposed to HIV infection. Research on the effectiveness of this letter in terms of changing testing behaviour showed little change.98

a.3. In 2008, the British HIV Association, the British Association for Sexual Health and HIV and the British Infection Society published guidelines and recommendations on testing for HIV.99 In September 2010, NICE issued draft guidance on increasing the uptake of HIV testing among men who have sex with men100 and among black Africans101 in England. They all reached similar conclusions: we must scale up HIV testing to include general practice and other settings.

a.4. The UK national guidelines for HIV testing, prepared jointly by the British HIV Association, the British Association for Sexual Health and HIV and the British Infection

97 Publication in preparation
Society and published in 2008, recommend that HIV tests be offered and encouraged in a much broader range of settings, stating that testing should be considered for all men and women registering with GPs and all general medical admissions in areas where diagnosed HIV prevalence exceeds 2 per 1,000 of the population. This was the case in 43 English local authorities in 2008. Recent data has demonstrated that HIV testing is cost effective where prevalence is 1 per 1,000 of the population. HIV testing should be routinely offered and recommended to all patients presenting with conditions associated with HIV or with a sexually transmitted infection, all sexual partners of those known to be HIV-positive, all men who have sex with men, all women who have sex with bisexual men, all patients reporting a history of injecting drug use, all men and women from countries of high HIV prevalence, and all sexual contacts of individuals from countries of high HIV prevalence.

a.5. Similarly, in its draft 2010 public health guidance on HIV testing among men who have sex with men and among black Africans, NICE recommends that local strategies be developed to encourage individuals to consider testing, drawn up in consultation with local voluntary organisations and community members.

b. What can be done to increase take-up rates?

b.1. There is good evidence from antenatal screening that normalising HIV testing through the adoption of an opt-out approach to testing can dramatically increase uptake. In 2009, the uptake of HIV tests reached 95% in antenatal clinics nationally and also 95% among patients tested in sexual health clinics as part of the unlinked anonymous HIV testing survey.

b.2. Several prominent UK and international bodies have also concluded that issues such as late-diagnosed and undiagnosed HIV can only be tackled if testing is performed in a wider range of settings than sexual health and antenatal clinics. In 2010 the European Centre for Disease Prevention and Control (ECDC) published guidance on increasing the uptake and effectiveness of HIV testing. The ECDC guidance recommended that, in order to increase uptake, HIV testing should be offered in a variety of medical and non-medical settings, in cooperation with non-governmental organisations, and outside normal working hours. The guidance also recommended the implementation of outreach HIV testing services for marginalised groups in the community.

b.3. Evidence from the Department of Health and the Gilead UK and Ireland Fellowship Programme HIV testing pilots has consistently showed healthcare workers, regardless of setting, to be a bigger barrier to HIV testing than patients’ acceptability of being offered a test (which is high).

b.4. There is still a misconception among many healthcare professionals that specialist counselling is required before the offer of an HIV test can be made. In addition to this, poor communication between specialist HIV services and primary care means that many primary...
care staff feel very uncomfortable discussing HIV as they feel it is outside their area of expertise and is the role of specialist services.

b.5. Therefore changing healthcare professional behaviour may need to be encouraged in the first instance through a mixture of directives and incentives, education and training and the prioritisation of HIV testing as part of the Public Health agenda.

b.6. Rewarding good practice through existing incentive frameworks, both national and locally, is likely to be one of the most effective means of increasing, widening and normalising testing.

b.7. Regular offers of testing in general practice and other healthcare settings would help to normalise the practice, defuse notions of otherness and encourage understanding that HIV is just one of a range of causes of ill-health that should be considered when someone is at risk. Removing the stigma from HIV testing may also reduce late diagnosis in groups at particular risk such as men who have sex with men and black Africans.

Treatment

a. How can the NHS best commission and deliver HIV treatment?

a.1. It is important that HIV care remains led by appropriately trained specialists. However as HIV is a long-term condition, innovative care pathways could be explored which prioritise consultant time for complex patients. This could allow routine monitoring of stable, treated, well patients by a multi-disciplinary team, including the GP under consultant supervision. This also aligns well to the QIPP agenda and could release significant efficiency savings.

a.2. Specialist centres report many different pathways along which a patient will travel in accessing HIV services, and work is under way to “map” these and to evaluate the costs and subsequent benefits of each. This work is being coordinated by the national reference group which includes representation from Department of Health teams, Health Protection Agency, British HIV Association, British Association for Sexual Health and HIV, and a range of treatment centres from London, Birmingham and Manchester.

a.3. Outreach clinics could also be encouraged to enable better access to care. We note the success of initiatives such as the clinic at 56 Dean Street which is deliberately located in the heart of Soho, and offers a discreet and convenient service for both testing and aftercare.

a.4. There has been an increasing move to providing homecare-based treatment in recent years and this can be acceptable and convenient for patients. Further development of this approach would also realise savings to the NHS.

b. What impact might the proposed new commissioning reforms have on HIV treatment?

b.1. There are both challenges and opportunities to improve the management of HIV as a result of the proposed reforms. Above all we would stress the importance of HIV care remaining as a specialist-led service to ensure high quality care.
b.2 Creation of new patient pathways could allow stable, treated and well patients to be managed less frequently in a more expensive secondary care setting and closer to the community that they live in.

b.3 Engagement of GPs is not only required to reduce undiagnosed HIV but also to support the care of an ageing HIV-positive cohort of patients. Reforms to the NHS will need ensure that appropriate support is given to evaluating and implementing changes to the delivery of HIV care to patients.

b.4 Local commissioning of HIV may lead to inconsistencies in delivery of care. Therefore, HIV treatment and prevention should be a priority of both the NHS and the new public health service. A strong connection between Directors of Public Health in local authorities and commissioning of provider services is necessary to ensure that there is no disconnect in terms of new diagnosis and links to care. Currently there is no statutory requirement for this.

b.5 There is a need for a commissioning process that is able to deliver high quality care, ensure patients have ease of access to care, and that care is equitable nationally. We are particularly concerned that HIV services in low prevalence areas may be de-prioritised and so patients may be distanced, perhaps literally, from services of appropriate quality. An overview of all services should be maintained by the National Commissioning Board.

Cost

a. Have cost considerations been satisfactorily balanced with public health imperatives in HIV:

(i) Prevention policy?

a.1 Early diagnosis and prompt treatment can reduce onward transmission. It is estimated that the prevention of one new HIV infection would save the public purse between £280,000 and £360,000 in direct lifetime healthcare costs. Additionally, had all of the UK-acquired infections newly diagnosed in 2008 been prevented, there would have been a saving of approximately £1.1 billion in direct healthcare costs. This figure does not include additional indirect costs such as social care, time off work and cost of benefits, or any costs saved as a result of preventing further transmission.

a.2 In 2010, a study to demonstrate the cost effectiveness of screening in the French population was published and led to national recognition and support of a nationwide testing programme which was published by the HAS (French Department of Health) in late 2010. A subsequent publication cited the growing cost of HIV care in the UK.

a.3 The Public Health Interventions Committee of the National Institute for Health and Clinical Excellence recently observed: “Any interventions to increase HIV testing would also incur the additional costs of treating people who are HIV-positive. These costs were

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considered justifiable both from a moral perspective and from the perspective of reducing transmission of the virus.\textsuperscript{108}

(ii) Treatment policy?

a.4. Treatment of HIV is a cost-effective intervention which compares very favourably with other major therapy areas such as oncology.\textsuperscript{109}

a.5. Earlier treatment of HIV has been shown to be cost effective. The longer someone with HIV remains undiagnosed, the more likely it is that they will require more complex and expensive treatment. A Canadian study\textsuperscript{110} showed that, on average, the cost of treating HIV was two-and-a-half times higher for someone diagnosed late (with a CD4 cell count $\leq 350$ per mm$^3$) than for those diagnosed in a timely fashion in the first year. Five years on from diagnosis, patients in both groups had similar control of the virus; however, the cost of treating those diagnosed late was still 76% higher.

a.6. The comparative cost effectiveness of treatments for HIV versus other disease areas shows that treatments for HIV routinely produce incremental cost-effectiveness ratios below the common willingness to pay threshold of £30,000 per QALY and therefore represent an efficient use of NHS resources.\textsuperscript{111} We would encourage support for HIV to be considered as a long-term condition and benchmark cost-effectiveness accordingly.

Stigma

a. What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?

a.1. Since the beginning of the HIV and AIDS epidemic over 25 years ago, stigma has been a barrier to HIV prevention and care. Its significance and effect varies from setting to setting, but when present, stigma can create an environment where people may avoid HIV-related services.

a.2. Stigma not only makes it more difficult for people trying to come to terms with their own HIV and how they manage their illness, but it also interferes with the ability of the health service to tackle the disease.

a.3. On a national level, the stigma associated with HIV can deter governments from taking fast, effective action against the epidemic, while on a personal level it can make individuals reluctant to access HIV testing, treatment and care.

a.4. While recent research into the impact of stigma on HIV testing is limited, international research into the impact of stigma on HIV testing\textsuperscript{112} has shown that individuals with


\textsuperscript{110} Krentz HB and Gill J. Despite CD4 cell count rebound the higher initial costs of medical care for HIV-infected patients persist 5 years after presentation with CD4 counts less than 350 l. AIDS 2010, advance online publication, 16 September 2010. DOI: 10.1097/QAD.0b013e32833f9e1d.


stigmatising beliefs about HIV are less likely to test for the virus. Through the normalisation of HIV testing as part of a wider strategy of targeted public education and awareness-raising we can reduce the stigma associated with HIV.

b. Where are problems of stigmatisation most acute?

b.1. Stigma is most acute in those groups and individuals already stigmatised by racial and sexual orientation characteristics. It should also be noted that the failure of normal communication between secondary services and primary care with respect to HIV patients contributes to stigma.

c. What measures are currently taken to tackle HIV stigmatisation? What more should be done?

c.1. The following measures are recommended by the Halve It coalition:

- Make HIV a public health priority both locally and nationally.
- Include HIV as a specific area of priority in the new Public Health White Paper and include levels of HIV in the calculation of the ‘public health premium’.
- Ensure that the health service (whether the NHS or Public Health England) gives HIV the appropriate priority on the ground by requiring that it is systematically considered in local health needs assessments and health planning processes.
- Implement the forthcoming NICE public health guidance on HIV testing by encouraging the development and implementation of local strategies to increase HIV testing (eg testing for new GP registrants in high prevalence areas).
  - Increase and enhance the provision of education and information provided to those groups most at risk of HIV including men who have sex with men and black Africans to overcome stigma.
- Implement and enhance provision of educational information for healthcare professionals on overcoming stigma.
- Ensure that people diagnosed with HIV have access to antiretroviral therapy, known to reduce viral loads and potential onward transmission of HIV.
- Engage the wider health and social care services in prevention initiatives, which are currently largely delivered through the voluntary sector.

18 February 2011
Introductory

1. Could you please introduce yourselves and outline your role within HIV services?

I am Sarah Stephenson and I work for the Greater Manchester (GM) Sexual Health Network. The Network is funded by the 10 GM Primary Care Trusts (PCTs) and we work across all the Acute Trusts, PCTs, local authorities (LAs) and community and voluntary sector (CVS) organisations in GM. The Network's aim is to improve all sexual health services through proactive, collaborative working.

My role originally focused solely on resolving the inequity of funding in HIV adult outpatient services. My portfolio has grown to include leading on GM-wide policies to improve HIV services and also lead on specific pieces of sexual health commissioning and contracting.

GM has a population of about 3 million people and GM’s HIV population is approximately 4,000 people.

Treatment: costs

1. Research indicates that the cost of HIV treatment over time rose from £104m in 1997 to £482m in 2006; and that costs will rise above £720m by 2013. Why has the cost of care increased so dramatically?

It is likely that there are a number of reasons for this:

- The increasing complexity of drug regimes (because drugs are more sophisticated either to manage more complex HIV or because they are combination drugs that are designed to be easier for patients to take)
- Patients are being put on antiretroviral drugs (ARVs) earlier (BHIVA guidance recommends starting drug regimes when the CD4 count is 350 rather than 250 which means people are starting medication earlier)
- Because ARVs are more sophisticated, people taking them are living longer and therefore taking medication for longer
- People who have been on ARVs for a long time may have more complex health needs (e.g. secondary health problems related to drug toxicity) which may make their drug regimes more expensive
- There may be more patients who were diagnosed late (which can be more complicated to manage), especially if they, and their families, weren’t HIV tested until they arrived in the UK (although we think that the number of patients in this category decreases year on year).
a. How have commissioning arrangements been used to manage the costs of HIV treatment and care?

In GM, a range of innovations have been used to manage the costs of HIV treatment and care. This work has been centred around the revision and further development of the patient pathway and included:

- Moving patients from tertiary care to secondary care as skill levels increased
- Formalising the role of the CVS as a source of support and referral for patients
- Changing the intensity of treatment in line with improved drug regimes and increased self-care. This has led to patients being able to attend clinic less times a year and for clinics to use their resources in a different way, for example, by running telephone clinics. Some of these changes have been driven by a need to use resources as efficiently as possible where there are shortages of consultant posts (for example, during maternity leave)
- Improving equity and increasing clinic capacity by removing primary care provision at HIV clinics (HIV+ patients are now expected to register with and use a GP for their primary health care needs, in the same way that the rest of the population does)
- Development of an HIV adult outpatient tariff based on an updated pathway (a long-term condition pathway rather than on a palliative care model with a tariff based on actual costs of the agreed pathway rather than an average of all current costs).

Over that past 2-3 years we have focused on collaborative commissioning to manage our resources better, reduce transaction costs and pool our effort. This has provided more assurance in the system around partnership working (particularly with the CVS) and has helped standardise care.

We have had limited success in trying to collaboratively commission the AIDS Support Grant (ASG) with the 10 GM local authorities. The ASG is worth about £1 million in GM but its transparency and legitimacy of use are not clear. Although some LAs have collaborative contracting with the NHS to use the ASG for CVS projects, there are some areas that are spending the ASG on work unrelated to HIV.

We have been successful in implementing Home Delivery of HIV drugs. By delivery medicines direct to patients homes (or their local Post Office for collection), the NHS is able to recoup the VAT. It is a simple way to maintain the quality and confidentiality of the service whilst improving convenience and promoting HIV as a long-term condition amongst patients. Home delivery also means that we can limit the time wasted by patients waiting in pharmacy (often up to 2 hours). We are exploring ways to increase the number of patients on home delivery so that we can increase the savings made (56% of GM patients are on home delivery and this helps us save £2.5 million in VAT).

Last year, we were involved in regional procurement of ARVs. This has meant agreeing a regional price for some ARVs and means that smaller hospitals are no longer paying high premiums for using small volumes of ARVs which helps the NHS reduce its drugs bill. Some parts of England (not GM) are moving back to single drug combinations in an effort to further reduce their drugs bill, but we have heard that some drug companies are starting to increase the price of their drugs to negate any savings.
Memorandum by Sarah Stephenson, Programme Manager for Sexual Health & HIV, Greater Manchester Sexual Health Network (HAUK 82)

Treatment: price competition

2. Do you anticipate any effect on the commissioning of HIV treatment and care services arising from the prospect of competition based on price, as potentially allowed in the Health and Social Care Bill?

There are a limited number of potential providers of HIV care and there is a limited commissioning and clinical skills pool of ‘experts’ in the field of HIV. Our concern about competition would be a fragmentation of care and promotion of arrangements that would not foster collaborative relationships. We get added value from current arrangement where partners have an altruistic and collaborative approach.

Competitive behaviour – such as touting for business, undermining colleagues or ‘dumping’ high cost patients on particular centres - could undermine collaborative partnerships. We are also concerned that competitive behaviour could lead to cherry-picking of more lucrative, ‘easy’ work. A further risk is that since clinics would not gain from preventing HIV (because they would lose income), they would have no motivation to promote HIV prevention.

One problem we have is that the NHS doesn’t have sophisticated contracting and commissioning but this needs to be resolved in time for a national HIV adult outpatient tariff.

However, if commissioners had control of the whole pathway then they could decommission services to reinvest funding elsewhere which is particularly important in times of austerity.

Treatment: value-based pricing

3. The recent Equity and Excellence White Paper proposes that drug companies should be paid under a “value-based pricing” system. How has this proposal been received by commissioners? What will it mean for the price of antiretroviral drugs?

It isn’t clear from the White Paper how a ‘value-based pricing’ system could work for HIV drugs. Whilst we can imagine how this would work in relation to cancer drugs, it isn’t clear to us how this would work in practice for HIV drugs which are prescribed long-term.

HIV Commissioning: existing approach

4. At what scale do you believe HIV services should be commissioned? What have been the benefits of pan-London commissioning? Have there been any drawbacks or difficulties?

There are no HIV commissioners in GM only sexual health commissioners with HIV as part of remit.

In GM we have benefitted from having long-term engagement with colleagues across GM and the NW. The Network has been able to pool resources to work collaboratively or use collective pressure to improve services. Our typical way of working is to present a range of
options for addressing problems and let commissioners decide collectively which solution they prefer.

We haven’t removed their authority or their budgetary control but have made it easier for them to be involved and work collectively. On reflection, we’ve achieved more than if we were authoritarian, but we have had 7 years of engagement.

We have actively sought skilled individuals to lead specific pieces of work and have fostered participation and a culture of Network working. We have valued the development of the National AIDS Trust’s (NAT) commissioners’ e-notice board where commissioners from across the country can share good practice.

a. To what extent should this regional commissioning approach inform commissioning practice elsewhere in the country?

Commissioning on a larger scale has been beneficial both on a Greater Manchester level and regionally as it has allowed us to use our resources more effectively and pool knowledge. Even sharing good practice has been valuable locally, regionally and nationally.

There has been a vast improvement locally in our commissioning particularly over the last 12-18 months with new appointments and the development of the NAT website. Commissioners seem to have more collective strength through increased collaboration and we welcome this.

HIV commissioning: financial incentives

5. How have financial incentives such as CQUINs been used to improve service delivery? What role do payment incentives have to play in ensuring the effective commissioning of services and enhances clinical outcomes?

CQUINs represent 1.5% of income and in GM we have had more pressing issues that have needed to be addressed first, namely:

- Future redesign (as a result of the White Paper)
- Pathway redesign
- Equity of funding for HIV care.

We feel that the basics need to be in place first before addressing CQUINs. For GM, these basics would include:

- Equitable funding of HIV services
- Robust contracting arrangements
- A database of existing patients – confidentiality has sometimes hampered progress in relation to data but we do need better data systems
- A sophisticated system to monitor the pathway (and as such, a sophisticated system to monitor future contracting/tariff arrangements).
Proposed commissioning reforms

6. How will the reforms proposed in the Health and Social Care Bill affect the commissioning of HIV treatment and care? Is the national level the appropriate scale for such commissioning?

As HIV is a clinical service it makes sense for it to be commissioned through the National Commissioning Board (NCB) rather than through the Health and Wellbeing Boards (HWB). We would want to avoid any fragmentation of commissioning as this would be a retrograde step and it will take time to get all the LAs working together if they take responsibility for HIV commissioning. It is important to avoid incoherent and confusing commissioning. For example, for the CVS they could be commissioned through LA and Acute Hospitals which would mean their funding sources could be multiple but without a coherent strategy. For GM, it would make sense to put HIV commissioning under the NCB and commission from the GM cluster. We do need to avoid naïve commissioning as sexual health and HIV do require specialist expertise.

In GM we have no experience or history of good commissioning from local authorities (LAs) which, in relation to the ASG, resulted in poor outcomes. As HIV is not local authorities’ area of expertise it’s possible they could make naïve commissioning decisions (for example, questioning the level of expenditure on HIV drugs). In addition, if HIV is commissioned through LAs, will the public influence how LAs fund services and could this be inflammatory in relation to HIV care?

In GM we always look to commission across GM. There is still limited sophistication in contracting and commissioning but we are working to improve this. PH White Paper only mentions SH. For GM it would be best to have GM arrangements to build on good work already done. We would recommend that HIV commissioning needs to stay with sexual health commissioning (and by ‘sexual health’ we mean fully integrated genito-urinary medicine (GUM) and contraceptive and sexual health (CaSH) services).

HIV Commissioning: “Any Willing Provider”

7. The Health and Social Care Bill proposes to further develop competition within the NHS by allowing ‘any willing provider’ to deliver healthcare. What effect do you believe this might have on HIV services?

In GM we have encouraged other providers to avoid inequity of provision. Local hospitals have developed HIV management skills to manage HIV care closer to where patients live.

Commissioning and contracting needs to be excellent if you are developing competition and we are not convinced that the NHS has fully developed this expertise.

It isn’t clear whether there is a true market in HIV as expertise is limited. We are concerned about the negative effects of competition (as outlined in Q3) and as resources reduce it’s important to collaborate to get the best out of services.

HIV services cannot be allowed to fail because of the risk of transmission and the increase in financial costs this would cause.
Commissioner/clinician relationship

8. How, in your experience, has the relationship between commissioners and clinical staff operated? To what extent is commissioning practice informed by the experience of clinical staff?

Greater Manchester has a clinical sexual health network. The network concept is to include clinical engagement and involve clinicians in decision-making and this is how we operate.

The competency and capacity of commissioners has developed in the past few years as we have had practical problems to overcome (such as: finding a meeting room; commissioners having the mandate to make decisions; having colleagues senior enough to be able to make decisions; turnover of staff).

Integration of services

9. How have you worked to integrate HIV prevention, testing, treatment and care services? What value do you think this has had?

The pathway work helped people realise the value of other professionals and how they were able to offer complementary support. It is traditionally difficult to secure funding for prevention work as the outcomes are more difficult to measure.

10. Do you believe that the proposed NHS reforms will have any effect on the ability to deliver integrated HIV services?

It will depend on how HIV/SH services are commissioned. If funding is ring fenced and under public health and commissioned by health then we wouldn't foresee a problem in commissioning integrated HIV services. If services are to be commissioned by local authorities then we are concerned about a lack of experience and the greater level of political influence in local authorities which would affect commissioning and service delivery.

Being in a state of change distracts people from being able to get on with normal business so services will be affected by the proposed changes. Prevention work in particular always suffers during a period of change.

11. Is there a case to be made for a holistic approach to all GUM services? How best might one seek to develop a holistic service for those with HIV under the new commissioning arrangements? What are the risks and opportunities of such a development?

Our view is that we need a holistic view of services. It's about all SH services (GUM, CASH and HIV) being commissioned as an integrated service. It's not about the medical discipline but about the part of the body it relates to and we would want a service model where GUM, HIV and contraception can be addressed in the same SH appointment.

An integrated model allows you to have:

- Consistency across an area
- Flexibility to move work down the pathway and release resources
• Arrange cross cover to maintain service provision (for example in GM, we don’t have the optimum level of consultants but holistic, collective commissioning would allow us to make the best use of the resources we do have)
• Ensure an optimum service across an area
• Share resources to reduce transaction costs
• Avoids organisational boundaries that can hinder progress or collaborative working
• A lack of organisational boundaries is useful for commissioning and service provision.

There does need to be improved integration and joint working between paediatric and adult services to ensure a smooth transition for teenagers moving from paediatric services to adult services. These patient numbers will diminish over time so an exit strategy needs to be planned.

Treatment: measuring outcomes

12. Reforms to the NHS envisage service provision being driven by outcomes. In the new Public Health Outcomes Framework, only one indicator relates to HIV: the proportion of persons presenting with HIV at a late stage of infection. Is this a good choice? Is this single indicator sufficient?

It is unlikely that we would secure more than 1 indicator so if his is the only one then it is a good one as it also shows how many patients present early. Other indicators we’d recommend would be:

- % of people HIV tested
- % of children born with or developing HIV from vertical transmission.

A greater focus on prevention would be helpful to reduce infection and associated costs to the individual and the NHS113.

13. What can be learnt from the experience of the London SCG in using HPA indicators to monitor HIV treatment and care more widely?

113 "It is estimated that, ‘the monetary value of preventing a single onward transmission is between £0.5 million and £1 million in terms of individual health benefits and treatment costs’”


“Preliminary estimates of the HIV-related life-time costs for diagnosed individuals range between £280,000 and £360,000 in the UK.”

London SCG uses HPA SOPHID data to inform their HIV commissioning. In GM we receive the SOPHID annual report but our most frequently used data source is one which the North West PCTs commission through Liverpool John Moores' University (JMU). JMU data informs the HPA SOPHID database.

I personally use the JMU data more frequently because it is simpler to access and interrogate (specific data can be extracted online). JMU researchers are on hand to provide ad-hoc data tables for specific queries and we have a good working relationship based on years of collaboration. That said, I do use the HPA data to gather data about GM residents who access care in other parts of the country.

**Monitoring and surveillance**

14. **How have surveillance and monitoring of HIV prevalence been used to support effective commissioning practice?**
   
   b. **Do you believe the proposed public health reforms, and the abolition of the HPA, will impact upon these systems?**

We have specifically used JMU and HPA data to inform commissioning work around:

- Older people with HIV and highlighting the need for the local authorities to be aware of their future needs
- The number of HIV+ people attending multiple treatment sites (and the clinical and financial risks of this behaviour)
- PCT impact of HIV – the number of HIV+ residents
- Ratio of attendance by clinic and how this compares with the patient pathway
- PCT and Acute Trust impact of moving to an adult HIV outpatient tariff
- Back up anecdotal evidence in order to present a case for action to commissioners.

If we lose the data we currently collect we’ll:

- Lose the national picture as we won’t be able to compare areas although we would still have the North West data
- Lose verifiable data (which helps inform commissioning)

We had problems when the Termination of Pregnancy data reports were changed as it became impossible to compare like-for-like data for a range of years. This meant that for some years we were unable to fully assess the impact and value of the improvement work we had done.

April 2011
I. The Committee has received evidence that the balance of spending between prevention and treatment is disproportionate. Do you agree with this assessment?

Yes. From my experience, these seem to be some of the reasons for this:

Evidence for prevention is not always available. This can be because:

- The human resources or time and effort needed to carry out preventative programmes can be disproportionate to other branches of NHS work therefore it is seen as being more expensive.
- Prevention work that does not have a formal basis (i.e. contract or an infrequently reviewed contract) can be difficult to performance manage.
- Evidence sometimes isn’t always shared or documented which means it is ‘lost’.
- It is sometimes difficult to gather hard evidence about prevention work (e.g. assessing the efficacy of a condom distribution scheme is difficult. What are its measures of success? A lower STI rate? The number of condoms handed out?)
- Prevention programmes often do not show instant results but rather changes in behaviour over time. The monitoring and evaluation of these programmes is essential for identifying what works and what doesn’t work but takes time and money.
- There appears to be a culture of sharing evidence of what works but people are less keen to share what doesn’t work. This reluctance to share information on less successful initiatives means that others may make the same decisions with little success.
- There is a lot of evidence but it is held in lots of different places, with lots of different organisations which means it can be difficult to access.

It can sometimes be difficult to argue the case for prevention even though it makes public health sense. I get the impression that prevention work is sometimes seen as having woolly evidence or that public health has less influence because it’s not seen as a science in the way medicine is. Prevention work is still seen by some people as an added extra if there is funding left over from funding treatment services. If there are cuts to be made then prevention work will be reduced before treatment services, despite the evidence to show the savings made by prevention.

Treatment of people with HIV (or any other illness) is, in my view, seen as a priority because the patients are in front of you, rather than thinking about why they ended up in front of you in the first place. I think there is a fine line between practitioners coaching patients to take better care of their health (i.e. giving prevention messages) and feeling that they are lecturing patients and possibly putting them off using services in the future.
Prevention covers a wide range of initiatives including training professionals, brief intervention programmes, campaigns, providing information, providing prevention services (e.g. safer sex packs). The public health teams that lead on these areas need to demonstrate to commissioners that the initiatives have been evaluated and show the savings made. The success of this will depend on the evidence provided to commissioners and the willingness of commissioners to see the value in the work. Funding for treatments appears to be a much simpler process with an invoice sent to the commissioners for payment.

The NHS is not good at being proactive; it operates on a reactive model and therefore treatment (reactive medicine) is always prioritised over proactive (preventative) work. The culture in the NHS does not foster proactive working whether it’s forward planning for policy changes or treatment models because it tends to be concerned with the present rather than the future. In addition, the size of the NHS and the frequency of change can be a hindrance to fostering a proactive culture.

a. **Is it the case that resources must be balanced between the two? Would more spending on prevention require additional resources, or are there efficiencies within treatment spending which can be achieved to boost funding for prevention activities?**

Resources should be more balanced between treatment and prevention (based on the public health adage that rather than trying to pull people out of the river downstream, you should walk upstream to find out why they fell in in the first place). Current prevention spends are very low at around 4% of total PCT budgets.

I feel that there are many inefficiencies in health services that could be addressed in order to release funding to spend elsewhere without compromising quality of care (and in some cases improving quality). These include:

1. Home delivery of HIV drugs (in Greater Manchester this could release up to £3 million in VAT savings (you don’t pay VAT on drugs delivered to patients’ homes/local Post Office/place of work). Home delivery is already set up in Greater Manchester but isn’t being used to its full capacity (something we are working on at the moment)
2. Better use of IT to make record-keeping more efficient (e.g. if there is a drug recall clinics often have to do a manual trawl through paper notes but use of IT can reduce this wasted time)
3. Better use of 'brief interventions' to reduce the number of repeat attenders therefore reducing costs
4. Collaborative purchasing of drugs to reduce costs
5. Collaborative contracting – instead of 10 PCTs/PBC consortia commissioning 10 separate contracts with an organisation to do a piece of work/provide a service, they have a collaborative contract that they all contribute to. Efficiencies would be seen in a reduction of effort required to manage the contracts (GM has several such collaborative contracts)
6. Dual-trained staff – having staff that can deliver genito-urinary (GU) and contraceptive services so that patients have all their sexual health needs dealt with in one appointment. It’s better for the patient and it reduces costs because the patient doesn’t have to be seen twice (which currently incurs two attendance costs)
7. In HIV services, stopping prescribing primary care medicines that can be done in primary care would reduce the drug bill (not significantly), reduce the amount of time HIV services are spending on non-HIV care and would have a significant effect on promoting HIV as a long term condition and promoting self-care and self-management (we already have this in place in GM).

8. Ringfencing of the AIDS Support Grant (ASG). This was ringfenced until April 2011 but even when it was ringfenced our experience in GM is that it wasn’t always used on HIV-related activities. If the ASG was ringfenced and better managed then this would improve efficiencies. As an example, in GM, the ASG was used in the past to purchase ‘fridges for people with little money so that they could keep their medicines refrigerated. However, there was no way of managing these assets so that ‘fridges were redistributed to other people that needed them rather than buying new ones every time. A lack of scrutiny means that ASG money is not necessarily always used on HIV-related activities and we have anecdotal evidence of ASG money being used to inappropriately fund staffing costs.

It should be noted that contracting and financial accounting systems are not sophisticated enough to ringfence budgets in order to implement this ‘save to spend’ methodology. Currently, sexual health service payments go in to Acute Trust baselines and, as with many other services, are used to cross-subsidise other services. If they were ringfenced then commissioners and providers would have more incentive to make efficiencies because they’d be able to invest those savings back in to services. At the minute, for service providers in particular, it can be frustrating that they make savings that they cannot reinvest in services. There isn’t always the motivation to be efficient because even if you are, the savings don’t come back to the department. Altruism sometimes isn’t enough of a motivation.

2. How, in your experience, has the relationship between commissioners and clinical staff operated? To what extent is commissioning practice informed by the experience of clinical staff?

In Greater Manchester we have a managed clinical network so there are close relationships between commissioners and clinical staff. We work with clinical staff to inform commissioning and this has been valuable as there are often practical implications of commissioning plans that clinicians are best placed to highlight. I think the difficulty comes when commissioners and clinicians disagree on the best way forward as ultimately the commissioner is responsible for commissioning the service so they sometimes have to make tough decisions that clinicians sometimes don’t agree with.

8 June 2011
Memorandum by the Haemophilia Society (HAUK 42)

The Haemophilia Society would like to draw the Committee’s attention to a frequently overlooked group of HIV positive individuals. There are less than 360 people with bleeding disorders living with HIV in the UK who were all infected as a result of being treated with contaminated NHS blood products. Over 1200 people with bleeding disorders and their partners were infected in the 1970s and 80s as a result of this disaster.

It is notable that this group of HIV positive people with haemophilia, infected through their medical treatment, are all co-infected with hepatitis C and have lived with HIV since before it was even identified as HTLV-III in 1984. The haemophilia community therefore has a distinct perspective on the issues of monitoring and stigma.

HIV Prevention

Continued vigilance is required to maintain the safety of the blood supply. Decisions about which individuals or groups are excluded from blood donation must continue to be based on scientific evidence alone. We do not consider it is safe to rely on donor testing to exclude HIV from blood-based medical treatments, since there is usually a short period after infection when the test is not effective.

Treatment

Most people with bleeding disorders and HIV access HIV services through referral from their Haemophilia Centre. When HIV is being treated in combination with HCV and a bleeding condition, effective co-ordination between services is very important. The commissioning structures must not make it more difficult of specialist and non-specialist services to work together.

Stigma

As one of the first groups of people to be identified with AIDS in the early 1980s, people with haemophilia and HIV lived with intense stigma that accompanied the virus during that period. There were cases of doors daubed with graffiti, lost jobs and children not allowed to mix with other children at school – in short people were denied a normal family life. This has had a lasting impact. Often HIV status is a closely guarded secret, and the fear of discovery leads to anxiety and stress. We would urge the Committee to remember that the psychological impact of previous persecution continues even if current attitudes are comparatively enlightened. The stigma that still exists can often trigger fears related to severe discrimination suffered in the past. As recently as 2004, the Macfarlane Trust helped a registrant to move home to escape persecution.

A recent opinion poll found that 75% of the British population believe there is still a strong stigma attached to HIV. One fifth of HIV-positive people questioned had recently experienced discrimination and rejection. Almost half had experienced problems with self-confidence in the previous twelve months. Internalised stigma also contributes to mental health problems, which occurs more frequently in people with HIV than the general population. One of our members said:
'I was about fifteen, beginning to get seriously involved with a girl and I decided to tell her about my status. She seemed fine, but a couple of weeks later she told me she’d met someone else. It was a real body blow. Took me years to get over.'

People with HIV report a temporary or even permanent deterioration in their relationships with friends and family after their diagnosis. In some instances, housemates and family members have refused to use the same crockery and cutlery as people they know to be HIV positive, and sheets have been burnt after HIV-positive people have slept in them. The majority of people with HIV in the UK have not told some or all of their family. One in three Macfarlane registrants said nobody other than the Trust and medical professionals knew their HIV status. This often includes people with whom they are living, making it difficult to manage treatment or access support.

There is currently little of no specialist psychological support available although the The Rt Hon Andrew Lansley MP announced a small amount funding stream on 10 January 2011 in the House Commons.

Groups representing people with HIV have repeatedly identified the need for public awareness and education campaigns. Prejudice is usually based on ignorance, and it is hoped that such campaigns would reduce stigma, help overcome discrimination and possibly even aid disclosure.


Further Information

There is a range of organisations or projects which the Committee may find useful in the course of their Inquiry:

- The MacFarlane Trust – A trust set up to aid people with haemophilia and other bleeding disorders infected with HIV through their medical treatment. (http://www.macfarlane.org.uk). The Trust is aware of 334 people with a bleeding disorder and HIV and 41 infected intimates. They also work with 270 non infected widows and 60 dependents under 21 years old.
- The Elieen Trust – a trust set up to aid people who contracted HIV through NHS blood transfusions (contacted through the MacFarlane Trust).
- The Living Stories Project at the British Library - an oral history archive which stores recordings of victims of the contaminated blood disaster telling their stories (http://www.livingstories.org.uk).
- The Archer Inquiry (http://www.archercbbp.com)

February 2011
Memorandum by the “Halve It” Coalition (HAUK 50)

The following evidence has been prepared in collaboration with members of the Halve It Coalition

“Halve It” coalition

“Halve It” is a coalition of HIV and healthcare experts who are determined to tackle the continued public health challenges posed by HIV.

Our members represent the following organisations:

- African Health Policy Network
- All-Party Parliamentary Group on HIV and AIDS
- British Association for Sexual Health and HIV
- British HIV Association
- Gilead Sciences Ltd
- London Sexual Health Programme
- Medical Foundation for AIDS and Sexual Health
- National AIDS Trust
- National HIV Nurses Association
- Sex, Drugs and HIV Group of the Royal College of General Practitioners
- Terrence Higgins Trust

There are over 22,000 people in the UK who are HIV positive but do not know it, and of those who are diagnosed, more than half are diagnosed late.114 The “Halve It” coalition calls upon all levels of government to make HIV a public health priority both locally and nationally. “Halve It” are working to halve the proportion of people living with undiagnosed HIV and halve the number of people diagnosed late with HIV over the next five years.

Halving undiagnosed HIV by 2015 will mean fewer new HIV infections, fewer early deaths and more money saved by the NHS at a time when every penny counts. The campaign recognises that early testing for HIV can save lives and prevent onward transmission and calls on the government to make HIV a public health priority.

Please find overleaf the “Halve It” coalition response to the call for evidence from the House of Lords Select Committee on HIV and AIDS in the UK.

Summary

Monitoring

It is imperative that, as accountabilities for monitoring and surveillance change, the characteristics of the HPA are retained and further enhanced. Current recommendations regarding an information warehouse may threaten the involvement of local public health

experts closely involved in surveillance and reporting and who are crucial in leading the local response to HIV.
We need to strengthen the relationship between national surveillance and HIV testing by enhancing local HIV reporting procedures while maintaining a world-class national surveillance capability. We need to improve the level of transparency by requiring the local public health service to report back to the public on local progress in tackling late HIV diagnosis and new levels of infection.

**Prevention**

Government policy is not sufficiently focused on HIV prevention. Public awareness of the dangers of HIV has fallen and unnecessary transmissions are occurring. We believe it would be possible to halve the number of undiagnosed HIV cases and this is the reason for creating the “Halve It” campaign. This would have a profound impact on HIV transmission and hence prevention.
Incentives should be put in place to encourage local healthcare providers and Directors of Public Health to increase their focus on HIV prevention, deliver appropriate services and evaluate the impact of these measures. HIV and HIV prevention should be a priority of the NHS and Public Health England, which should play a lead role in the coordination and evaluation of prevention initiatives.

**Testing**

Issues such as late-diagnosed and undiagnosed HIV can only be tackled if testing is performed in a wider range of settings than sexual health and antenatal clinics. Regular testing should be offered in high prevalence areas and this needs to be accompanied by a mixture of directives and incentives. Such testing should be open access for those at risk and routine in new GP registrants.
If HIV testing were a national priority, barriers to individuals taking tests and healthcare professionals promoting tests would be overcome. Regular offers of testing in general practice and other settings would help to normalise practice, defuse notions of otherness and encourage understanding that HIV is one cause of ill-health that should be considered when someone is at risk.

**Cost**

Early diagnosis and prompt treatment can reduce onward transmission. The prevention of one new infection could save £280-360K in direct lifetime healthcare costs.115 £1.1 billion in direct healthcare costs would have been saved if all newly diagnosed infections in 2008 been prevented, excluding indirect costs eg time off work, state benefits, or the prevention of onwards transmission.116

**Stigma**

Stigma not only makes it more difficult for people trying to come to terms with their own HIV and how they manage their illness, but also interferes with the ability of the health

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service to tackle the disease. Through the normalisation of HIV testing as part of a wider strategy of targeted public education and awareness-raising we can reduce the stigma associated with HIV.

“Halve It” coalition response

Monitoring

a. How robust is the current system for monitoring the number of people with HIV in the United Kingdom?

a.1. The current system is effective in monitoring the number of people with HIV in the UK. At present, the UK’s surveillance and monitoring process led by the Health Protection Agency (HPA) is capable of publishing robust data on the following, at least annually:

- Estimated number of people living with HIV
- New HIV diagnoses
- Recently acquired HIV infections
- Late diagnosis, AIDS and deaths among HIV-infected individuals
- People in HIV care
- HIV among adults 50 years of age and over
- Prevalence of undiagnosed HIV infection in STI clinic attendees
- HIV among pregnant women and children
- HIV testing
- Monitoring HIV care in London

a.2. The indicators set out above are comprehensively sourced, and interpreted by expert staff. The HPA’s data are reliable and widely respected as a definitive source of information. Furthermore, the HPA plays a valuable role as a crucial international partner with the European Centre for Disease Control and Surveillance, based in Stockholm, as with the World Health Organisation (WHO) and UNAIDS globally.

a.3. In its 2010 report on HIV the HPA\(^{117}\) recommended that the clinical outcome indicators recorded to assess the quality of HIV care received by patients in London should be adopted nationally.

b. Will the proposed public health reforms impact on this system?

b.1. The current approach to monitoring trends has proved to be very effective. The HPA has adopted a comprehensive approach to understanding and communicating the changing face of HIV in the UK. It is imperative that, as accountabilities for monitoring and surveillance change under the forthcoming healthcare reforms, the positive characteristics of the agency are retained and further enhanced.

b.2. Currently, clinicians voluntarily report data to a national centre; this is coordinated by the HPA, which has capacity to deliver large-scale data collection, analysis and reporting. This capacity has proved a cornerstone in delivering a coordinated public health response.

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b.3. The current recommendations regarding an information warehouse potentially threaten
the involvement of local public health experts who are closely involved in many aspects of
surveillance and reporting, and they are crucial in leading the local response to HIV.

b.4. There is a danger to outsourcing the aggregation of data; indeed it can lead to a
separation in the responsibilities of those collecting data and those who analyse it. This
separation has the potential to reduce the quality of the findings on HIV trends and
therefore the response to it.

c. Could anything be done to improve monitoring?

c.1. We need to improve HIV information systems in the NHS. At present these are quite
limited for HIV, particularly in primary care. In high prevalence areas this information is
especially crucial for training, increasing awareness for healthcare professionals and
prevention, as well as service planning for GP consortia (in particular, expanding HIV testing
or HIV long-term condition service planning). This is especially concerning as HIV is likely
one of the fastest growing chronic conditions in the UK.

c.2. We need to strengthen the relationship between national surveillance and HIV testing
by enhancing local HIV reporting procedures while maintaining a world-class national
surveillance capability.

c.3. We need to improve the level of transparency by requiring the local public health
service to report back to the public on local progress in tackling late HIV diagnosis and new
levels of infection.

d. What groups in particular are at risk from HIV?

d.1. Predominantly HIV is transmitted among the following populations:

- Men who have sex with men
- Black Africans
- Injecting drug users

d.2. However, in recent years there has been an increasing case-load of heterosexual
transmission in the UK. Given there is lower prevalence in the general population than in
the populations listed above, identifying HIV among the general population can present a
challenge in that HIV tests are less likely to be offered, those infected remain unaware of
their own status and HIV may be diagnosed late. It should also be noted that black
Caribbean’s also have elevated rates of HIV prevalence.


d.3. In addition, the joint British HIV Association, British Association of Sexual Health and
HIV; and British Infection Society guidelines for HIV testing recommend offering HIV tests
to the following groups, who may be regarded as being ‘at risk’ of HIV infection:

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118 Health Protection Agency. Sexually transmitted infections in black African and black Caribbean communities in the UK:
February 2011.

119 British HIV Association, British Association of Sexual Health and HIV, British Infection Society. UK National Guidelines
Memorandum by the “Halve It” Coalition (HAUK 50)

- All patients presenting for healthcare where HIV, including primary HIV infection, enters the differential diagnosis (see table of indicator diseases and section on primary HIV infection)
- All patients diagnosed with a sexually transmitted infection
- All sexual partners of men and women known to be HIV positive
- All men who have disclosed sexual contact with other men
- All female sexual contacts of men who have sex with men
- All patients reporting a history of injecting drug use
- All men and women known to be from a country of high HIV prevalence (>1%*)
- All men and women who report sexual contact abroad or in the UK with individuals from countries of high HIV prevalence.

Prevention

a. Is government policy sufficiently focused on HIV prevention?

a.1. Government policy is not sufficiently focused on HIV prevention. There is also a problem that public awareness of the dangers of HIV has fallen and therefore unnecessary transmissions are still occurring.

a.2. HIV prevention has historically largely focused on behavioural prevention only. There is limited UK-based, formally evaluated evidence on the effectiveness of UK prevention programmes in the anti-retroviral therapy (ART) era, particularly for black Africans.

a.3. There is also insufficient focus upon testing. Increasing the uptake of HIV testing raises the proportion of people who are aware of their status. Once an individual’s HIV infection has been diagnosed, they can access appropriate care. Effective treatment significantly reduces viral load and infectiousness, and thus the likelihood of transmitting HIV. Few transmissions take place when one sexual partner is HIV positive and on antiretroviral therapy and the other is HIV negative.

a.4. A study has shown that those living with HIV who are aware they have been infected are more likely to take precautions, such as using condoms, to prevent transmission to partners. A study of newly diagnosed HIV-positive men who have sex with men reported that 76% had eliminated the risk of onward transmission 3 months after diagnosis.

a.5. A negative HIV test, on the other hand, provides an opportunity to offer preventive education and advice and may also lead to changes in behaviour. Notification of current and former sexual partners to recommend testing and treatment is also possible following diagnosis. Treatment during pregnancy and careful management of delivery allows women aware that they are HIV positive to plan for HIV-free births and childcare. More widespread testing, earlier diagnosis and treatment, especially in areas of high prevalence and among groups at increased risk, provide a clear public health benefit by reducing onward transmission rates.


a.6. With a determined effort we believe it would be possible to halve the number of undiagnosed HIV cases and this is the reason for creating the ‘Halve It’ campaign. This would have a profound impact on HIV transmission and hence prevention.

a.7. Back in the 1980s HIV and AIDS had a very high profile – and rightly so. Patients were dying, there was no cure for it and there were no drugs to treat it. That is why, as Secretary of State for Health, Lord Fowler mounted an extensive public education campaign using television, radio and poster advertising, and sent letters to all households to prevent the spread of HIV and AIDS.

a.8. Today the profile is nothing like as high and more people are living with HIV than ever before. The assumption is that new drugs have solved the problem and that fewer people are infected. Nothing could be further from the truth. There is still no cure and, away from the public gaze, HIV has developed into one of Britain’s fastest growing health conditions. According to the HPA’s 2010 HIV report, the number of people living with HIV in the UK had reached an estimated 83,000 by the end of 2008. A quarter of these were unaware of their infection and over 50% of them were diagnosed late.122

a.9. Thanks to combination ART, the life expectancy of someone living with HIV has increased markedly over the last 15 years. Recent research123 found an individual diagnosed with HIV at the 35 years of age, with prompt access to ART, can expect to live to 72 years of age, only a few years less than a person without HIV.

a.10. The stigma associated with HIV has ensured that the growth of the epidemic has been silent, but each year, thousands of individuals are infected, by people who are not even aware they are living with HIV themselves. Lives are being harmed, even lost, because people are being diagnosed either late or not at all.

a.11. More than two decades after the ‘tombstone’ campaign, it is time we refocused on HIV and those most at risk of being infected. We call upon government to increase and enhance the provision of education and information to specific vulnerable groups. In particular, black Africans and men who have sex with men are critical groups on which to focus HIV prevention services. There is, however, another important factor: the fact of living in a high prevalence area is a surrogate risk in itself and so the concept of routine testing in these areas is important and efficient for case-finding and transmission reduction.

b. Have the right groups been targeted in recent prevention campaigns?

b.1. Current prevention campaigns have focused on HIV prevention among men who have sex with men, among black Africans; and injecting drug users. We consider that these groups are the most at risk. These campaigns have been reasonably effective in generating awareness; however, they have not been supported to the degree required to be wholly effective to communicate with these groups throughout the country. There is also a need to further target complementary prevention (e.g. behavioural and biomedical) in these at-risk groups.


c. To what extent have prevention initiatives targeted at injecting drug users been successful?

c.1. Prevention strategies aimed at injecting drug users have enjoyed mixed success.

Highlighting the challenges inherent in this strategy, a recent HPA report stated that the prevalence of HIV among current injectors has increased from 0.7% to 1.5% over the past decade, and is now similar to the level found in the early 1990s.\(^{124}\)

c.2. In addition, needle and syringe sharing has declined in recent years, but around one-quarter of injecting drug users continue to share.\(^{125}\)

c.3. Infections are common among injecting drug users. Around one-half of injecting drug users have been infected with hepatitis C, one-sixth with hepatitis B and about one-third reported a symptom of a bacterial infection (such as a sore or abscess) at an injecting site in the past year.\(^{126}\)

c.4. The prevalence of HIV among those who have injected drugs remains low in the UK; however, within the overall average of 1.5%, prevalence varies from 0.6% in Scotland to 4.1% in London.\(^{127}\)

c.5. The uptake of HIV testing is improving, with three-quarters of injecting drug users now reporting that they have had a test; however, almost a third of injecting drug users with HIV remain unaware of their infection.\(^{128}\) The vast majority of HIV-infected injecting drug users in contact with specialist HIV treatment services are receiving ART.\(^{129}\)

c.6. Specific settings such as prisons may be particularly appropriate to conduct testing initiatives. One such example is an inter-agency framework for blood-borne viruses (BBVs) screening in prisons in Dorset which was established in 2008. In this project a targeted approach to testing supported by technology-based educational packs and videos for prisoners in multiple languages was adopted. The project, run by the local genito-urinary medicine (GUM) service and prison staff, sourced HIV and AIDS information videos in many languages, uploaded to touch screen computers for prisoners to access in their own language to encourage screening for BBVs. In 2008/09, before the introduction of the initiative, only 27% of HIV-positive inmates, seen by GUM had been diagnosed HIV positive. After the intervention in 2009/10, 78% of HIV-positive inmates seen by GUM had already been diagnosed HIV positive.

d. How could prevention initiatives be better delivered and evaluated?

d.1. The Public Health White Paper consultation proposes sexual health/HIV prevention and sexual health services to be commissioned locally through local authorities; HIV treatment

services, however, are expected to be commissioned through the National Commissioning Board. The resulting prevention and treatment split provides few incentives for prevention-treatment pathway developments.

d.2. Incentives should be put in place to encourage local healthcare providers and Directors of Public Health to increase their focus on HIV prevention, deliver appropriate services and evaluate the impact of these measures.

d.3. The Department of Health has been running 8 testing pilots in high prevalence settings over the last year, and the Gilead Sciences Fellowship Programme, in operation since 2009 has funded 25 pilot projects on HIV testing. Both initiatives created forums for sharing best practice and learning among key stakeholder groups. The Outcomes of these projects should be considered by the Committee. Work is now being undertaken to demonstrate the cost-effectiveness of such testing strategies.\(^{130}\)

d.4. HIV and HIV prevention should be a priority of both the NHS and the new Public Health England. Public Health England should play a leading role in the coordination and evaluation of prevention initiatives.

d.5. The NHS and Public Health England should give HIV the appropriate priority on the ground by requiring that it is systematically considered in health needs assessments and other relevant local health planning processes.

d.6. Public Health England should also be transparent in reportage and be accountable for informing the public of both local and national progress in tackling late HIV diagnosis and levels of new infection.

d.7. The full implementation of the upcoming National Institute for Health and Clinical Excellence (NICE) public health guidance on HIV testing will further enable the improvement of HIV prevention efforts.

Testing

a. Are current testing policies adequate across the country?

a.1. Several prominent bodies have concluded that issues such as late-diagnosed and undiagnosed HIV can only be tackled if testing is performed in a wider range of settings than sexual health and antenatal clinics.

a.2. In 2007, the UK Chief Medical Officers wrote to healthcare professionals, including GPs, urging them to offer and recommend a HIV test to their patients if they may have been exposed to HIV infection. Research on the effectiveness of this letter in terms of changing testing behaviour showed little change.\(^{131}\)

a.3. In 2008, the British HIV Association, the British Association for Sexual Health and HIV and the British Infection Society published guidelines and recommendations on testing for

\(^{130}\) Publication in preparation

\(^{131}\) Prescription for change, Barton S, The House Magazine, 25 May 2009

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HIV. In September 2010, NICE issued draft guidance on increasing the uptake of HIV testing among men who have sex with men and black Africans in England. They all reached similar conclusions: we must scale up HIV testing to include general practice and other settings.

a.4. The UK national guidelines for HIV testing, prepared jointly by the British HIV Association, the British Association for Sexual Health and HIV and the British Infection Society and published in 2008, recommend that HIV tests be offered and encouraged in a much broader range of settings including genitourinary medicine (GUM) or sexual health clinics, antenatal and pregnancy termination services, drug dependency programmes, and healthcare services for those with tuberculosis, hepatitis B, hepatitis C and lymphoma.

a.5. Testing should be considered for all men and women registering with GPs and all general medical admissions in areas where diagnosed HIV prevalence exceeds 2 per 1,000 of the population. This was the case in 43 English local authorities in 2008. Recent data has demonstrated that HIV testing is cost effective where prevalence is 1 per 1,000 of the population. HIV testing should be routinely offered and recommended to all patients presenting with conditions associated with HIV, with a sexually transmitted infection, all sexual partners of those known to be HIV-positive, all men who have sex with men, women who have sex with bisexual men, patients reporting a history of injecting drug use, all men and women from countries of high prevalence and all sexual contacts of individuals from countries of high prevalence.

a.6. Similarly, in its draft 2010 public health guidance on HIV testing among men who have sex with men and Africans, NICE recommends that local strategies be developed to encourage individuals to consider testing, drawn up in consultation with local voluntary organisations and community members.

b. What can be done to increase take-up rates?

b.1. Firstly, regular testing should be offered in high prevalence areas and, realistically, this needs to be accompanied by a mixture of directives and incentives. Such testing should be open access for those at risk and routine in new GP registrants. This is a clear

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b.2. Patient acceptability of the offer of testing has been repeatedly demonstrated; the principal barrier appears to lie in the lack of offers of testing from healthcare professionals.

b.3. If HIV testing were a national priority, many of the barriers to individuals requesting/taking tests and healthcare professionals actively promoting tests would be overcome. Healthcare professionals in primary care undoubtedly have many different expectations and targets to meet; however, the need for HIV testing to become a greater priority in general practice is clear.

b.4. The Quality and Outcomes Framework (QOF) has been successfully used to encourage general practice to meet national targets by the provision of financial incentives; in secondary care CQUIN has been used to similar effect. Rewarding good practice through existing incentive frameworks, both national and locally, is likely to be one of the most effective means of increasing, widening and normalising testing.

b.5. Regular offers of testing in general practice and other healthcare settings would help to normalise the practice, defuse notions of otherness and encourage understanding that HIV is just one of a range of causes of ill-health that should be considered when someone is at risk. Removing the stigma from HIV testing may also reduce late diagnosis in groups at particular risk such as men who have sex with men and black Africans.

b.6. There is good evidence from antenatal screening that normalising HIV testing through the adoption of an opt-out approach to testing can dramatically increase uptake. In 2009, the uptake of HIV tests reached 95% in antenatal clinics nationally and also 95% among patients tested in sexual health clinics as part of the unlinked anonymous HIV testing survey. This is a survey of residual syphilis blood samples in a sentinel network of sexual health clinics.

b.7. Since 2000, most pregnant women have been routinely offered HIV tests. Those testing positive are provided with a course of ART, may undergo a Caesarean section and are advised not to breastfeed. Mother-to-child transmission rates have fallen sharply as a direct result of these interventions (Figure 1), which demonstrates the key role testing can play in HIV prevention.

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b.8. Evidence from the Department of Health and the Gilead UK and Ireland Fellowship programme HIV testing pilots appear to show that the barriers to expanded testing may be greater amongst healthcare workers than amongst patients, consistent with the initial introduction of antenatal testing. In addition there are practical obstacles which must be overcome to expand HIV testing in primary care settings in high prevalence areas. For example, there are currently no primary care National READ codes for point-of-care tests (POCT).

b.9. Current proposals are that HIV prevention and testing should be commissioned by local authorities within their broad ‘public health’ remit/budget. As it has now been announced that local authorities will be responsible for commissioning GUM services it will be important that they do not see this as fulfilling their requirements to commission testing as, in addition to GUM, we need to see testing made available in a wide range of healthcare settings, including community settings. The GP consortia will be responsible for commissioning other secondary care services, so it will be important that they include a requirement for HIV testing in service specifications.

b.10. There is a need for more training for GPs and other healthcare professionals likely to offer a HIV test. Directors of Public Health, local authorities and local Health and Wellbeing Boards will be the key local policy co-ordinators of the future, with opportunities to develop local GP training programmes. This is especially relevant for HIV, where much of the burden arising from late diagnosis for patients and services is localised, such as in the cities of Brighton, London and Manchester.

b.11. There is still a misconception among many healthcare professionals that specialist counselling is required before the offer of an HIV test can be made. In addition to this, the poor communication between specialist HIV services and primary care means that many primary care staff feel very uncomfortable discussing HIV as they feel this is outside their area of expertise and is the role of specialist services.

b.12. Several prominent international bodies have also concluded that issues such as late-diagnosed and undiagnosed HIV can only be tackled if testing is performed in a wider range of settings than sexual health and antenatal clinics. In the same year that the UK Chief Medical Officers wrote to healthcare professionals urging them to offer and recommend...
HIV tests to patients if they may have been exposed to HIV infection,\textsuperscript{142} WHO issued guidance on provider-initiated HIV testing and counselling in health facilities\textsuperscript{143}. The WHO guidance recommended a greater level of provider-initiated implementation in settings ranging from medical inpatient and outpatient facilities, services for younger children and adolescents, surgical services, in addition to health services for the most at-risk populations.

b.13. The WHO guidance was followed in 2010, by the European Centre for Disease Prevention and Control (ECDC) publishing guidance on increasing the uptake and effectiveness of HIV testing.\textsuperscript{144} The ECDC guidance recommended that, in order to increase uptake, HIV testing should be offered in a variety of medical and non-medical settings, in co-operation with non-governmental organisations, and outside normal working hours. The guidance also recommended the implementation of outreach HIV testing services for marginalised groups in the community.

Treatment

a. How can the NHS best commission and deliver HIV treatment?

No response supplied

b. What impact might the proposed new commissioning reforms have on HIV treatment?

No response supplied

Cost

a. Have cost considerations been satisfactorily balanced with public health imperatives in HIV:

(i) Prevention policy?

a.1. Early diagnosis and prompt treatment can reduce onward transmission. It is estimated that the prevention of one new HIV infection would save the public purse between £280,000 and £360,000 in direct lifetime healthcare costs.\textsuperscript{145} Additionally, had all of the UK-acquired infections newly diagnosed in 2008 been prevented, there would have been a saving of approximately £1.1 billion in direct healthcare costs.\textsuperscript{146} This figure does not include additional indirect costs such as social care, time off work and cost of benefits, or any costs saved as a result of preventing further transmission.


a.2. In 2010, a study to demonstrate the cost effectiveness of screening in the French population was published.\textsuperscript{147} This evidence led to national recognition and support of a nationwide testing programme which was published by the HAS in late 2010. A subsequent publication\textsuperscript{148} cited the growing cost of HIV care in the UK. It is becoming increasingly important for health policy relating to HIV to focus on reducing the long term burden on the NHS by effectively capping the spread of the epidemic.

a.3. Earlier case-finding would result in increased costs by the extra months of therapy that an individual would require but this should be set against:

1) The increased costs caused by treating the complications of late presentation (see comments under treatment policy below); the HPA report for 2009 showed that about a third of diagnoses are made very late (i.e. with a CD4 count below 200 mm\textsuperscript{3})

2) A reduction in potential transmissions, as discussed above

(ii) Treatment policy?
No response supplied

b. Is research funding correctly prioritised?

b.1. There is an absence of any clear strategy for HIV research in the UK (which there was historically). There has been very little research into barriers to testing amongst different communities or amongst healthcare professionals. There has also been little consistent or robust evaluation of different national testing campaigns.

Stigma

a. What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?

a.1. Since the beginning of the HIV and AIDS epidemic over 25 years ago, stigma has been a barrier to HIV prevention and care. Its significance and effect varies from setting to setting, but when present, stigma can create an environment where people may avoid HIV-related services.

a.2. Stigma not only makes it more difficult for people trying to come to terms with their own HIV and how they manage their illness, but it also interferes with the ability of the health service to tackle the disease.

a.3. On a national level, the stigma associated with HIV can deter governments from taking fast, effective action against the epidemic, while on a personal level it can make individuals reluctant to access HIV testing, treatment and care.

\textsuperscript{147} Yazdanpanah Y, Routine HIV Screening in France: Clinical Impact and Cost Effectiveness, 2010 PLoS ONE, (5) 10
a.4. While recent research into the impact of stigma on HIV testing is limited, international research into the impact of stigma on HIV testing\(^\text{149}\) has shown that individuals with stigmatising beliefs about HIV are less likely to test for the virus. Through the normalisation of HIV testing as part of a wider strategy of targeted public education and awareness-raising we can reduce the stigma associated with HIV.

b. Where are problems of stigmatisation most acute?

b.1. Stigma is most acute in those groups and individuals already stigmatised by racial and sexual orientation characteristics. It should also be noted that the failure of normal communication between secondary services and primary care with respect to HIV patients contributes to stigma.

c. What measures are currently taken to tackle HIV stigmatisation? What more should be done?

c.1. The following measures are recommended by the Halve It coalition:

- Make HIV a public health priority both locally and nationally
- Include HIV as a specific area of priority in the new Public Health White Paper and include levels of HIV in the calculation of the ‘public health premium’
- Ensure that the health service (whether the NHS or Public Health England) gives HIV the appropriate priority on the ground by requiring that it is systematically considered in local health needs assessments and health planning processes
- Implement the forthcoming NICE public health guidance on HIV testing by encouraging the development and implementation of local strategies to increase HIV testing (e.g. testing for new GP registrants in high prevalence areas)
  - Increase and enhance the provision of education and information provided to those groups most at risk of HIV including men who have sex with men and black Africans to overcome stigma
- Implement and enhance provision of educational information for healthcare professionals on overcoming stigma
- Ensure that people diagnosed with HIV have access to ART, known to reduce viral loads and potential onward transmission of HIV
- Engage the wider health and social care services in prevention initiatives, which are currently largely delivered through the voluntary sector

18 February 2011

Memorandum by Professor Graham Hart, Director of the Division of Population Health, University College London (HAUK 8)

PLEASE NOTE:
The views expressed here are given in a personal capacity and DO NOT represent those of the UK Medical Research Council, the UK Department of Health or University College London.

This submission relates to:

Prevention
\[d. \text{How could prevention initiatives be better delivered and evaluated?}\]

and

Cost
\[b. \text{Is research funding correctly prioritised?}\]

Summary
Research funding bodies should acknowledge that targeted efforts to address the HIV prevention research agenda are necessary, and create a joint HIV Prevention Research Committee to meet this challenge

1. Introduction

1.1
From 1986 to 2002 the UK Department of Health’s Policy Research Programme (PRP) contributed funding to the UK 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). After the publication of the National Strategy for Sexual Health & HIV (2001), PRP and MRC in 2002 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).

1.2
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 4 Highlight Notices, calling for proposals in specified areas of policy concern. Over that period more than 150 submissions were made, of which 28 were funded. Successful applications focused variously on improved surveillance, epidemiology, clinical science and health services research, with most centring on populations at high risk for HIV and/or other STIs, or unwanted pregnancies. The programme also provided some support to longitudinal cohort studies: for example, on transmission of HIV from mother to child; and on HIV treatments.
1.3

The SHHRSC was disbanded in 2008, along with its ‘parent’ board at MRC, the Health Services & Public Health Research Board. This was because after the Cooksey review of health research funding, health services research became the responsibility of the National Institute for Health Research (NIHR).

1.4

There is no committee within NIHR, MRC or Wellcome (the main funders of HIV research in the UK) dedicated to research into HIV and sexual health. This leaves a gap in the strategic overview of HIV prevention research, and recommendations and action to address this. There is now a much improved evidence base in UK sexual health but the absence of a body to direct research and surveillance will hamper future HIV prevention efforts. The remainder of this submission reviews the current situation with regard to HIV prevention, and argues for an HIV Prevention Research Committee to develop and co-ordinate the UK’s strategy for world-class research into HIV prevention.

2. Behavioural interventions

2.1

The UK produces high quality observational studies of HIV risk behaviours in the two groups at most risk of infection: men who have sex with men (MSM) and people of African origin. These data have informed prevention programmes at national and local levels, but there have been no formal evaluations of these programmes, and so there is no evidence of their impact on these populations.

2.2

The majority of prevention interventions for MSM that have been subjected to rigorous evaluation are from the USA; 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.

2.3

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 evaluations of HIV prevention for people of African origin in the UK.

2.4

Most HIV prevention programmes are concerned with primary prevention: 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, to reduce the risk of onward transmission. 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). This needs to be investigated in populations of MSM. It is estimated in
some settings that up to 50% of HIV transmission is from people who are recently HIV infected, and not on treatment. Fourth-generation HIV test are able to identify those who have been recently infected, but no behavioural interventions with this population are in place in the UK; they are urgently needed, as are behavioural interventions for people who have lived with HIV for some time. These need to be developed, piloted and evaluated rigorously, to address this gap.

3. HIV Prevention Research Committee

3.1
There is now a much improved evidence base in HIV prevention but the absence of a body to direct research and surveillance will hamper future HIV prevention efforts. An HIV Prevention Research Committee, that brings together research funders, scientists, service providers and people affected by HIV, could address this problem and develop and co-ordinate the UK’s strategy for world-class research into HIV prevention.

3.2
In 2008 a series of papers in The Lancet argued for ‘combination prevention’. That is, interventions that work at multiple levels (individual, couples, families, institutions and communities) using social, behavioural and biomedical approaches.

3.3
These developments demand renewed engagement with the science of HIV prevention, and an HIV Prevention Research Committee could address 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) Support the development of innovative methodologies for HIV prevention research in clinical and non-clinical populations
(iii) Fund efficacy research into different combinations of new and established intervention technologies for HIV prevention (Phase III)
(iv) Initiate 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 prevention initiatives, using economic and disease modelling to predict their impacts
(vi) Support increased national and international expertise in health transfer in the HIV prevention field; deliver expert advice to government, health providers, patients and community groups.
(vii) Provide a national focus for capacity building in HIV prevention science.

3.4
Although the main focus of the HIV Prevention Research Committee would be HIV prevention, meeting many of these objectives will have outcomes for and impacts on the prevention of other sexually transmitted infections, and the promotion of sexual health more broadly.
4. Conclusion

With the loss of the Sexual Health and HIV Research Strategy Committee, there exists in the UK 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. Research funding bodies need to acknowledge that targeted efforts to address the HIV prevention research agenda are necessary, and should begin a process of addressing this problem soon. An HIV Prevention Research Committee could meet this challenge.

Submission Status:

INDIVIDUAL:

From 2002 – 2008 I was Chair of the MRC/DH Sexual Health & HIV Research Strategy Committee.

10 February 2011
Memorandum by the Department of Health (HAUK 19)

Summary

The attached memorandum sets out the Government’s policy on HIV and AIDS in England including steps taken to prevent transmission of HIV infection, encourage testing and reduce stigma. It also sets out how the Department of Health proposes to commission HIV services following the planned reforms to the NHS and the setting up of Public Health England.

Over the last 25 years there have been unprecedented advances in the treatment of HIV and today, for the majority of people, an HIV diagnosis is no longer seen as an acute illness leading to imminent death. The availability of antiretroviral treatment has transformed the lives of people with HIV. Diagnosed early, most people can expect a near normal life expectancy. However, despite advances in treatment, HIV remains a serious life-long communicable disease for which there is no sign of any cure and it continues to attract stigma. Prevention therefore remains a key element of our national response to tackling HIV. Over the last 25 years our approach has evolved and changed, informed by our world-class HIV monitoring and surveillance systems, but prevention and health promotion remain just as relevant today as they did in the 1980s.

We are aware that challenges remain including the need to reduce undiagnosed and late diagnosis of HIV and reduce stigma. The new Sexual Health Strategy and the health reform programme provides us with an important opportunity to take stock of progress to date, examine the on-going challenges and assess what further work is needed to ensure a strong and sustained response to tackling HIV.

Introduction

1. This memorandum sets out the Government’s policy on HIV and AIDS in England including steps taken to prevent transmission of HIV infection, encourage testing and reduce stigma. It also sets out how the Department of Health (DH) proposes to commission HIV services following the planned reforms to the NHS and the setting up of Public Health England.

Background and Overview

2. The Government’s high profile and comprehensive response to HIV and AIDS in the 1980s, led by the Department of Health, has contributed to the UK having a relatively low prevalence of HIV in the adult population. Although some groups are disproportionately affected by HIV in the UK, in their 2009 report UNAIDS estimated that overall UK adult prevalence was 0.2% which was similar to Sweden, the Netherlands and Denmark and lower than Spain (0.4%), France (0.4%) and Portugal (0.6%). The Government’s early response included high profile awareness campaigns, introduction of needle exchange schemes for injecting drug users, screening of the blood supply, investment in confidential self-referral genitourinary medicine (sexual health) clinics, and responsive monitoring and surveillance systems.

150 UNAIDS Report on the Global AIDS Epidemic 2010
3. Men-who-have-sex-with-men (MSM) remain the group most at risk of HIV infection in the UK. In their 2010 HIV Report\(^1\) the Health Protection Agency (HPA) estimated an approximate HIV rate of 3.00 per 1,000 MSM. The majority of heterosexuals with diagnosed HIV acquired their infection abroad, predominantly in sub-Saharan African countries. Infections transmitted heterosexually within the UK, are stable at around 1,100 new diagnoses a year.

4. The introduction of antiretroviral (ARV) treatment in the mid-1990s has transformed the lives of the majority of people with diagnosed HIV. Thanks to effective treatment, the number of AIDS diagnoses and deaths have declined dramatically. Today if HIV is diagnosed at an early clinical stage many people can expect a near normal life expectancy. In 2009, one in five of all adults seen for HIV care were over the age of 50. This reflects an aging cohort of people with HIV as well as new diagnoses in the over 50s especially in MSM.

5. However, despite the fact that the majority of people living with HIV can remain fit and well, we know from our world-class surveillance and monitoring programmes, that a significant number of people are unaware of their HIV infection. In 2009, the HPA estimated that around a quarter of people with HIV were unaware of their infection. This means they are unable to benefit from effective treatment and also risk passing the virus on to others unwittingly, given that HIV often has no symptoms. Linked to this is late diagnosis of HIV. Today this is the most important factor associated with HIV-related morbidity and mortality in the UK.

6. Despite the unprecedented advances in treatment, HIV remains a serious life-long communicable disease for which there is no sign of any cure. Prevention and health promotion therefore remain key elements of our response. People infected and affected by HIV, including their families, often experience stigma linked either directly or indirectly to HIV. This can have a negative impact on the uptake of HIV testing and treatment services as was as on individual’s wider health and well-being.

7. **Summary of key data**

- In 2009 there were an estimated 86,500 people living with HIV in the UK of whom almost a quarter, almost 21,000 people, were unaware of their infection.

- There were 6,630 new diagnoses of HIV in the UK during 2009. This represents a fourth year-on-year decline from a peak of 7,975 seen in 2005. This is predominantly due to fewer diagnoses among heterosexuals who acquired their infection abroad.

- In 2009, there were 516 deaths and 547 AIDS diagnoses compared to a peak of 1,723 deaths and 1,792 AIDS diagnoses in 1995.

- New diagnoses among MSM remain high with an estimated 2,760 diagnoses in 2009 accounting for 42% of all new diagnoses. While it is too early to indicate a trend,
since 2007, diagnoses appear to be levelling off and declining from a peak of 2,950 in 2007.

- Among MSM diagnosed in 2009, 83% probably acquired their infection in the UK.
- An estimated 54% (3,560) of people diagnosed in 2009 acquired their infection heterosexually, two-thirds of which were acquired in sub-Saharan Africa.
- 170 new diagnoses were acquired through injecting drug use.
- An estimated 52% of patients were diagnosed with a CD4 cell count of less than 350 within three months of diagnosis in 2009, the threshold at which treatment is recommended to begin.
- 74 children (median age 7 years) were diagnosed with HIV in the UK in 2009. Almost all had been infected through mother-to-child transmission, and 68 of them were born abroad.

**National HIV prevention programmes**

8. Since the early 1980s, UK governments have funded national awareness campaigns and programmes of work on HIV prevention. At that time little was known about how HIV would develop and affect the wider population or groups of people. Therefore, the early response addressed the whole population and included prime-time television advertising and the leaflet *AIDS: Don’t Die of Ignorance*, which was sent to all households.

9. By the mid-1990s, the pattern of HIV transmission in the UK was much clearer and in 1995, UK Health Departments undertook a review of HIV health promotion strategy. This concluded that some groups including MSM and men and women who travel to or have family links to high prevalence countries, for example in sub-Saharan Africa, were disproportionately affected by HIV and required more immediate encouragement to adopt and sustain safer behaviour. For the general population, the review concluded that HIV remained a serious issue but more attention should be given to health promotion which addressed their immediate sexual health concerns including preventing more prevalent sexually transmitted infections (STIs) such as chlamydia and gonorrhoea. Promoting behaviour change including condom use would also protect against HIV.

10. Following the review, the DH has provided information about HIV, for young adults (16-24 years) as part of its broader STI awareness programmes including the former Sex Lottery, Condom Essential Wear and Sex Worth Talking About campaigns. Independent market research done by TNS in 2010 to inform the Sex Worth Talking About campaign indicated that awareness of HIV in the general population was high. For example, awareness of HIV in young people aged between 11 and 15 was 60%, in 16-24 year olds 84% and in 25-34 year olds awareness was 91%. In all age groups, awareness of HIV was exceeded only slightly by awareness of chlamydia. The challenge remains however translating high awareness into sustained behavioural change.

11. The 1995 review also concluded that community-based groups were well placed to develop targeted health promotion work for those groups whose behaviour put them at increased of HIV, and that safer sex interventions might be better undertaken by the
community-based groups rather than by Government or its agencies. Annex A summarises
government funding on HIV and sexual health awareness programmes since 1987.

National HIV prevention programmes for MSM and African communities

12. Since 1996/97, the DH has funded the Terrence Higgins Trust (THT) for a national
HIV prevention programme for MSM, and since 2000, the African Health Policy Network
(AHPN, formerly the African HIV Policy Network) for work with African communities living
in England. The Department has formal contracts with both organisations that are
monitored through quarterly meetings with DH and a formal annual accountability review
with a senior official. Programmes include communications using gay and African media and
increasingly the internet, social networking and social marketing tools, capacity-building of
the HIV sector, outreach work and work to challenge stigma. THT manage a partnership
of 12 organisations to implement the Community HIV/AIDS Prevention Strategy, known
widely by its acronym CHAPS. The AHPN works with 11 organisations in developing and
delivering the National African HIV Prevention Programme (NAHIP).

13. From the outset, both programmes have been developed and delivered in
partnership with other MSM and African community-based groups throughout England to
agree messages and ensure they are relevant, acceptable and non-stigmatising. Both
programmes work to strategic frameworks which reflect a consensus on priorities for
action agreed by all partner organisations, other community-based groups and experts. The
Making it Count framework has underpinned the CHAPS programme since 1997 and since
2008 the Knowledge, the Will and the Power has underpinned the African programme. The
Department of Health has confirmed funding for 2011/12 of £1.9 million for THT and £1m
for the AHPN.

Monitoring and Evaluation

14. Since their inception, research and evidence-based HIV health promotion have been
at the core of both programmes. Following a competitive tender exercise THT and AHPN
currently sub-contract Sigma Research (part of the University of Portsmouth) and the
London School of Hygiene and Tropical Medicine to monitor and evaluate both
programmes. Both CHAPS and NAHIP programmes have been held up by health
promotion experts in other countries, including Australia and the United States as
international examples of good practice of collaboration between research and health
promotion practice, with evidence informing the direction of the programmes’
interventions.

15. Monitoring and evaluation accounts for approximately 15% annually of the current
contract with the THT and 11% of the contract with AHPN. For the larger CHAPS
programme, evaluation and monitoring consists of five broad areas including evidence of
needs, evaluation of individual interventions, basic research and knowledge transfer.
Awareness campaigns and other interventions are informed by consumer research surveys
with MSM and African people which help identify the health promotion needs of both
groups. For MSM the Gay Men’s Sex Survey (GMSS) has been part of the CHAPS programme
since 1997, and since 2008 the BASS Line survey for African communities has helped identify
the HIV health promotion needs of Africans.
16. Over the coming year, both programmes are developing work to evaluate more rigorously the outcome and effectiveness of HIV health promotion interventions using social marketing techniques and rigorous quasi-experimental methods. Attributing behavioural outcomes to specific health promotion interventions can be problematic given other external influences and the fact that behaviour change is not always immediate. However, there are some indications that these HIV programmes are effective, alongside other measures undertaken as part of our wider programme of work on sexual health. For example for MSM:

- HIV testing increased from 59% in 2003 to 75% in 2008.
- Awareness of post-exposure prophylaxis (PEP) following sexual exposure to HIV increased from 22% before the CHAPS campaign to 56% after the campaign. No other factor could obviously explain the rise in PEP awareness and knowledge given the absence of any mainstream coverage of the issue.
- Preliminary analysis of GMSS data suggests that between 2001 and 2008 there was a drop in numbers of sexual partners among MSM.

HIV Testing and Diagnosis

17. As previously noted, the earlier HIV infection is diagnosed the sooner a person can access treatment and care and make any behavioural changes to prevent HIV transmission to others. It is enshrined in law\textsuperscript{152} that GUM clinics are available on an open-access self-referral basis and people can choose to attend clinics in areas other than where they live. NHS services are non–judgmental and confidential and information is not shared routinely with other health care professionals unless the individual agrees.

18. Uptake of HIV testing in GUM clinics has increased significantly since 2001. Uptake increased from 51% in 2001 to 77% in 2008 and 2009. The challenge is to increase this further and normalise testing in other settings. Diagnosis rates of HIV in pregnant women have increased significantly since the introduction in 1999 of the universal offer and recommendation of an HIV test to all pregnant women in England as a routine part of antenatal care.

Reducing undiagnosed and late diagnosis of HIV

19. Despite the increased uptake of HIV testing in GUM and antenatal services, a major audit of deaths from HIV among adults reported that in around a quarter of cases, diagnoses occurred too late for effective treatment and late diagnoses accounted for at least 35% of HIV-related deaths\textsuperscript{153}. There was also evidence that a significant proportion of people diagnosed late had been seen by healthcare professionals in the preceding year with symptoms which, in retrospect, were likely to be related to HIV\textsuperscript{154}.

20. In the light of these findings, in 2007 the Chief Medical Officer (CMO) and Chief Nursing Officer wrote to all doctors and nurses highlighting best practice about offering and recommending, where appropriate, HIV testing in all healthcare settings and not just in

\textsuperscript{152} NHS (Functions of SHAs and PCTs and Administrative Arrangements) (England) Regulations 2002

\textsuperscript{153} see: http://www.bhiva.org/files/file1001379.ppt

those traditionally offering testing (ie in GUM and antenatal services). The letter also addressed two common misconceptions regarding HIV testing that created barriers to the offer and uptake of HIV testing in General Practice and other non-HIV specialist healthcare settings. Firstly, lengthy pre-test HIV counselling was not a requirement, unless requested or needed by a patient. The minimum requirement was to provide an opportunity for pre-test discussion to ensure informed patient consent to the test. This reflected standing guidance and good practice including from the British HIV Association. Secondly, the letter confirmed that GPs did not need to disclose negative HIV test results on applications for insurance by their patients.

**DH Testing Pilots**

To build upon this, following the CMO/CNO letter and publication by BHIVA and others of the UK National Guidelines for HIV testing in 2008, the DH invested £750,000 in eight pilot projects to assess the feasibility and acceptability of more routine testing in primary, secondary and community settings. All except one pilot were in high prevalence areas defined as having a diagnosed HIV prevalence in adults greater than 2 per 1000 population. The pilots took place in hospital settings in London, Brighton and Leicester, primary care settings in London and Brighton and community settings in London and Sheffield. DH also funded the Health Protection Agency to take an overview of all the projects and produce a report with recommendations. On 1 December 2010 the HPA published *Time to Test* with interim findings from all pilots. They expect to publish a final report later this year.

The findings indicate that expanding HIV testing in hospital, GP and community settings is feasible, and acceptable to patients and staff (with training and support). In total 10,478 tests took place and picked up 50 people in high prevalence areas who were previously undiagnosed. Pilots in Leicester, Lewisham and Brighton have led to changes in local practice and HIV testing is continuing. The findings from the pilots expand the evidence base for wider HIV testing. Three of the pilot sites have commissioned work to analyse the costs and cost effectiveness of different models of routine HIV testing. The findings from this work are expected later this year (2011) and they will assist in identifying the best approaches to any expansion of HIV testing and the costs.

In addition to the pilots DH has funded the Medical Foundation for AIDS and Sexual Health to produce *Tackling Testing* – a resource pack to support non-specialist healthcare professionals in hospitals in offering HIV testing.

**HIV-related stigma**

Historically, STIs have attracted stigma and shame, which is why services are provided on a self-referral basis and information is not shared with GPs and other health professionals without the patient agreeing. Within NHS sexual health services, modernisation and investment in new buildings and facilities making them more patient-focused, visible and welcoming should have gone a small way to removing any actual or perceived stigma about using GUM or sexual health clinics.

However, for HIV, stigma can be more complex and is perhaps compounded by the fact that people may also experience stigma linked to their sexuality or race. Also, unlike most other STIs, there is no cure for HIV. Stigma linked to HIV can be fuelled by lack of
knowledge and understanding by individuals, healthcare professionals and the media as well as prejudice. Left unchallenged it can prevent people from accessing information about preventing HIV, as well as using testing and treatment services.

26. DH very much welcomes the contribution that NGOs and civil society organisations make in this complex area. Following publication of the 2001 sexual health and HIV strategy the Department funded three NGOs – NAM Publications (formerly the National AIDS Manual), the National AIDS Trust and the Medical Foundation for AIDS and Sexual Health to work with others to produce a range of resources for people with HIV, healthcare professionals and the media. All were developed together with people living with HIV. The Department has also contributed funding towards the African Health Policy Network’s programme with faith leaders – Changing Perspectives – which recognises the role of faith groups and leaders in challenging HIV-related stigma within communities.

NHS and Public Health Reforms

27. Improving the sexual health of England remains a priority. While considerable progress has been made in the past few years, more can and will be done. On 30 November 2010, we published the White Paper Healthy Lives, Healthy People, Our strategy for public health in England. The White Paper outlined a radical shift in the way we will tackle public health challenges including sexual health.

28. The White Paper noted that DH will publish later this year, a new Sexual Health Strategy, which will include HIV. We are currently finalising the remit and scope of the new strategy, but we will work with the new stakeholder advisory group, the Sexual Health Forum (the successor to the former Independent Advisory Group on Sexual Health) in developing the new Strategy.

29. The publication of the White Paper was followed by related documents including consultations on the funding and commissioning routes for public health, and proposals for a Public Health Outcomes Framework. The consultation on commissioning proposes that sexual health services will in future be commissioned through local authorities as part of their ring-fenced public health budget. This includes testing and treatment for STIs, termination of pregnancy services and specialist community contraceptive services. Routine contraception provided by GPs will continue to be funded through the GP contract via the NHS commissioning board.

30. For HIV the situation is different as prevalence is not evenly spread throughout the country and treatment is more specialised. It is therefore proposed that HIV prevention and testing should be funded through local authorities but HIV treatment and care should be funded from the NHS budget, and commissioned by the NHS Commissioning Board, in line with their other responsibilities for commissioning treatment for non-sexually transmitted infectious diseases. The consultation document proposes that Public Health England should work closely with the NHS Commissioning Board in the commissioning of these services, where efficiencies can be made from procuring drugs and services at scale.

31. The consultation document proposed that local authorities would be responsible for commissioning and funding open-access sexual health services which will include HIV testing services, (but not HIV treatment and care). For HIV therefore this means that only HIV testing will be funded from the ring-fenced grant and commissioned by local authorities.
The Department is currently consulting on what conditions should be placed on the ring-fenced grant in order to ensure it is used as it should be – to improve the health of the local population. The consultation document asks for views on what services should be mandatory for local authorities to commission; the need for all areas to provide open-access sexual health services in a universal fashion is suggested as an example.

32. The DH is also currently consulting on proposals for a Public Health Outcomes Framework. This includes an outcome to reduce the proportion of persons presenting with HIV at a late stage of infection. If selected, over time this should increase opportunities for HIV testing and earlier diagnosis.

Conclusion

33. It has not been possible within the scope of this document to set out all the work that has been done across Government, by the NHS and the voluntary sector to improve the care and support available to those living with HIV and to prevent transmission of infections. This work has had a real impact, but we cannot be complacent. The new Sexual Health Strategy and the health reform programme provides us with an important opportunity to take stock of progress to date, examine the on-going challenges and assess what further work is needed across the health and social care system to ensure a strong and sustained response to tackling HIV.

ANNEX A

Summary of DH investment in HIV and sexual health awareness programmes

Table 1: DH spend on all sexual health awareness campaigns including sexually transmitted infections (including HIV), contraception awareness and helplines

<table>
<thead>
<tr>
<th>Year</th>
<th>Amount £m</th>
<th>Real Terms 2009/10 prices £m</th>
</tr>
</thead>
<tbody>
<tr>
<td>1987/88</td>
<td>11.21</td>
<td>23.0</td>
</tr>
<tr>
<td>1988/89</td>
<td>10.00</td>
<td>19.2</td>
</tr>
<tr>
<td>1989/90</td>
<td>12.00</td>
<td>21.5</td>
</tr>
<tr>
<td>1990/91</td>
<td>10.00</td>
<td>16.6</td>
</tr>
<tr>
<td>1991/92</td>
<td>11.00</td>
<td>17.2</td>
</tr>
<tr>
<td>1992/93</td>
<td>11.23</td>
<td>17.1</td>
</tr>
<tr>
<td>1993/94</td>
<td>9.41</td>
<td>13.9</td>
</tr>
<tr>
<td>1994/95</td>
<td>9.87</td>
<td>14.4</td>
</tr>
<tr>
<td>1995/96</td>
<td>8.06</td>
<td>11.4</td>
</tr>
<tr>
<td>1996/97(^{135})</td>
<td>4.33</td>
<td>5.9</td>
</tr>
<tr>
<td>1997/98</td>
<td>3.325</td>
<td>4.4</td>
</tr>
<tr>
<td>1998/99</td>
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<td>4.4</td>
</tr>
<tr>
<td>1999/00</td>
<td>4.60</td>
<td>5.9</td>
</tr>
<tr>
<td>2000/01</td>
<td>3.10</td>
<td>3.9</td>
</tr>
<tr>
<td>2001/02</td>
<td>3.10</td>
<td>3.8</td>
</tr>
</tbody>
</table>

\(^{135}\) Spend before 2006/07 includes the Sexual Health Information Line (formerly the National AIDS Helpline). The contract for both services was delivered as part of a broader contract which included FRANK and Drinkline.

\(^{136}\) Before 1996/97 expenditure also includes a contribution towards the overhead costs of the former Health Education Authority.
Table 2: DH spend on HIV prevention programmes for MSM and African communities (delivered through contracts with the Terrence Higgins Trust and African Health Policy Network)

<table>
<thead>
<tr>
<th>Year</th>
<th>Amount £m</th>
<th>Real Terms 2009/10 prices £m</th>
</tr>
</thead>
<tbody>
<tr>
<td>1996-97</td>
<td>0.920</td>
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<tr>
<td>1997-98</td>
<td>1.375</td>
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<tr>
<td>1998-99</td>
<td>1.400</td>
<td>1.8</td>
</tr>
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<td>1999-00</td>
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<td>1.8</td>
</tr>
<tr>
<td>2000-01</td>
<td>1.500</td>
<td>1.9</td>
</tr>
<tr>
<td>2001-02</td>
<td>1.500</td>
<td>1.9</td>
</tr>
<tr>
<td>2002-03</td>
<td>1.600</td>
<td>1.9</td>
</tr>
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<td>2003-04</td>
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<td>2004-05</td>
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</tr>
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<td>2005-06</td>
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<td>1.8</td>
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</tr>
<tr>
<td>2008-09</td>
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<tr>
<td>2009-10</td>
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<td>2.9</td>
</tr>
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<td>2010-11</td>
<td>2.900</td>
<td>2.8</td>
</tr>
<tr>
<td>2011-12</td>
<td>2.900</td>
<td></td>
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February 2011

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157 Funding from 2006-09 includes a contribution of £2m a year to the former Dept for Children, Schools and Families
Supplementary Memorandum by the Department of Health (HAUK 70)

1. In the session, annual expenditure on HIV prevention interventions was discussed. What has been the expenditure on awareness-raising activities relating to HIV and AIDS in each year from 1986-87 to 2009-10? What is the projected spend in 2010-11?

1.1 Annual Department of Health (DH) expenditure on HIV prevention programmes since 1987 was included in Annex A of the DH memorandum of evidence sent to the Committee on the 17 February. This is attached again at Annex A and now includes expenditure for 1986/87 as requested. The tables exclude expenditure on HIV prevention undertaken by the NHS as data on this is not collected centrally by DH.

2. Professor Harper referred to evidence that supported the "efficacy and effectiveness" of targeted prevention campaigns. What evidence does this refer to?

2.1 Following a review of HIV health promotion strategy in 1995, the Department of Health has contracted with the Terrence Higgins Trust (THT) and the African Health Policy Network (AHPN) for national HIV prevention programmes for men who have sex with men (MSM) and African communities, the groups behaviourally most at risk of HIV in the UK. The THT manage 12 partnership organisations who implement the Community HIV/AIDS Prevention Strategy, known widely by its acronym CHAPS. The AHPN work with 11 partnership organisations in developing and delivering the National African HIV Prevention Programme (NAHIP).

2.2 A key strength of both prevention programmes is that they are underpinned by collaborative strategic planning frameworks. These reflect a consensus on priority actions to reduce HIV transmission in MSM and African communities in England. Priorities are agreed by the community-based organisations who make up the CHAPS and NAHIP partnerships, researchers and other experts. A revised version of Making it Count, the planning framework focused on reducing HIV transmission during sex between men in England will be published in March 2011. The current version is available at www.sigmaresearch.org.uk along with The Knowledge, The Will and The Power, the corresponding framework for African communities. Both frameworks describe what partners working on the national prevention programmes will do to reduce HIV transmission in MSM and African men and women.

2.3 From the outset, evidence-based health promotion has been at the core of DH-funded programmes. Both national programmes are informed by the latest epidemiology on HIV and quantitative and qualitative national and international research and other available evidence. This includes the annual Gay Men's Sex Survey (GMSS) and since 2008, the Black African Sex Survey (BASS-Line). Both programmes and the wider HIV and sexual health sector use extensively the findings from both surveys. For example, findings from the 2008 BASS-Line survey indicated low awareness of confidential open-access HIV testing services. This informed the Do it Right awareness campaign on HIV testing developed by the African Health Policy Network and its partners. The GMSS has also demonstrated the effectiveness of the campaign in 2005 to increase awareness of post exposure prophylaxis (PEP)
treatment. Before the campaign the GMSS reported that only 22% of MSM sampled were aware of PEP. This increased to 38% in 2005 and 56% in 2007. Awareness also resulted in more men seeking PEP, up from 1% before the campaign to 2.4% in 2007. No other factor could obviously explain the rise in PEP awareness and knowledge given the absence of any mainstream coverage of the issue.

2.4 The main research partner for both programmes is Sigma Research, a social research group specialising in the behavioural and policy aspects of HIV and sexual health. Following a competitive tender exercise in 2009, Sigma Research were awarded a further contract for monitoring and evaluation of CHAPS. In February this year Sigma Research moved from the University of Portsmouth to the London School of Hygiene & Tropical Medicine where it will continue its monitoring and evaluation of both CHAPS and NAHIP.

2.5 Partner organisations along with THT and AHPN decide collectively what campaigns should focus on, based on the HIV prevention needs identified by research generated by both programmes (eg the GMSS and Bass-Line) and other external research and evidence. Campaigns are pre-tested during their development to assess their acceptability and effectiveness to the target audiences and amended if necessary. After implementation, their impact is measured in “end user evaluations” and coverage surveys carried out by Sigma Research. Sigma Research publish all their evaluation reports including on their website. Annex B sets out a sample of some qualitative findings from the end-user evaluations of three CHAPS campaigns. However, comprehensive details of all campaigns from 2003 to 2006 are included in the CHAPS evaluation report Form and Focus – Evaluation of CHAPS national interventions from 2003-2006.¹⁵⁸

2.6 While it is too early to indicate a trend, it appears that new diagnoses in MSM are levelling off and declining from a peak of 2,950 in 2007 to 2,760 in 2009. It is also encouraging that more MSM are testing for HIV. In GUM the uptake of HIV testing was 90% in 2009 up from 61% in 2001. While it is not possible to demonstrate precise cause and effect, it is likely that the CHAPS programme would have contributed to these outcomes.

3. Professor Harper referred to the use of up-to-date "social marketing" information in guiding awareness-raising activities. What information does this statement refer to?

3.1 This referred to the Change4Life programme which was created as a social movement to bring together individuals and organisations to play an active role to help change behaviour and help people to maintain a healthy weight. It is intended to be an innovative approach, grounded in the evidence base. Change4Life was informed by a number of scientific literature reviews of behaviour change techniques and a focused review of using behaviour change to effect healthy eating and activity behaviours (Jebb S, et al 2007).

3.2 In addition, a major programme of market research was undertaken including a quantitative segmentation of English families supplemented by qualitative research (Swanton, 2008). A comprehensive programme of monitoring and evaluation has been established. Change4Life is already showing evidence of behaviour change. More than one million mothers say they have made changes to their children’s diet or activity levels as a result of

¹⁵⁸ http://www.sigmaresearch.org.uk/go.php?/projects/gay/project23
the Change4Life campaign. Additional results from campaign activities will be published when available. The Change4Life One Year On report was published earlier this year.159

3.3 With their focus on consumer insights, qualitative research and the needs of those groups with greatest unmet HIV prevention needs, both the CHAPS and NAHIP programmes take account of social marketing principles.

4. During the session there was discussion of the messages that prevention campaigns sought to convey. What are these core messages, and can you provide some specific examples of how they are conveyed? How do the messages vary across the range of individuals and groups who the work focuses upon?

4.1 We have sent separately, examples of some of the printed information resources delivered by the two national HIV prevention programmes. More examples are available on the programmes' supporting websites (www.chapsonline.org.uk http://www.nahip.org.uk/campaigns/). Core messages focus on condom use and more recently, the importance of HIV testing including where to get tested. Messages are delivered through a variety of media and settings including mass-media adverts in the gay and African press, magazines, discreet pocket-sized information cards, websites and on-line ads that lead to micro sites that provide more detailed information about the campaign topic. As previously stated, campaigns are informed by the priorities set out in the strategic planning frameworks, Making it Count and the Knowledge, the Will and the Power, and findings from the Gay Men's Sex Survey and BASS-Line Survey. Examples of two recent campaigns for MSM are as follows:

**CHAPS THIVK Testing campaign**

4.2 This addressed the strategic aim of reducing the time between HIV infection and diagnosis. In particular, the specific campaign aim was to ensure Men are more knowledgeable about their HIV testing options and understand the benefits of HIV testing and early diagnosis.

The campaign also aimed to ensure:
- Men know their HIV status may not be what they think it is
- Men know that rapid (20 minute) HIV tests exist and how to access them
- Men know that HIV treatments are more effective and the sooner someone with HIV has their infection diagnosed, the better off they will be

4.3 The **THIVK Testing** campaign had the following overarching message: *Consider how HIV testing gives you control* The target audience for the campaign was men who had not had an HIV positive diagnosis, in particular men who thought they were HIV negative but had not tested recently, and men fearful of testing positive. The aim was that the following men were more likely to see the campaign: BME men, men with lower levels of education and men with higher partner numbers. Campaign resources included three press adverts, three posters, leaflet about testing and clinics, a website covering undiagnosed infection, testing and clinics, web banner ads. A campaign briefing and a briefing for professionals on undiagnosed infection and HIV testing also supported the campaign. Details of the campaign evaluation are at Annex B

I Did It HIV testing campaign

4.4 Building on from the above campaign and its focus on testing, in December 2010 CHAPS launched a three month campaign encouraging MSM to test and talk about HIV testing with the expectation of making it easier for others to test. The ‘I Did It’ campaign includes outdoor advertising, gay press ads and banner ads on popular gay internet sites.

Aim of the campaign

4.5 HIV (and STI) testing before taking a new sexual partner was an important issue identified by the CHAPS partners, to support MSM in reducing the likelihood that they will pass on or pick up HIV. In developing the campaign, the CHAPS programme was keen to demonstrate a switch from its traditional mode of broadcasting messages to its audience, to one involving greater engagement with it. There was also recognition that behaviour change in MSM was influenced by what peers say or do.

Campaign messages

4.6 The ‘I Did It’ campaign addresses barriers and incentives to testing across its three adverts and posters including:

- convenience issues around getting tested (eg types of test, where to test)
- testing as a protective behaviour for men in or starting relationships
- testing as a means to certainty or peace of mind

4.7 Men were encouraged to engage with the campaign regardless of their testing history. HIV positive men were asked to engage with campaign by sharing their experiences of testing. Men under 25 were especially targeted through press titles most popular with them and youth-orientated web sites. These men had greater need around testing due to their lack of knowledge and greater anxiety about the issue stemming from less experience of testing and testing centres. The use of digital technology in the campaign such as social networking sites, Facebook and Twitter were also designed to boost engagement with younger men. The campaign will be evaluated.

5. How will the NHS Commissioning Board be structured, so as to enable it to discharge its responsibilities for nationwide commissioning?

5.1 The Health and Social Care Bill published on 19 January 2011 sets out details about the membership of the Board including a Chair, Chief Executive, Executives and Non Executives and the process for their appointments. As an independent body, the Board will be free to appoint members to the Board and in turn other appointees below board level to form its structure. During 2011/12, the Board will operate in shadow form and how it will carry out its responsibilities will be determined so that it is fit for purpose and ready to go live from 1 April 2012. Precise details of how and what the Board will commission at a national level will take account of the outcome of the current consultation which closes on 31 March.

6. The National Strategy for Sexual Health and HIV expires this year. In the evidence session, there was reference to a sexual health document linked to the White Paper due for publication in the Spring. Is this the replacement for the National Strategy?

a. What will be the key priorities of a new strategy?
6.1 The Department of Health will this year publish a new Sexual Health Strategy to replace the previous National Strategy for Sexual Health and HIV. It is planned that the new Strategy will:

- set out DH policy and ambitions on improving sexual health taking a life course approach
- reflect wider Government policy where appropriate
- set sexual health in the context of health reform and proposed new commissioning arrangements
- include separate chapters of preventing teenage pregnancy and HIV

The DH will consult with the new Sexual Health Forum in developing the new Strategy including identifying priority areas.

7. Reforms to the NHS envisage service provision being driven by outcomes with "health premiums" being awarded when progress is made. For example, in the new Public Health Outcomes Framework, there is an indicator analysing the proportion of persons presenting with HIV at a late stage of infection. Can you explain exactly how you envisage this outcome-based system will operate?

a. How will the "health premium" operate?

7.1 Healthy Lives, Healthy People: Transparency in Outcomes. Proposals for a Public Health Outcomes Framework, proposed that the Outcomes Framework should have three purposes:

1. to set out the Government's goals for improving and protecting the nation's health, and for narrowing health inequalities through improving the health of the poorest, fastest;
2. to provide a mechanism for transparency and accountability across the public health system at the national and local level for health improvement and protection and inequality reduction; and
3. to provide the mechanism to incentivise local health improvement and inequality reduction against specific public health outcomes through the 'health premium'.

7.2 The consultation asks questions about which indicators should be included in the public health outcomes framework. The indicator measuring the proportion of persons presenting with HIV at a late stage of infection was proposed as a possible indicator to sit under domain 4, with the objective of reducing the number of people living with preventable ill health. A final public health outcomes framework will be published in the summer.

7.3 In Healthy Lives, Healthy People, a consultation on the funding and commissioning routes for public health we proposed that building on the baseline allocation, local authorities would receive an incentive payment, or premium. We proposed that the health premium should be based on the following principles:

- It will apply to that part of the budget that is for health improvement;
- It will reward local authorities for the progress they make in improving the health of the local population and reducing health inequalities, based on elements of the Public Health Outcomes Framework.

7.4 The Consultation asks questions about what approach we should take to the Health Premium, and which indicators it should apply to. We proposed that health promotion,
prevention and HIV testing would be a local authority function, so we would want local authorities to make progress in reducing the proportion of persons presenting with HIV at a late stage of infection. Data on national and local performance against this outcome would be published, should it be selected for inclusion in the final public health outcomes framework. The consultations on the funding and commissioning routes for public health and the public health outcomes framework close on 31 March 2011.

8. The recent *Equity and Excellence* white paper proposes that drug companies should be paid under a "value-based pricing" system. How will this work? What savings do you anticipate from procuring antiretroviral drugs using this new system of drug pricing?

8.1 Under value-based pricing, the price of a new drug to the NHS will be based on an assessment of its value, rather than pharmaceutical companies being free to set the price. Value-based pricing will ensure licensed and effective drugs are available to NHS clinicians and patients at a price to the NHS that reflects the value they bring.

8.2 It is the Government’s intention that value-based pricing will apply to new active substances placed on the market from 1 January 2014. For branded medicines already covered by PPRS at the end of 2013, a successor scheme to the Pharmaceutical Price Regulation Scheme (PPRS) will be required. The details of this will be developed alongside value-based pricing.

8.3 The consultation document *A new value-based approach to the pricing of branded medicines* sets outs our proposals for value-based pricing. The consultation runs until 17 March 2011 and responses to the consultation will inform work to develop the new system. We will carry out financial modelling on the impacts of the new system as work to develop the new approach progresses. Before we have carried out this detailed modelling, it is too early to say what the impact on the drugs bill will be. We will, of course, ensure that it is affordable within the health budget.

9. In response to an oral question on medical treatment for asylum seekers, Earl Attlee said, "as far as I know those who test positive for HIV in the UK, as long as they have not exhausted all their appeal rights, have exactly the same access to NHS treatment as the rest of the population". Could the Department please clarify who can be charged for treatment under the NHS (Charges to Overseas Visitors) Regulations 1989?

a. Within those categories of people who can be charged, in what circumstances would they not be charged?

9.1 Asylum seekers are entitled to the full range of NHS services, including treatment for HIV free of charge. Failed asylum seekers are also usually entitled to continue a course of treatment, free of charge, which began whilst their claim and any appeal remained outstanding. This includes treatment for HIV which, once started, is never withdrawn. All failed asylum seekers remain eligible for free HIV testing and advice.

*Overview of the Charging Regulations*

9.2 When a person who is not ordinarily resident in the UK needs NHS treatment provided by a hospital in England, they will be subject to the *National Health Service (Charges
9.3 The Charging Regulations place a legal obligation on NHS bodies in England to establish whether a person is an overseas visitor to whom charges apply or whether they are exempt from charges by virtue of the Charging Regulations for the NHS services provided. A charge cannot be waived but it is up to individual hospital trusts to decide to what extent they pursue charges, or if they write off costs, taking into account the personal individual circumstances on a case-by-case basis.

Exemptions from Charging and Safeguards
9.4 The Charging Regulations and DH guidance on their implementation include a number of exemptions from charging and safeguards to prevent serious suffering. These include:

- Access to free NHS treatment for asylum seekers as long as their application and any appeal remain current;
- Continuation of an existing course of treatment even if the asylum application and any appeal fails up until a person is deported or leaves the country (so HIV treatment once started by an asylum seeker is never withdrawn). It is for a clinician to determine what constitutes a particular course of treatment;
- Guidance which makes clear that immediately necessary or other urgent treatment should not be delayed irrespective of a person’s inability to pay, (although not free, the guidance makes clear that treatment should take place even without advance payment), and that decisions on level of urgency are clinical only.
- Guidance which makes clear that antenatal HIV treatment must be considered as immediately necessary.

HIV and the Charging Regulations
9.5 Given the exemptions set out above, charges would usually only apply to HIV treatment for undocumented migrants and failed asylum seekers if HIV was diagnosed once a visa had run out or after all asylum appeals had failed.

9.6 The current policy on HIV has been in place since the Charging Regulations were introduced in 1989. However, in 2004, the previous charging exemption for all NHS treatment that applied for visitors who had been resident for a year was modified to those who have been lawfully resident for a year. This had the effect of excluding failed asylum seekers and other undocumented migrants who could no longer rely on a qualifying period of undetected, but unlawful, presence to claim exemption from charges for any NHS hospital treatment, including HIV treatment.

9.7 HIV is not listed in the annex to the Charging Regulations as one of the infectious diseases for which NHS treatment is provided without charge to all overseas visitors. Regulation 3 provides that diagnosis and treatment for sexually transmitted infections (STIs) is free to all visitors. However, for HIV, free care is limited to HIV testing and any associated counselling, therefore HIV treatment must be paid for by overseas visitors not otherwise covered by one of the charging exemptions.
ANNEX A

Summary of DH investment in HIV and sexual health awareness programmes

Table 1: DH spend on all sexual health awareness campaigns including sexually transmitted infections (including HIV), contraception awareness and helplines\(^{160}\)

<table>
<thead>
<tr>
<th>Year</th>
<th>Amount £m</th>
<th>Real Terms 2009/10 prices £m</th>
</tr>
</thead>
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<tr>
<td>1986/87</td>
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</tr>
<tr>
<td>1987/88</td>
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<tr>
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</tr>
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</tr>
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</tr>
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<td>2009/10</td>
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<td>10.6</td>
</tr>
<tr>
<td>2010/11</td>
<td>To be confirmed</td>
<td></td>
</tr>
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</table>

\(^{160}\) Spend before 2006/07 includes the Sexual Health Information Line (formerly the National AIDS Helpline). The contract for both services was delivered as part of a broader contract which included FRANK and Drinkline.

\(^{161}\) Before 1996/97 expenditure also includes a contribution towards the overhead costs of the former Health Education Authority.

\(^{162}\) Funding from 2006-09 includes a contribution of £2m a year to the former Dept for Children, Schools and Families.
Table 2: DH spend on HIV prevention programmes for MSM and African communities (delivered through contracts with the Terrence Higgins Trust and African Health Policy Network)

<table>
<thead>
<tr>
<th>Year</th>
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<th>Real Terms 2009/10 prices £m</th>
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<td>2000-01</td>
<td>1.500</td>
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</tr>
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<td>2001-02</td>
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</tr>
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<td>2002-03</td>
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</tr>
<tr>
<td>2011-12</td>
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<td></td>
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Annex B

Qualitative Findings from end-user evaluations of three CHAPS campaigns

‘Biology of Transmission’ campaign

This CHAPS campaign explains basic HIV transmission information to gay men. It ran in 2002 and was repeated with minor changes in 2009.

Views of men from focus groups and end user evaluation:

“The images were felt to be novel and engaging …. and unusual in the context of sexual health messages. Participants felt the imagery worked well on a metaphorical level. The text and tone were perceived as purely factual and therefore appropriate.”

“Many participants said that this intervention made them think about the type of sex they had. They felt the information related directly to them and that the intervention gave them clear information to enable more informed decisions about the sex they had.”

Post-exposure prophylaxis campaigns

This CHAPS campaign increased awareness of post-exposure prophylaxis in order to reduce HIV infections among gay men. It ran as a pilot in London and Brighton in 2004 and nationally in 2005, again in 2007 and a separate non-CHAPS London-only PEP campaign ran in 2008.
“When end users were asked what they felt was the aim of the campaign, there was universal agreement that it was communicating new and detailed information for men who may have been exposed to HIV.”

“The PEP ads had the highest readership rates among those that recognised them suggesting the campaign was needed and provided new information”

**THIVK undiagnosed infection/testing campaign**

In 2008-09 CHAPS ran two campaigns aimed at reducing numbers of gay men with undiagnosed HIV by raising the possibility of undiagnosed infection among them and by promoting HIV testing.

“Almost all of the end user groups discussing this intervention expressed their unreserved support for the approach and the aim. The majority said that they liked the bold, arresting look of the headline, and that the colours were a powerful means of getting attention.”

“When asked what they felt the advert was trying to achieve, most end users agreed that it was prompting men who had not had a recent HIV test to reflect on the possibility that they might be infected, and that they should consider having a test….the majority of end users felt that the confrontational tone used in the intervention would spur them and other readers to act, because upon reading it, undiagnosed men could no longer fool themselves.”

(End user evaluation)

“The two groups of men with diagnosed HIV chose to discuss this intervention because of its perceived effectiveness at gaining attention and increasing HIV testing. Although they acknowledged that it did not target them personally, they demonstrated full support for it as an important component of HIV prevention. Respondents in the one young men’s group discussing it unanimously voted for Think HIV as the best campaign of all those they were asked to consider.”

25 February 2011
Further Supplementary Memorandum by the Department of Health (HAUK 94)

House of Lords HIV Inquiry – Follow-Up Questions (26 April)

1) Cost data

An estimate of the holistic cost of HIV and AIDS is the primary area that the Committee wishes to inquire into. In terms of prior conversation, Kay Orton kindly gave me the response detailed underneath in January, but I have been asked to see whether there has been any developments as regards cost estimates within the Department, as well as to put any response onto a more formal footing.

I have alerted the Committee to the Department of Health Programme Budget for 2009/10, which estimates the cost of HIV at £760m for 2009/10. However, the Committee are looking to see how that figure breaks down, and in particular whether it only includes treatment and care; if so, they wish to know what estimates can be made for other facets of spending on HIV and AIDS. The Committee are also keen to see what spending is accounted for at a national level, and what spending is dealt with as part of local or regional arrangements.

There have been no developments since Kay Orton’s reply of 5 January. DH has published the estimates of NHS programme expenditure for 2009/10 which we have already provided. Programme budgeting estimated gross England level expenditure on HIV and AIDS of £762 million (2009/10) includes estimates of expenditure by PCTs, Strategic Health Authorities and Special Health Authorities. The services included within PCT level expenditure on the HIV and AIDS subcategory include:

• In-patients
• Out-patient procedures
• Out-patient attendances
• Community and outreach nursing
• High Cost Drugs
• Prescribing

An element of PCT overheads may also be included. Programme budgeting data cannot be disaggregated to allow estimation of the proportion of HIV expenditure on the services listed above. GP expenditure, expenditure on prevention and social care expenditure are not included within disease specific categories and are reported in separate categories which cannot be disaggregated further to estimate the proportion of HIV expenditure within them. As part of the work to develop the public health budget, we are identifying spend on those activities that could be funded from the public health budget, (which includes HIV testing and prevention).

The response from Kay Orton refers to social care and local authorities: if an answer was able to include estimates of these costs from local authorities, that would be extremely useful; if not, do you have an idea of how such data is collated and the best source for seeking it out?

Up to 2010/11, the Department contributed to local authorities HIV-related social care costs through the AIDS Support Grant (ASG). LAs are not required to report on their
HIV social care expenditure covered by the ASG or other local authority funding. The ASG in 2010/11 was £25.5 million which was allocated to LAs in-line with data from the Survey of Prevalent HIV Infections Diagnosed. The ASG is not an estimate of the total costs incurred by LAs since some may be contributing more to a person’s care from other LA funding and some may have been spending less than their ASG allocation.

2) Drug procurement

The Committee would like to ask whether antiretroviral drugs for HIV are procured on a national basis, or whether it is individual PCTs (or regional structures such as the London HIV Consortium) that procure drugs from pharmaceutical companies themselves.

Antiretroviral drugs are not procured on a national basis. In London, the HIV Consortium commissions HIV treatment on behalf of all PCTs, and undertakes the procurement of ARVs. Outside London, there is a mixed picture with some procurement done through regional arrangements but in certain cases local arrangements may apply between individual providers of HIV care and pharmaceutical companies.

3) NHS (Charges to Overseas Visitors) Regulations 1989

a) What estimate does the Department make as to the number of people who are liable to incur charges for HIV treatment and care as a result of the Regulations? What estimate does the Department make as to the number of people who are actually charged?

b) Does the Department of Health have any evidence regarding the idea that "health tourism" - where people would enter the UK with the main and sole purpose to access HIV health services - would occur should HIV treatment and care be provided for free?

Routine reporting for HIV does not include detail of a person’s residency status (eg asylum seeker, failed asylum seeker, visitor etc) which would indicate those who may be liable for charging. The NHS does not collect detailed data on the overseas visitors it treats or charges so the precise scale of health tourism is difficult to quantify. However, NHS frontline staff regularly report examples of people who have apparently travelled to the UK to seek healthcare treatment, sometimes even arriving with their medical notes to show to clinicians. The UK Border Agency also report regular cases where visitors arrive at ports and airports with evidence of hospital appointments and medical records.

4) Directors of Public Health

In oral evidence before the Committee, the question was raised by public health specialists as to whether Directors of Public Health would be required to be specialised in the field under the new structure. There are two resulting questions:

a) Will Directors of Public Health be required to have any qualification or specialisation within the field of public health under the proposed new public health framework?

b) Will there be any requirement as to the level of seniority of Directors of Public Health within local authorities under the proposed new public health framework; for example, will Directors be required to be on the senior management or a cabinet member at a local authority?
Under the provisions of the Health and Social Care Bill, it will be for local authorities and the Secretary of State to jointly appoint appropriately qualified and experienced directors of public health. The position will clearly be a senior one, but the Government does not intend to prescribe its status within the local authority structure.

18 May 2011
Memorandum by the joint Department of Health and National Offender Management Service’s Offender Health Unit (HAUK 92)

1. What general provisions are made within prisons to prevent the spread of HIV / AIDS?

Offender Health (OH) has worked with a range of partners, including the National AIDS Trust (NAT) and the Health Protection Agency (HPA), to develop policies, programmes and implement practices that reduce the risk of the transmission of HIV/AIDS and other blood-borne viruses (BBVs) within the prison estate. The overarching objective of our policy is to increase knowledge and awareness among both staff and prisoners to improve the identification of those at risk of infection, and the offer of a test for HIV and other BBVs and/or screening for other sexually transmitted infections (STIs). Health promotion initiatives have included the development of information resources ranging from DVDs to posters and leaflets which have been specifically designed to be accessible and acceptable to the target audience. OH has also led improvements in the treatment of prisoners who are drug dependent through the Integrated Drug Treatment Service (IDTS) which allows injecting drug users to be treated appropriately thus reducing risk behaviours such as injecting and sharing of equipment. OH have also provided disinfectant tablets to all public adult prisons and information on how to use them to reduce the risk of infection from contaminated materials including tattooing equipment, needles and other injecting paraphernalia etc. This was supported by a Prison Service Instruction. OH also ensured that prisoners had access to condoms and dental dams to reduce transmission of infection through sexual contact in prisons.

Governors have a responsibility to ensure that prisoners under their care have access to condoms etc. OH have also worked with NHS Commissioners and service providers to improve access to sexual health services in prisons to allow more opportunities for testing for infection and advice on how to avoid infection and its transmission. Practice in prisons in relation to provision of condoms and access to sexual health services is monitored by Strategic Health Authorities via the Prison Health Performance and Quality Indicators (PHPQIs). OH has commissioned NHS South West to collect information on PHPQIs from all public prisons in England and data for last year 2010-11 will be published soon. OH has worked with the HPA to improve disease surveillance in prisons and prison-specific data on STIs including HIV and as of January 2011 we will be able to disaggregate data on diagnoses made on people in prison specifically. This will be published soon. OH and the NAT have jointly developed a resource for prison services, NHS commissioners and service providers on tackling BBVs in prisons, including HIV and this is due to be published in June 2011.

2. Do needle supply programmes or needle exchange facilities exist within any prisons currently? If not, have such facilities existed previously? Has the trial of such facilities been considered?

Needle exchange programmes (NEX) do not exist in any prisons in England or Wales and there are no plans to introduce them currently.
NICE evaluated evidence of effectiveness of NEX programmes in prisons and stated that there was a need for more research on the added value of NEX programmes in prisons. NICE also recognised that approaches to controlling BBVs, including HIV, which did not use NEX in prisons had a value and that programmes that included vaccination against Hepatitis B; provision of condoms, dental dams and lubricants; increased access to testing and treatment facilities; increased access to disinfectant tablets; improved treatment of drug dependence, and increased health promotion activities, can contribute to control and prevention of infection with BBVs in prisons. Prisons in England and Wales have never had NEX facilities. Prisons in Scotland have been exploring establishing a form of NEX but this has only been trialled in a limited number of prisons there and in a limited way. OH recognise the value of clinical research trials into the added value of NEX programmes in prisons in England & Wales. But we have no plans to conduct such trials currently and no other external partner has submitted any proposal to do so as far as we are aware. OH is interested in supporting research in prisons and funds the Offender Health Research Network. However, we are also aware of the challenges of such a trial in a prison environment and the risk for harm as well as benefit.

3. Do condom supply facilities exist within any prisons currently? If not, have such facilities existed previously? Has the trial of such facilities been considered?

All public prisons in England and Wales currently provide condoms and dental dams and water-based lubricant to prisoners on application to help prevent the transmission of STIs and HIV through sexual contact.

A prison can request condoms from a prison doctor, nurse or other suitability qualified healthcare worker. Therefore, the application process is as per all other requests for healthcare in prisons.

4. How is the treatment of HIV positive patients managed within the prison setting? How is continuity of treatment and care ensured when prisoners are moved between different geographical locations and facilities?

Prisoners living with HIV infection in prison are provided care from the NHS equivalent to care they would receive in the community. OH recognise the special challenges the prison environment can place on treatment of any disease but we are committed to providing high quality care for all our prisoners, including those with HIV infection. OH have developed healthcare information management systems (SystmOne) to allow for improved continuity of care for prisoners as they move around the prison estate by sharing information on an integrated national computer system accessible to all public prisons. Continuity of care is considered as part of programmes of through-care and after-care by healthcare workers in prisons. People living with HIV are provided access to specialist services in acute hospital trusts when they are prisoners and prisons endeavour to ensure that prisoners have a named GP to provide continuity of care when they are discharged back to the community. OH recognise that people living with HIV are partners in their own care and we endeavour to support the ability of prisoners to do so by providing them with information about their disease and its treatment when they
Memorandum by the joint Department of Health and National Offender Management Service’s Offender Health Unit (HAUK 92)

are in prison so they are more empowered to seek appropriate healthcare themselves on returning to their communities.

OH has worked with the British HIV Association to understand the challenges of continuity of care for people living with HIV in prison and we believe that we have made significant improvements over recent years. However, we remain vigilant and seek to learn from any incident when standards of care fall below the quality expected, and work with our NHS partners and prison governors to implement learning from any untoward incidents.

Prisoners living with HIV are managed according to their clinical needs within prison and are not routinely 'segregated' simply because they have HIV infection.

23 May 2011
Memorandum by the Health Protection Agency (HAUK 67)

1. Introduction

The Health Protection Agency welcomes the enquiry of the House of Lords Select Committee into HIV and AIDS in the UK, and is grateful for the opportunity to provide written evidence to supplement the oral evidence given in January 2011. We comment specifically on areas in the call for evidence which are relevant to our expertise.

The United Kingdom has some of the best surveillance systems in the world for tracking transmission of HIV and the quality of HIV care received. We believe that the synergy of data collection and collation from multiple complementary systems coupled with analysis and interpretation has been critical to providing timely information for public health action and policy development. Furthermore, HPA surveillance and monitoring systems continue to evolve in order to respond to the changes taking place in this field. It is critical that the late diagnosis indicator proposed in the draft Public Health Outcome framework is adopted. This indicator will be crucial in ensuring essential local prevention efforts are prioritised and formally evaluated (see section 2.3).

We have used the HPA’s most recently available HIV data throughout our evidence. Data on new diagnoses of HIV reported to end of December 2010 will be available however in the next few weeks. We will provide these data as soon as they are available to ensure that the final report from this Committee includes the most up to date data on the epidemiology of HIV in the UK.

2. Monitoring

2.1 How robust is the current system for monitoring the number of people with HIV in the United Kingdom?

HIV surveillance in the UK is one of the most comprehensive in the world. The surveillance relies on the routine reporting of HIV, AIDS diagnoses and deaths and CD4 counts by clinics and laboratories; annual survey of persons accessing HIV care nationally (biannual in London) and seroprevalence studies in targeted settings. Coupled with statistical analyses and modelling, these systems provide timely and robust data on the following: the estimated number of people living with HIV; the number of persons newly diagnosed with HIV and those who recently acquired HIV infections; late diagnosis, AIDS and deaths among HIV-infected individuals; number of people in HIV care and those on treatment; HIV testing uptake in antenatal and STI clinics.

HPA data outputs are presented by key parameters (including risk groups, ethnicity, age, gender and geography) and are accessible on the HPA website. Major epidemiological trends and policy recommendations are available in a series of reports also accessible on the HPA website. The HPA plays a crucial role in surveillance developments at the European level (particularly with the European Centre for Disease Prevention and Control (ECDC) and with the World Health Organisation (WHO) and UNAIDS globally.

Few countries routinely monitor persons in HIV care. In England, Wales and Northern Ireland, this is achieved through an annual survey of all adults accessing HIV services (data
The Survey of Prevalent HIV Infections Diagnosed (SOPHID) collects basic demographic, risk factor and clinical information including uptake of antiretroviral drugs at date last seen at the clinic. The data are de-duplicated at the national level and provide a census of all persons in HIV care in a given year (twice yearly in London). In addition to providing valuable epidemiological information, these data are used by local commissioners and more recently the survey has enabled the development and monitoring of clinical outcome indicators to assess the quality of HIV care received by patients. The four indicators are timely access to HIV care following an HIV diagnosis and virological and immunological indicators of treatment and care success and death rates among the newly diagnosed. In 2008, the level of care received by London HIV patients was high: 80% of patients had a CD4 count within one month of HIV diagnosis (used as a proxy for entry into care) and almost 95% within three months; 90% of patients had an undetectable viral load (<50 copies) one year after starting anti-retrovirals; and 93% had a CD4 count 200 cells per mm3 and over after one year in HIV care. Between 2005 and 2008, 1.5% of patients died within a year of diagnosis, almost all deaths occurred among those diagnosed with a CD4 count <200 cells per mm3. These indicators, already in place in London, should be extended to the rest of the country in the next year.

Another unique feature of HIV surveillance in the UK is the estimated number of both diagnosed and undiagnosed persons living with HIV. The estimates of undiagnosed infections rely on data from unlinked anonymous (UA) serological surveys conducted in four selected adult populations: pregnant women, injecting drug users attending drug agencies, sexual health clinic attendees tested for syphilis and men who have sex with men (MSM) recruited through the Gay Men’s Sexual Health Survey (conducted in collaboration with University College London). The key health and demographic factors collected as part of these surveys enable the monitoring of prevention initiatives within particular groups, such as those presenting with an acute STI. These data, in addition to other surveillance and sexual behaviour data, are fed into a Multi-Parameter Evidence Synthesis (MPES) model to provide estimates of diagnosed and undiagnosed HIV infected populations aged 15 to 59 years by geographical regions. The estimates are provided with a credible interval to account for a degree of uncertainty and are comparable with other estimates of undiagnosed infections produced in countries with similar epidemics such as France, Canada and the United States. Importantly the application of the same methods to calculate the undiagnosed fraction of persons living with HIV year on year provides valuable trend data over time.

It was decided again within the past two years that HIV infection should not be made statutorily notifiable. HIV surveillance continues to depend on the willingness of physicians and virologists to continue to comply with requests by the Chief Medical Officer to voluntarily report all HIV diagnoses to the national centre. The proposed revision of the STI Regulations (consulted upon in 2004) should be seen as an opportunity to strengthen the basis for central reporting of HIV and STIs for ‘secondary uses purposes’, thus removing any ambiguity around interpretation of the word ‘prevention’ in the current STI regulations.

2.2. Will the proposed public health reforms impact on this system?

The recommendation from the Arms Length Body Review that the NHS Information Centre (NHSIC) act as the clearing house for NHS information has produced the current
‘Fundamental Review of Data Returns’ process. This has led to suggestions that all ‘routine’ quarterly and annual returns from the NHS should be managed by the NHSIC. Whilst we understand the importance of reducing the burden of returns, we are concerned at the possible reduction in the current close involvement of specialist public health experts in all aspects of HIV surveillance and in other HPA work that this could imply. Our view is that there is a risk of compromising the quality and timeliness of the data provided.

This risk results from the separation of collection and collation of HIV data from its analysis and interpretation. We consider the alignment of these functions to be critically important in maintaining the quality of the information produced, and are concerned that the ability of the information systems to adapt to changing priorities could be curtailed. Aligning data collection and collation with its analysis and interpretation recognises the synergies obtained through having a number of complementary systems that together ensure maximum ascertainment of persons newly diagnosed with HIV infection as well as the total number of persons living with diagnosed and undiagnosed infections.

The collaborative approach embodied within the NHS, whereby clinicians voluntarily report extensive HIV related data to a national centre, coupled with the capacity of the HPA to coordinate and undertake large-scale serosurveillance, has been the cornerstone of the flexibility required to ensure high quality information is available to guide the clinical and public health response. Of concern to the HPA is that substantial reductions (possibly up to 30%) in the budget available for our services are planned over three years, because they are not classified as “front line”. Whilst we are taking action as far as possible to protect our HIV and sexual health functions, there is a strong possibility of a reduction in the specialist support, surveillance and information that the Agency is able to provide to tackle these diseases. The Agency’s view - which has been clearly set out to the Department of Health - is that these services should be clearly identified as “front line” services in tackling HIV and AIDS, in the same way as NHS treatment services are.

The public health White Paper - *Healthy Lives, Healthy People*, published in late November, sets out the Government’s commitment to health protection and to integrating and strengthening existing public health functions. It is encouraging to see that Public Health England will encompass all the current functions of the HPA which are so crucial in protecting health, and we look forward to playing an important role within the new service.

We welcome the plans for Health Protection Units to continue to act as the local delivery arm of Public Health England, providing consistent, high quality specialist health protection as part of the national public health service. This will mean working very closely with local public health colleagues to deliver health protection services, in particular Directors of Public Health, and exactly how these relationships will work in practice is still under discussion.

There remains some issues in the development of Public Health England that need examining in more detail. For example, a critical element in the HPA’s successful service delivery is the independence of its expert advice. Robust arrangements will need to be put in place to ensure public trust and confidence is maintained under Public Health England.

Maintaining independence is critical in terms of retaining credibility and the trust and confidence of the public, health professionals and others working in the field of health protection - locally, nationally and internationally. Clearly if the integrity of advice provision
were to be eroded, or perceived to be so, then the impact on our ability to influence, protect and improve public health would be seriously affected (in the absence of a recognisably independent expert source, the public could turn to potentially less informed and less reliable sources of information).

Scientific advisory committees (soon to become Expert Committees of the Department, on which devolved Administrations may only have Observer status) can address some, though not all, of the aspects of independence of advice. These committees are an excellent way of ensuring that the evidence base being used to inform policy on recognised issues is well founded and balanced. However, such committees are not an appropriate means either of ensuring that expert professional advice is available in real time in response to typical incidents (the HPA responds to hundreds of incidents each year - many of which are local rather than national), and nor are they a suitable mechanism to ensure that the right topics are researched (for example, when evidence of a new problem starts to emerge). Their ability to respond rapidly and flexibly is necessarily limited, and they do not have a budget to direct research.

When the HPA’s functions and staff are transferred to Public Health England, within the Department of Health, there is a risk that its advice will no longer be seen to be independent of Government unless steps are taken to preserve its independence. To credibly fulfil the role of provision of independent expert advice, particularly to the public, Public Health England needs to be seen to have both a separate identity and an independent voice, and to be able to initiate work in areas it deems of importance to health protection. The high approval ratings enjoyed by the equivalent organisation in the USA, the Centers for Disease Control and Prevention (CDC) demonstrate how such a model can be made to work within Government. A further example is the Medicines and Healthcare Products Regulatory Agency (MHRA) which we understand to be an Executive Agency, and which has a solid reputation for independent authoritative advice and action.

2.3. Could anything be done to improve monitoring?

- Monitoring late diagnosis

Earlier diagnosis of HIV infection is associated with reduced morbidity (such as hospital admissions) and HIV related death. Furthermore, earlier diagnosis and prompt treatment has a knock-on effect on public health in reducing onward transmission. To this end, the late diagnosis indicator proposed in the draft Public Health Outcomes framework is welcomed. As the sole HIV indicator in the proposed framework, the late diagnosis indicator will be critical in ensuring that local HIV prevention and testing initiatives are prioritised and successful in reducing ill health associated with HIV as well as transmission.

- Improving estimates of HIV incidence

Recent Infection Test Algorithm (RITA) test results together with clinical data allow for the distinction of recent from long standing infections. For surveillance purposes, the accuracy of RITA testing is improved when test results are combined with clinical data (history of previous HIV tests, AIDS indicator diseases and ARV treatment) and biological data (CD4 count), data routinely available for newly diagnosed individuals in the UK. At present a RITA test is conducted on a quarter of all new HIV diagnoses throughout England and it is
important that RITA testing is expanded throughout the country to provide a means of measuring recently acquired HIV infections at a local level and among population groups.

Additionally, local RITA data will create an opportunity for targeting and evaluating ‘accelerated’ partner notification; for developing responses to clustering or to increases of recent infections; and a means of evaluating local prevention efforts. Findings from RITA testing will also strengthen estimates HIV incidence nationally – such analyses are already being conducted in France and the US.

- Monitoring behaviour

The monitoring of sexual and other risk behaviours for HIV is essential to the overall epidemiological picture of HIV. Fewer robust community behavioural surveys of MSM have been conducted in recent years due to reduced funding, and only two behavioural surveys (based on convenience samples) among African communities have been ever conducted in England.

- Monitoring of access to care following HIV diagnosis

Prompt access to care and treatment following diagnosis is very high in London (>95%) with little variation by population groups. We recommend that the monitoring of access to care after diagnosis, already in place in London, should be extended to the rest of the country. This will be especially important with the expansion of testing outside traditional settings. Accelerated clinical pathways are required in the establishment of new testing strategies to ensure prompt HIV care following diagnosis.

2.4. What groups are particular at risk from HIV?

The HIV pandemic continues to grow and evolve. In the UK, the epidemic is largely concentrated in subpopulations namely; men who have sex with men (MSM); black African heterosexuals (mostly among migrants from parts of the world where the epidemic is ‘generalised’) and to a lesser extent injecting drug-users. The annual number of new diagnoses among MSM has remained at record high level for the past five years (>2500), and this group remains the most affected in the UK. The high proportions of recently acquired HIV infections among newly diagnosed MSM of all age groups underscores the need for ongoing prevention efforts tailored to all ages in this group.

Heterosexually transmitted infections, mostly among black Africans and to a lesser extent black Caribbean populations, began to rise in the late 1990s. Historically the majority of MSM acquired their infection in the UK whilst most heterosexuals acquired their infection outside the UK in the country of origin of migrants. Recent data, however, show that infections acquired through heterosexual contact within the UK are slowly on the rise.

Although the prevalence of HIV among those who have injected drugs remains low (particularly compared to many other western countries), there is some variation across the country with higher rate in London and a concern that overall rates may be on the rise.

We have been very successful in ensuring that HIV infection rates remain very low in the wider population as shown by overall low rates among pregnant women. Furthermore, mother to child transmission rates fell (from almost 30% to 2%) following the introduction of a routine offer of an HIV test to all pregnant women and treatment of those infected.
3. Prevention

3.1. Have the right groups been targeted in recent prevention campaigns?

In the first decade of the HIV epidemic in England, campaigns were used to raise awareness about HIV and AIDS in the general population. Using taglines such as “Don’t Die of Ignorance”, these campaigns aimed to improve knowledge of HIV transmission and prevent new infections in the absence of effective treatment. Most campaigns resulted in a positive impact on knowledge and attitudes of HIV and a rapid decline in HIV transmission and AIDS deaths among MSM in the UK.

Whilst these early general campaign had a positive impact on knowledge about overall attitudes to HIV, it should be remembered that in the 1980s the magnitude of the threat was much greater than in the 2010s: HIV was untreatable and universally fatal and the risk factors for heterosexual transmission were much less delineated. Today the rate of transmission within the wider heterosexual population of England is much less than feared in the 1980s, and heterosexual transmission much lower (although increasing) than in societies where intense social mobilisation and campaigning has been successful in retarding heterosexual HIV transmission.

In the past decade, with effective antiretroviral treatment resulting in greatly improved prognosis for persons diagnosed with HIV, campaign messages have changed, with increased emphasis on HIV testing and access to treatment, as well as reducing risky sexual behaviour in high-risk populations. Over this period prevention campaigns have largely targeted populations most at risk of HIV in the United Kingdom that is; MSM and black African communities. This approach has been based on epidemiological evidence showing that the overall rates of HIV remain very low in the UK coupled with limited funds dedicated to prevention activities.

Although media campaigns aimed at the general population conducted abroad in recent years have shown some effectiveness in increasing the uptake of HIV testing, the evaluation of the campaigns also show reductions in the proportion of HIV positive persons among those tested suggesting that mass media may disproportionately attract low risk individuals and are therefore unlikely to be cost-effective.

It is critical that health promotion campaigns are adequately evaluated and that success as well as process measures are incorporated into the design of a campaign from the outset. Public Health England should ensure public health including surveillance expertise is included in the planning, implementation and evaluation of future prevention campaigns.

3.2. To what extent have prevention initiatives targeted at injecting drug users been successful?

Although the prevalence of HIV among those who have injected drugs remains low and is estimated to be 1.5% overall in the UK, it varies across the country from 0.6% in Scotland to 4.1% in London, and among current injectors increased from 0.7% to 1.5% over the past decade, and is now similar to the level found in the early 1990s. Furthermore, around one-quarter of injecting drug users continue to share needles and almost a third of injecting drug users with HIV remain unaware of their infection. Co-infections are common among
injecting drug users. In addition, around one-half of injecting drug users is infected with hepatitis C, one-sixth with hepatitis B and about one-third report a symptom of a bacterial infection (such as a sore or abscess) at an injecting site in the past year.

Harm reduction programs providing clean needles and substitution therapies have been important in curbing the spread of HIV among injection drug users. Recent increases in HIV among injecting drug users underscore the need for sustained funding of interventions that aim to prevent infections in this group and a review of current levels of provision to ensure adequate coverage. Those commissioning community-based services to reduce the harm associated with injecting drug use should give appropriate priority to preventing the spread of infections and reducing the harm that these infections cause.

3.3. How could prevention initiatives be better delivered and evaluated?

We believe Public Health England should play a leading role in the coordination, monitoring and evaluation of HIV prevention initiatives. The imminent national sexual health and HIV strategy is welcome. It will be important that a wide range of key stakeholders are involved in the development of the strategy and that a draft form is open to consultation. The strategy will need to take into account the many changes that have taken place (most notably in the areas of treatment, transmission and prevention) as well as address issues of stigma and access to care. Outcome measures that are measurable at the local as well as national level should be agreed and incorporated into sexual health profiles and toolkits fit for local use.

Prevention efforts should focus on several priority areas over the next 5 years. These include:

- **One to One Interventions**
  A formal review and auditing of NICE guidelines on one to one interventions to reduce the transmission of STIs (including HIV) should take place. HPA systems could be adapted to undertake this review.

- **Partner notification**
  The STI and antenatal setting provide a unique opportunity to ensure recent sexual partners of newly diagnosed persons are referred for HIV testing. However, little is known about the success of partner notification in these settings. The HPA will be looking at ways to audit and review partner notification in these settings using current surveillance and follow up mechanisms.

- **Sustained targeted health promotion in most at risk groups**
  MSM remain the group at highest risk of HIV. Current evidence suggests that behaviour change alone is unlikely to curb the epidemic in MSM. Effective prevention will require a combination of medical (including treatment), behavioural, social and structural interventions. A coordinated response, led by Public Health England, should be developed which include success markers to track these efforts.

Results of the recent pre-exposure prophylaxis (PREP) trial show a marked reduction in the number of new infections among MSM receiving antiviral therapy. The UK’s delivery of sexual health services and HPA surveillance systems provide a unique opportunity to assess the feasibility, acceptability, effectiveness and cost effectiveness of scaling up PREP among
high risk MSM and heterosexuals (mostly among black African and Caribbean communities) attending STI clinics.

- **Consolidation of efforts to improve testing uptake and frequency of testing in MSM (see Testing section 4.1)**
- **Geographically targeted testing (see Testing section 4.1)**

4. **Testing**

4.1 **Are current testing policies adequate across the country?**

The number of people living with HIV has increased rapidly over the past decade. This is due to infected individuals living longer as a result of very effective treatment, as well as ongoing transmission. Of particular concern is the high number of persons who remain unaware of their HIV infection. In 2009, of the estimated 86,500 people living with HIV over 22,000 (26%) remained undiagnosed. A recent HPA study showed that there was no evidence of a decline in the prevalence of undiagnosed infection between 2001 and 2008. Furthermore, over a half of all persons diagnosed present late with a CD4 count below 350 at a point at which treatment should have begun. This proportion is lower among MSM and women screened antenatally. Importantly, persons diagnosed late are more than ten times more likely to die within one year of their diagnosis.

To date, testing strategies have largely focused on the STI and antenatal setting. The high number of persons who remain undiagnosed and present late has led to a call for early and expanded testing. The offer and uptake of HIV testing could be improved in the following areas.

- **Further improvements in the coverage of HIV testing in STI clinics**
  The national recommendation of universal testing for all attendees of STI clinics should be audited and improved in many clinics; the existing national standard for HIV testing (currently 60%) in STI clinics should be reviewed so as to encourage better performance.

- **Increasing the uptake and frequency of HIV testing among MSM**
  The HPA recommends yearly tests among sexually active MSM. Behaviour data from convenient samples show that less than a third of MSM test annually. We propose to better monitor the frequency and uptake of HIV testing in STI clinics using the new Genitourinary Medicine Clinic Activity Dataset.

- **Targeted geographical testing in high prevalence areas**
  British HIV Association guidelines on HIV testing, developed in 2008 in collaboration with the HPA and others, recommend the offer of a HIV test to groups regarded as being ‘at risk’ of HIV infection, as well as all persons admitted for an acute medical problem or registering with a general practitioner for the first time in a high HIV prevalence areas. The HPA provides updates of high prevalence areas on an annual basis.

It remains unclear how well these guidelines have been implemented. Results from testing pilot studies conducted over the past twelve months indicate that these settings are acceptable to patients and staff and successful in diagnosing persons unaware of their HIV infections. Moreover the routine offer of a HIV test to all attendees (rather than a risk based triage) reduced perceived stigma among patients and was welcomed by staff.
Given that routine bloods are collected on admission, we believe the routine offer and recommendation of a HIV test to all patients admitted to a general medical ward offers a real opportunity to expand testing. This should be prioritised and widely implemented in high prevalence areas (greater than 2 per 1,000 people with diagnosed HIV infection). Similarly, testing new registrants in primary care should be implemented in high prevalence areas although the cost implications may be greater in this setting where there may be a greater reliance on point of care tests. Test offer, uptake and positivity and late diagnoses rates will need to closely monitored at the local and national level to track the success of these intervention. Cost-effectiveness studies of testing strategies in the UK are required to inform future testing policies and strategies.

5. Cost

5.1 Have cost considerations been satisfactorily balanced with public health imperatives in HIV in terms of Prevention policy?

A little under half of all person diagnosed with HIV each year were probably infected in the UK. Early diagnosis and prompt treatment can reduce onward transmission. We estimate that the prevention of one new HIV infection would save the public purse between £280,000 and £360,000 in direct lifetime healthcare costs. This means that had all of the UK-acquired infections newly diagnosed in 2009 been prevented (that is an estimated 3420 out of the 6630 total new diagnoses), there would have been a saving of approximately £1 billion in direct healthcare costs. This figure does not include additional indirect costs such as social care, time off work and cost of benefits, or any costs saved as a result of preventing further transmission.

Earlier diagnosis reduces hospital admission rates among HIV infected individuals and therefore leads to long-term cost savings. Nevertheless, it is expected that the expansion of testing, currently targeted to high prevalence areas, will be have a substantial initial cost and should be factored into local strategies to reduce late diagnosis. The HPA is working on local cost estimates of the routine offer and recommendation of a HIV test to all persons admitted to a medical ward in hospitals located in high prevalence areas.

The Public Health White Paper consultation proposes sexual health/HIV prevention and sexual health services to be commissioned locally through local authorities from their ring-fenced health improvement budget. HIV treatment services, on the other hand, are expected to be commissioned through the National Commissioning Board. The resulting split between prevention and treatment will mean that incentives will need to be put in place to encourage local healthcare providers and Directors of Public Health to increase their focus on HIV prevention, deliver appropriate services and evaluate the impact of these measures.

February 2011
Supplementary Memorandum by the Health Protection Agency (HAUK 68)

Additional questions posed to the Health Protection Agency during the House of Lords Select Committee on HIV and AIDS session on 18 January 2011

1. Describe the impact of HIV in Young People in the UK

HIV case reports show that one in ten new HIV diagnoses in the UK occur in young people aged 15-24 years and incidence estimates suggest that one in six new HIV infections occur in young people. Ongoing HIV transmission among young people reflects the higher rate of risky sexual behaviour, higher rates of STIs and multiple partnerships compared to older people. Like trends in syphilis or gonorrhoea diagnoses, HIV diagnoses in young people are disproportionately made in males, particularly gay men. In 2009, 46% of young people aged 15-24 diagnosed with HIV acquired the infection through sex between men.

<table>
<thead>
<tr>
<th>Year</th>
<th>New HIV Diagnoses (15-24)</th>
<th>HIV rate per 100000</th>
<th>Chlamydia (15-24)</th>
<th>Chlamydia rate per 100000</th>
<th>Gonorrhoea (16-24)</th>
<th>Gonorrhoea rate per 100000</th>
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<td>2002</td>
<td>686</td>
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<td>5466</td>
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<td>1204</td>
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</table>

A recent survey from National AIDS Trust and IPSOS MORI “Public Attitudes Towards HIV” from 2007, found that amongst young people (aged 16-24) 85% correctly identified that HIV can be passed through unprotected sex between a man and a woman. Over 70% correctly identified that HIV can be passed through unprotected sex between two men, through blood transfusion, and by sharing a syringe when injecting drugs. Similarly, high rates of young people rejected major misconceptions about HIV transmission. 73% of young people agreed with the statement “most people with HIV these days can work like anyone else”, and less than 5% believed that HIV can be passed from a public toilet seat or sharing a glass. The rates of correct answers were broadly in line with other age groups up to age 45 and similar to responses from a survey in 2005.\(^{163}\)

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2. **Provide trends in New HIV diagnoses over time: 1986-2009**

Number of new HIV diagnoses by prevention group, UK: 1986-2009*

*Adjusted for missing risk information in recent years.

Number of new HIV and AIDS diagnoses and deaths, UK: 1986 - 2009
3. When will the expected number of People living with HIV reach 100,000?

The estimated year when the number of people living with HIV is likely to reach 100,000 is 2012. This assumes a steady increase of 4,000 additional individuals seen for care and a constant in the proportion undiagnosed (27%).

4. What is the association between alcohol and HIV?

Although there is little evidence to specifically link HIV infection with alcohol consumption\(^{164}\), several observational studies have examined the link between alcohol consumption and sexual behaviour and found that alcohol use is a strong determinant of sexual risk behaviour\(^{165,166}\). Additionally, in a systematic review of 11 observational studies examining the relationship between alcohol consumption and sexually transmitted infection, 8 studies found a significant association between alcohol consumption and infection with at least one STI\(^{167}\). This association was more marked in men who have sex with men, heterosexual men, young adults and drug users. A recent UK area-based analysis of alcohol attributable hospital admissions had higher rates of chlamydia and genital warts, this association was strengthened in areas of high deprivation\(^{168}\). Overall, the literature supports an association between problematic alcohol consumption, sexual risk behaviour and sexually transmitted infections; although a causal relationship cannot be determined with certainty from observational studies.

5. What is the awareness of HIV in the general population?

An IPSOS MORI survey on behalf of the National AIDS Trust was undertaken in 2007 using a nationally representative quota sample of 1,981 adults in face-to-face interviews\(^{169}\). The survey found that most people feel that there is stigma attached to HIV and AIDS and that more needs to be done to tackle prejudice against people with HIV. Since 2000 there has been a steady decrease in the proportion of people who agree that there is still a great deal of stigma in the UK today around HIV and AIDS. However, it still remains the case that over two-thirds of people feel that there is a great deal of stigma.

A substantial proportion of the British public appear to be unsympathetic to people who become infected through drug use and unprotected sex. Almost half agreed that people


who become infected through unprotected sex only have themselves to blame and almost two thirds strongly agreed or tended to agree that those people who became infected through using drugs only have themselves to blame. The proportions agreeing with these two statements decreased between 2000 and 2005, but increased again in 2007. Stigma remains associated with older age, lower education level and lower socioeconomic status. Individuals with high knowledge and awareness about HIV are least likely to agree with negative statements about HIV.

In HIV infected individuals, qualitative studies have shown that fear of stigma and discrimination is cited as a major barrier to early HIV testing among African migrants, who often fear the perceptions and reactions of community members and possible impact on immigration status. Migrants have been disproportionately prosecuted for HIV transmission and exposure in several European countries which may explain, in part, the high rates of late HIV diagnosis in this community.

Stigma and discrimination is also frequently cited by those with HIV as a deterrent to finding and gaining employment. While over half (58%) of the respondents of one survey by National AIDS Trust said being HIV positive had no impact on their working life, one in five recall experiences of discrimination in the workplace after disclosing their HIV status.

6. What is NATSAL?

The National Survey of Sexual Attitudes and Lifestyles (Natsal) is a stratified national probability sample survey of sexual attitudes and lifestyles in residents of Britain. Natsal was originally set up because of an urgent need for information about sexual lifestyles in the context of the HIV/AIDS epidemic. The first Natsal survey was in 1990, with the second study taking place in 2000. The third Natsal survey began in 2010 and its results will be published in 2013.

7. Women and Human Immunodeficiency Virus (HIV)

The number of women living with HIV continues to rise with an estimated 30,000 people living with the virus (either diagnosed or undiagnosed) in the UK in 2009, equivalent to a rate of 0.9 women per 1,000 population (compared to 1.8 per 1,000 men). An estimated three in ten women remained unaware of their HIV infection.

Over 21,700 women (aged ≥15 years) were living with diagnosed HIV infection in 2009 comprising 34% of the total number of persons in HIV care. The 2009 figure represents an increase of 6% from 2008 (20,524), and almost quadruple the number seen in 2000 (5,136). More than three-quarters (78%) of diagnosed women are prescribed ART; an equal proportion of men received ART.


Almost 34,000 women have been diagnosed in the UK since the beginning of the epidemic. The large majority (over 90%) acquired their infection through heterosexual contact, whilst about 5% have a history of injecting drug use, 3% acquired their infection through mother to child transmission and 1% received contaminated blood or blood products (almost all abroad or prior to screening).

The number of new HIV diagnoses among women remained low until the late 1990s and the rise since then is predominantly attributed to a rise in women who most likely acquired their infection heterosexually in sub Saharan Africa. This rise was also seen among heterosexual men diagnosed over the same period. The large majority of women infected heterosexually are of black African ethnicity (75%) followed by white (15%). In contrast the majority of women who reported injecting drug use were of white ethnicity and acquired their infection in the UK. Over the past few years, women have represented about a third of all persons diagnosed with HIV each year.

However, the large rise in new diagnoses among women has not been sustained. Since 2004, new diagnoses among women have fallen from 3,290 to 2,230 largely due to changes in migration patterns. Furthermore, although there has been an overall decline in heterosexual infections in recent years, national surveillance indicates a steady number of new diagnoses acquired heterosexually within the UK (1,030 in 2007; 1,150 in 2008; 1,130 in 2009). Two thirds of these infections are among women.

Furthermore, 61% of women (aged over 15 years) are diagnosed late (CD4 cell count <350 per mm3 within three months of diagnosis) in the UK, after the time at which treatment should have begun. The proportion diagnosed late was higher than MSM (43%) but lower than heterosexual men (66%). Late diagnosis is lower among pregnant women than those who are not pregnant. This indicates that the recommendation of testing during pregnancy provides an opportunity for women to be diagnosed earlier in the course of their infection. Uptake of HIV testing in women attending antenatal care and genito-urinary medicine clinics continues to improve reaching over 90% and 75% and in these setting in 2009 respectively.

Areas covered by unlinked anonymous surveillance for pregnant women indicate rates of HIV infection of 2.1 per 1,000 women, that is around one in every 486 women giving birth is HIV infected (this includes women diagnosed before and during antenatal care, as well as those who remained undiagnosed during pregnancy). HIV prevalence among women giving birth remained highest in London (3.7 per 1,000) and has been stable since 2004. Among UK-born women giving birth in 2009, HIV prevalence was 0.5 per 1,000; while this remains relatively low, a gradual increase in prevalence has been observed since 2000 when the prevalence was 0.16 per 1,000.

8. Creation of the Health Protection Agency

On 10 January 2002, the Chief Medical Officer published his infectious diseases strategy for England in ‘Getting ahead of the curve’ and announced the setting up of the National Infection Control and Health Protection Agency with effect from 1 April 2003. This new agency would combine existing functions of the Public Health Laboratory Service (PHLS), the National Radiological Protection Board (NRPB), Centre for Applied Microbiology and Research (CAMR) and the National Focus for Chemical Incidents. Subsequently, the National Institute for Biological Standards and Control merged with the HPA after the
necessary legislation had been passed. The steps taken to establish the Health Protection Agency (HPA) are summarised in Table 1.

### Table 1 Setting up the Health Protection Agency (HPA)

<table>
<thead>
<tr>
<th>Year</th>
<th>Date</th>
<th>Event</th>
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<tbody>
<tr>
<td>2002</td>
<td>10 January</td>
<td>Sir Liam Donaldson (Chief Medical Officer for England) publishes ‘Getting ahead of the curve’ which includes a proposal to set up the National Infection Control and Health Protection Agency with effect from 1 April 2003</td>
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<tr>
<td>2002</td>
<td>17 June</td>
<td>Hazel Blears (Minster for Public Health) announces consultation on the new agency</td>
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<td>2002</td>
<td>7 August</td>
<td>Chairman of HPA Board appointed</td>
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<td>2002</td>
<td>15 November</td>
<td>Hazel Blears writes to CAMR, NRPB and PHLS announcing that the HPA will be set up as a special health authority which will take on functions under the NHS Act from 1 April 2003 and that NRPB will not be included until the necessary primary legislation has been enacted</td>
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<tr>
<td>2003</td>
<td>27 January</td>
<td>Chief Executive of HPA appointed</td>
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<tr>
<td>2003</td>
<td>1 April</td>
<td>HPA comes into existence</td>
</tr>
<tr>
<td>2003</td>
<td>2 April</td>
<td>Non-executive directors of HPA announced</td>
</tr>
<tr>
<td>2003</td>
<td>29 October</td>
<td>Scottish ministers announce their decision that the HPA should take responsibility for the functions that the NRPB carries out for the Scottish Executive</td>
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<tr>
<td>2003</td>
<td>20 November</td>
<td>Health and Social Care Act (Community Health and Standards Act) 2003 - which includes the abolition of PHLS - receives the Royal Assent and becomes law</td>
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<tr>
<td>2003</td>
<td>27 November</td>
<td>Presentation of HPA bill in the House of Lords and first reading</td>
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<tr>
<td>2005</td>
<td>1 April</td>
<td>HPA became an executive non-departmental body</td>
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<tr>
<td>2009</td>
<td>1 April</td>
<td>National Institute for Biological Standards and Control joined the HPA</td>
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<tr>
<td>2010</td>
<td>30 November</td>
<td>The Government launches the White Paper – <em>Healthy Lives, Healthy People</em>. The paper sets out the Government’s commitment to establish Public Health England, a service which would include the current functions of the Health Protection Agency.</td>
</tr>
</tbody>
</table>
**Funding arrangements**

Proposals in Healthy Lives, Healthy People: consultation on the funding and commissioning routes for public health

(link to Consultation on the funding and commissioning routes for public health (link to doc, pg 16 has these details):

To be funded from new public health budget: contraception, testing and treatment of STIs, fully integrated termination of pregnancy services, all outreach and prevention.

Proposed commissioning route: Local Authority to commission all sexual health services apart from contraceptive services commissioned by the NHS Commissioning Board (via GP contract).

Associated activity to be funded by NHS budget: HIV treatment and promotion of opportunistic testing and treatment.

This document indicates the proposed role of the NHS Commissioning Board for the commissioning of HIV treatment and care (rather than through Public Health England or GP consortia). The details of how this might happen (e.g. national commissioning or sub-regional) would need considering.

25 February 2011
Further Supplementary Memorandum by the Health Protection Agency (HAUK 97)

Responses to questions discussed on Tuesday, 3rd May

I. What are the methods that the Health Protection Agency use to work out the total number of those infected with HIV, including the proportion of those who are undiagnosed?

National estimates of the number of individuals living with HIV in the UK are obtained using a Bayesian Multi-Parameter Evidence Synthesis (MPES) model. Multiple surveillance data in addition to survey type prevalence data and sexual behaviour data are fed into MPES to provide estimates of diagnosed and undiagnosed HIV infected in key mutually exclusive exposure groups of the population aged 15 to 59 years.

Routine surveillance data including new diagnoses and data from the survey of HIV positive persons accessing care (SOPHID) are used to provide data on the diagnosed populations. The estimates of undiagnosed infections rely on data from unlinked anonymous (UA) serological surveys conducted in four selected adult populations: pregnant women, injecting drug users attending drug agencies, sexual health clinic attendees tested for syphilis and MSM attending community venues recruited through the Gay Men’s Sexual Health Survey (conducted in collaboration with University College London). The key health and demographic factors collected as part of these surveys enable the monitoring of prevention initiatives within particular groups, such as those presenting with an acute STI.

The annual estimates are provided with a credible interval to account for a degree of uncertainty and are comparable with other estimates of undiagnosed infections produced in countries with similar epidemics such as France, Canada and the United States. Importantly the application of the same methods to calculate the undiagnosed fraction of persons living with HIV year on year provides valuable trend data over time.

Details of the MPES methodology is available (Goubar 2007 & Presanis 2008) on the HPA website and recent analyses of trends in HIV prevalence in the UK were recently published in AIDS (Presanis 2010)

References:


2. What methods do the Health Protection Agency use to calculate or estimate yearly incidence levels of HIV?

It is difficult to calculate the true incidence of HIV. This is because people can remain without symptoms and will therefore remain unaware of their infection for many years before they are diagnosed.

A number of techniques are used by the HPA to get an insight and estimates of HIV incidence in the UK.

1. New diagnoses
Although the new diagnoses are subject to rise with increases in testing uptake, they provide a very good insight into ongoing transmission within specific subpopulations. Our latest data indicate that new diagnoses for people infected with HIV in the UK almost doubled over the past decade (from 1,950 in 2001 to 3,780 in 2010). Furthermore CD4 count and age at diagnosis provide further insights. There have no substantially change in the median age at diagnosis or the distribution of CD4 over the past decade in key risk groups such as MSM indicating high transmission rates among this group.

2. MPES method
The data indicate an rise in prevalence of diagnosed infections over the past decade with no decrease in the undiagnosed prevalence suggesting that diagnoses rates are not high enough to reduce the pool of individuals unaware of their infection and that new infections must be occurring. More recently, the model was further developed to estimate incidence among MSM (Presanis 2011 in press).

3. Algorithm of recent infection (RITA) in GUMANON survey
Between 1996-2004, HIV incidence was measured among MSM accessing 16 sentinel STI clinics using blood left over from routine STI testing to determine. TRI were applied to determine whether patients with new or undiagnosed HIV infection acquired their infection within the last 4-6 months. The number of incident cases was divided by the number HIV negative MSM accessing STI clinics, and adjusted for repeat STI clinic attendees, to provide annual HIV incidence estimates.

4. RITA on all newly diagnosed samples.
More recently, the HPA is testing samples from people newly diagnosed with HIV. These data are then linked to the new HIV diagnoses database for epidemiological data, allowing to better distinguish recent from long standing infections. By the end of 2010 over 50 laboratories and 90 clinics in England and Northern Ireland are submitting samples with almost 40% of new diagnoses RITA tested in 2010.

3. How have levels of estimated incidence changed over time?
How do levels of estimated incidence vary across the population? Have different patterns emerged in different groups over time?

New HIV diagnoses continue to rise among MSM and heterosexuals who acquire their infection in the UK.
The MPES model suggests no declines in the number of undiagnosed infections despite increases in diagnoses. Recent analyses reveal a small but significant increase in incidence among MSM between 2002 and 2007. The estimated number of incident cases derived from the model is similar to the annual number of new diagnoses among MSM.

The GUMANON survey. Annual HIV incidence among MSM varied between 2-3.5% during 1995-2002 with no significant changes over time.

The Recent HIV Infection Testing Algorithm. Results for 2009 and 2010 indicate that 14% of individuals diagnosed probably acquired their infection within the previous 4-5 months. This proportion was particular high among MSM (24%) followed by heterosexual women (10%) and men (8%). The proportion of recent infections among MSM is highest among those aged 15-24 years (32%) followed by 25-34 years (29%). Although heterosexual women present with a similar trend to MSM with the highest proportion in those aged 15-24 years (20%) and 25-34 years (10%), among heterosexual men the highest proportion was seen in those aged 25-34 years (14%).

4. The term black African is often used as a description of one of the two main prevention groups. Which population groups are encompassed within this classification?

Black African specifically refers to the ethnicity or ethnic group which is self-identified by the patient. This is in accordance with NHS Data Model and Dictionary which states that the ethnicity of a person must be specified by the person. A comprehensive definition of black African was published by the recent NICE guidelines and is as follows:

“The term ‘black African’ includes anyone who identifies themselves as black African, whether they are migrants from Africa, African descendants or African nationals. Black African communities encompass diverse population groups including people from a range of cultural, ethnic and faith backgrounds who may be heterosexual, bisexual or homosexual […] and whose knowledge or understanding of English may be limited.”

HPA reporting forms have a tick box question on Ethnicity/Ethnic group which gives 7 options which are relevant to the HIV epidemic in the UK including: White, black African, black Caribbean, black Other, Indian sub-continent, Other/Mixed or not known. Reporters are strongly encouraged to report this data, and it is over 95% complete after follow up.

Within the black African prevention group, how do levels of HIV diagnosis and infection break down? Specifically:

a. Where infection was acquired abroad, are those who are diagnosed mainly people who are new entrants into the United Kingdom, or those living in the UK who have travelled abroad and acquired HIV before re-entering the UK?

Although heterosexuals represent a number of different ethnic groups, three quarters (74%) are of black African ethnicity and almost 95% of black Africans are included in the heterosexual risk group.
Year of first arrival in the UK is collected for individuals born abroad. Using this information for black Africans diagnosed between 2006 and 2010 who were probably infected abroad, the median time from first entry to diagnosis was 4 years [IQR: 1 – 6 years]. Less than one in five (17%) newly diagnosed black Africans were diagnosed in the year of their arrival (see Graph 1). In fact, over half (53%) of diagnoses in this population are made between 2 and 7 years after arrival suggesting that many HIV positive black Africans migrated to the UK early in the 2000s and have lived in the UK for a number of years prior to being diagnosed. This is corroborated by high rates of late (<350 cells/mm³) and very late (<200 cells/mm³) diagnosis among black Africans, indicating that HIV testing is commonly delayed until a very late stage of infection in this group. There will be a proportion of black Africans normally resident in the UK who acquired their HIV infection while travelling abroad; however we estimate this number to be relatively small.

b. Is data maintained on country of origin and country of infection? If so, are there any trends from within that data that are of particular significance or interest?

Data are maintained on country of origin (as country of birth) and country of infection with high rates of reporting for these among black Africans (89% had a country of birth and 87% had a country of infection reported in 2009). Where country of birth was reported, of 96% black Africans were born in Africa. Where country of birth was reported, 84% of black Africans were probably infected in Africa.

Over the past decade, newly diagnosed HIV infections among black Africans rose sharply between 2000 and 2003 mainly among migrants from eastern African countries with high HIV prevalence, such as Zimbabwe and Uganda. Most of these individuals also acquired their infections abroad. However, in the past five years there has been a steady decline in the number of HIV diagnoses made in black Africans, reflecting a drop in the overall number of migrants arriving from sub-Saharan Africa.

Despite this decrease, black Africans remain the second most important HIV prevention group in the UK, after men who have sex with men. In 2009, one third (34%) of newly diagnosed infections were in black African individuals. There is some evidence of an increase in UK acquired infections among black Africans. Of black Africans diagnosed in 2009, one in seven was infected in the UK, compared to one in 16 in 2000.

5. To what extent do levels of HIV and STI diagnoses (and incidence) correlate over time?

Diagnoses of new sexually transmitted infections (STI) in STI clinics in the UK have risen steadily between 2001 and 2009 (by 29%) and over 380,000 new STIs were diagnosed in 2009. During this time, new HIV diagnoses also increased by 29% (from 5,128 to 6,617 in 2009) although the overall increase masks the year on year decline in diagnoses observed since 2005.

While there is no evidence of a decline in new STI diagnoses, numbers have plateaued over the last three years to between 383,349 and 390,785. While there is some overlap in the
populations affected by HIV and STIs, there are also some important differences. Young people (aged 16-24) account for 57% of the top five STIs\textsuperscript{172} in England in 2009, but only 11% of new HIV diagnoses. Conversely, black/black British individuals account for 39% of new HIV diagnoses, but only 8% of the top five STIs. Groups most affected by STIs are young people, black Caribbeans and men who have sex with men (MSM) while those most affected by HIV are MSM and black Africans. Presence of STIs among HIV positive individuals is a good indication of recent unprotected sex and highlights the risk of onward HIV transmission in sero-discordant sexual partnerships because STIs enhance HIV transmission (Ward H 2010).

Evidence for co-infections comes from individuals attending STI clinics in England between 2008 and 2009. 3.7% (95%CI 3.5% - 3.9%) of HIV positive individuals presented with an acute STI within the next year which increased to 11% (95%CI 8.0% - 14.5%) among MSM aged <25 years (Peters 2010).

References
Ward H, Rönn M. The contribution of STIs to the sexual transmission of HIV. Curr Opin HIV AIDS 2010; 5: 305–310


6. To what extent can the effect of awareness and education campaigns relating to sexual health be linked to any reduction in levels of HIV diagnoses (or incidence), or vice versa?

There is evidence to suggest that during the early period of the AIDS epidemic, awareness and education campaigns among MSM had a substantial impact on HIV transmission (Nicholl 2001). Transmission was most intense in 1983 with approximately 6,000 transmissions occurring by 1984 after which transmission declined and stabilised to 1,300-1,400 new annual transmissions. However, attributing changes in transmission to HIV prevention campaigns is difficult as a number of factors including policy changes could also impact HIV transmission.

A public knowledge and attitudes survey conducted by the National AIDS Trust in 2010 found that 80% of respondents were aware that HIV is transmitted by sex without a condom between a man and a woman and only 30% were able to correctly identify all the ways HIV is and is not transmitted. This survey highlights that there is still a need to improve awareness in the general population about HIV transmission (NAT).

References

\textsuperscript{172} chlamydia, herpes, warts, gonorrhoea and syphilis


7. **Does the HPA maintain any data on the costs of HIV prevention, testing, treatment or care? If so, what are the headline costs both across and within those areas?**

**Treatment**

We know from the Department of Health that health care costs of HIV are substantial; over £600 million is spent each year to provide health care and treatment of the 65,300 people living with a diagnosed HIV infection.

We have also conducted research into the life-time costs of HIV infection and estimate the direct life time cost to be around between £280,000 and £360,000 per positive person.

**Testing**

NICE have recently estimated that the costs of the expanded programme for HIV testing in medical and community settings to be approximately £8.4 million in total or for PCTs £91,000 per 100,000 population.

Focusing on our recommendation of expanded testing in high prevalence areas we estimate that the costs of this to be:

- approx £6.1m per annum for new registrants in general practice (coverage of 75% for 625,000 registrants) to a maximum of £11.25m (assuming coverage of 90% and cost for HIV test of £20)
- there are an estimated 220,000 general medical admissions in hospitals annually in high prevalence areas, costs could range from a minimum of £2.1m to a maximum of £3.9m

**Prevention**

We understand from the Department of health that about £2.9 million are spent on HIV prevention per annum.

Importantly, we believe that if these the estimated 3,800 UK-acquired HIV cases in 2010 had been prevented, over £32 million annually or £1.2 billion over a lifetime in costs would have been saved.

8. **What methodology was used in research conducted by the HPA in 2009 around the cost-effectiveness of HIV prevention; particularly the estimate of direct lifetime costs of between £280,000 and £360,000 of one HIV diagnosis? How robust are those data?**
The project conducted in 2009 together with the National AIDS Trust consisted of estimating the direct life time cost of HIV infection using:

1. A literature review showing that 56-73% of overall costs are attributable to ART and that the life expectancy for a 35 year old diagnosed with HIV to be around 37 years.
2. The mean price of drugs was applied to the number of ARV drugs that HIV-positive patients in the UK are prescribed. This produces a mean annual ART cost of about £5,500 per person.
3. The annual total cost estimates were then calculated to take into account non-ART costs giving an approximate cost of £7500 - £10,000 per annum.
4. Given the average age at diagnosis is 36 years, we assumed 37 years of treatment after diagnosis providing an undiscounted lifetime cost of around £280,000 - £360,000 and a lifetime cost of £120,000 with 3.5% discounting.

Although these are simple estimates which do not for instance take into account the stage at which the infection is diagnosed (we know from the literature that the costs of persons diagnosed late are likely to be substantially higher than those diagnosed promptly largely due to inpatient costs from AIDS illnesses), nevertheless these results are largely in agreement with more complex cost models recently developed. One such model has been developed in collaboration with colleagues at University College London. It relies on a stochastic computer simulation model was to project the progression of HIV infection and the effect of ART on a man infected with HIV in 2010 at age 30.

The model is comprehensive and incorporates a large number of factors including age at diagnosis, viral load, CD4 count, clinical events, use of specific drugs, resistance and adherence. The model allow for clinical and treatment events to be updated every 3 months and allows for unit costs associated with each of these events over a lifetime. Preliminary results from this model estimates the mean lifetime cost at £350,000. With discounting at 3.5% per annum, the lifetime cost estimate is £145,000. This work is close to submission for publication.

A recent published study (Mandalaia et al.) from Imperial college and others concluded that the annual population cost of HIV was £683 million for 2006 or £13,000 per patient per year (given 52,000 people were living with diagnosed HIV in 2006). Using the median age of diagnoses of 36 years old, and assuming 37 years of HIV care and treatment post HIV diagnosis, this finding provides an annual life-time cost of £485,000. Of note however, this study assumed a larger proportion of persons living with AIDS illnesses in a given year (>20%) considerably higher than is likely to be case (<2%), therefore these estimates are likely to be somewhat elevated and provide a “worst case scenario” picture of HIV costs. Consequently, we believe that these published estimates should be interpreted with some caution.

**9. Does that data provide any direction for the future of HIV and AIDS policy in the United Kingdom, particularly regarding the priority afforded to HIV prevention activities?**

Our data suggest that HIV prevention activities deserve further investment. Preventing the 3,800 or so infections acquired in the UK and subsequently diagnosed during 2010 would have reduced future HIV-related costs by £1.2 billion.
Testing pilot projects also indicate that considerable savings can be made in the short and long term with expanded testing in high prevalence areas. This is because early diagnosis leads to fewer hospital admissions and deaths as well as a decrease in transmission following diagnosis associated with reduced high risk behaviours and the effect of ART on viral load.

10. In evidence before the Committee on 18 January, the HPA suggested that levels of risk behaviour amongst men who have sex with men may have increased since the advent of highly active antiretroviral therapy. Is there any data to support this idea?

There is indeed evidence from a number of studies showing an increase in risk behaviours among MSM in the period following the introduction of highly effective therapy. However, cause-and-effect at a population is difficult to establish and treatment optimism is unlikely to have been the only explanation for the increase in unsafe sex among MSM.

details

Behaviour studies on MSM conducted by City University (Elford, J., G. Bolding, et al. 2004) for the period 1998-2003 when effective ART was introduced show a significant increase in the percentage of men reporting unprotected anal sex with both other men regardless of their known HIV status and that of their partner (non-concordant UAI incr 15% to 22%) and concordant UAI (10% to 15%).

Another study of MSM in London over the same period 1999-2000 (Stephenson, J. M., J. Imrie 2003) found high levels of sexual risk behaviour among homosexual men regardless of HAART with significantly lower rates among men on HAART compared to those not on treatment.

Elford J (AIDS 2002) report that MSM who were optimistic were indeed more likely to report high-risk sexual behaviour. However, the dimension of HIV optimism associated with high-risk behaviour varied by status so that high risk behaviour among HIV-positive men was associated with a belief that new drug therapies make individuals with HIV less infectious whilst on the other hand, for HIV negative men high-risk behaviour was associated with being less worried about HIV because treatments had improved.

Stolte (AIDS 2004) showed that in general, US homosexual men in this longitudinal study seemed quite realistic about the effectiveness and consequences of HAART. Most men disagreed with the beliefs measuring less perceived threat of HIV/AIDS and less perceived need for safe sex since HAART. Furthermore, men did not endorse the belief that HAART is effective in curing HIV/AIDS. Despite this realism, the study shows that men who incline towards agreement with perceiving less HIV/AIDS threat since HAART are more likely to change from protected to URAI.

References


11. In your evidence on 18 January 2011, the HPA welcomed the indicator in the draft Public Health Outcomes Framework relating to the proportion of those diagnosed with HIV late. Do you believe that this indicator should be included in the final, published Outcomes Framework, and should it be a mandatory reporting requirement for all local authorities?

The proposed health indicator “Proportion of persons presenting with HIV at a late stage of infection” is an essential indicator to evaluate and promote public health and prevention efforts to tackle the impact of HIV infection.

The health care costs of HIV are substantial – over £600 million is spent each year to provide health care and treatment of the 65,300 people living with a diagnosed HIV infection. If the estimated 3,780 UK-acquired HIV cases in 2010 had been prevented, over £32 million annually or £1.2 billion lifetime treatment and clinical care costs would have been saved, a figure that does not include the cost of psychosocial treatment and support.

The high number of new HIV diagnoses and the high proportion of HIV-positive individuals unaware of their HIV status represent a major public health problem in the UK. This emphasises the importance of expanding HIV testing; an earlier diagnosis will lead to improved prognosis for individuals, reduce onward transmission of HIV and is associated with lower healthcare costs.

Late diagnosis also means that an individual has remained unaware of their infection and infectious for many years, increasing the risk of onward transmission. In 2009, the 22,000 people estimated to be unaware of their HIV infection may have unknowingly put their sexual partners at risk of infection. Prompt HIV diagnosis prevents further HIV transmission through ensuring patients’ viral load is low (through regular monitoring and/or administering anti-retroviral therapy where clinically appropriate) and providing earlier opportunities for partner notification and behaviour change counselling.

**Reducing late diagnosis as a key outcome indicator**

Reducing late diagnosis is therefore of great benefit to individuals, their sexual partners and in reducing health care costs. The late HIV diagnoses indicator is a critical measure to track efforts to reduce the morbidity and mortality associated with HIV infection as well as reducing onward transmission of the virus.

HIV surveillance systems in the UK are robust and comprehensive. Late diagnosis has been routinely measured nationally and at the local level for many years. Additional resources to
measure this indicator will not be required as the data are already routinely collected through existing surveillance systems. Importantly, the implementation and successes of public health and prevention interventions can be tracked in defined risk groups and local areas and compared with robust historical trends.

The late diagnosis indicator has already been implemented in London as part of the London Tool Kit for commissioners. It has been very valuable in driving and tracking public health efforts to expand HIV testing in the capital. The expansion of HIV testing in high prevalence areas, strongly advocated by the HPA, has been recommended through BHIVA guidelines as well as in the National Institute for Health and Clinical Excellence (NICE) guidance published last week. The guidance advocates the development of local policies for HIV testing among black Africans and MSM and the routine offer of a test in a range of health care settings in high prevalence areas. The late diagnosis indicator is the only outcome indicator that can be measured routinely and robustly to drive efforts to curb the HIV epidemic in the UK.

12. Do you believe that there should be an additional indicator relating to HIV prevention? If so, what form should such an indicator take?

The late indicator will be interpreted with a range of other routine data including new diagnoses and proportion of recent infections. We do not believe other specific indicators are required.

As stated in our evidence submitted in February 2011, we believe that transmission rates of HIV remain unacceptable. Prevention efforts to reduce late diagnosis and its associated consequences must be strengthened. We believe these should focus on several priority areas over the next 5 years including:

- **One to One Interventions**
  A formal review and auditing of NICE guidelines on one to one interventions to reduce the transmission of STIs (including HIV) should take place. HPA systems could be adapted to undertake this review.

- **Partner notification**
  The STI and antenatal setting provide a unique opportunity to ensure recent sexual partners of newly diagnosed persons are referred for HIV testing. However, little is known about the success of partner notification in these settings. The HPA will be looking at ways to audit and review partner notification in these settings using current surveillance and follow up mechanisms.

- **Sustained targeted health promotion in most at risk groups**
  MSM remain the group at highest risk of HIV. Current evidence suggests that behaviour change alone is unlikely to curb the epidemic in MSM. Effective prevention will require a combination of medical (including treatment), behavioural, social and structural interventions. A coordinated response, led by Public Health England, should be developed which include success markers to track these efforts.

Results of the recent pre-exposure prophylaxis (PREP) trial show a marked reduction in the number of new infections among MSM receiving antiviral therapy. The UK’s delivery of sexual health services and HPA surveillance systems provide a unique opportunity to assess the feasibility, acceptability, effectiveness and cost effectiveness of scaling up PREP among
high risk MSM and heterosexuals (mostly among black African and Caribbean communities) attending STI clinics.

- **Consolidation of efforts to improve testing uptake and frequency of testing in MSM**
  The HPA recommends yearly tests among sexually active MSM. Behaviour data from convenient samples show that less than a third of MSM test annually. We propose to better monitor the frequency and uptake of HIV testing in STI clinics using the new Genitourinary Medicine Clinic Activity Dataset.

- **Geographically targeted testing**
  Results from testing pilot studies conducted over the past twelve months indicate that these settings are acceptable to patients and staff and successful in diagnosing persons unaware of their HIV infections. Moreover the routine offer of a HIV test to all attendees (rather than a risk based triage) reduced perceived stigma among patients and was welcomed by staff.

Given that routine bloods are collected on admission, we believe the routine offer and recommendation of a HIV test to all patients admitted to a general medical ward offers a real opportunity to expand testing. This should be prioritised and widely implemented in high prevalence areas (greater than 2 per 1,000 people with diagnosed HIV infection). Similarly, testing new registrants in primary care should be implemented in high prevalence areas although the cost implications may be greater in this setting where there may be a greater reliance on point of care tests. Test offer, uptake and positivity and late diagnoses rates will need to closely monitored at the local and national level to track the success of these intervention. Cost-effectiveness studies of testing strategies in the UK are required to inform future testing policies and strategies.

13. **Reforms to the health service propose to subsume the functions of the HPA into the new Public Health England service. In evidence before the Committee on 18 January 2011, the HPA noted that there were “benefits as well as risks” to this reconfiguration. Nearly 5 months later, has your opinion changed as to what the future may hold, particularly around the quality of the United Kingdom’s HIV surveillance, and the independence of work around HIV monitoring?**

The HPA supports the establishment of a national public health service and we think there are great benefits to be gained from this.

However there are two areas we have particular concerns about.

1. the risk of losing independence (or perceived independence) in Public Health England as currently envisaged

2. the risk of losing critical scientific and public health expertise.

Independence (real and perceived) of scientific and public health advice to government, at national and local level, is essential if it is to be seen as credible within the scientific community and by partners and stakeholders; if it is not seen as credible it will not be effective.
When giving advice to the public, independence is one of the most significant factors determining how the public will receive and respond to that advice. The Health Protection Agency has, over the 8 years of its existence, developed a reputation with the public, the public health profession, and with the scientific community, for the provision of effective, high quality, public health advice. This confidence of the public in the agency and its advice has been tested and confirmed in surveys. The independent status of the agency has been an important element in ensuring that confidence.

We believe it is essential that Public Health England builds on that reputation and maintains the same level of public and professional confidence across its wider range of public health responsibilities if it is to be an effective leader of change and deliver health improvement through supporting people to make better choices about health risks. If Public Health England is viewed as part of government based within a department of state we believe that its independence, and therefore its credibility, will be seen as seriously compromised. PHE needs to have a distinct identity from the Department of Health and have its independence guaranteed in its constitution. It is notable, for example, that the significant loss of public confidence and trust in the advice of “government scientists” following the BSE incident was partly because they were seen to be part of the establishment and ‘not independent’. (In fact this was one of the drivers behind the establishment of the independent HPA).

The currently proposed arrangements could lead to a situation where the government, having established PHE as a national expert organisation, will find it necessary to seek advice from experts outside PHE in order to demonstrate independence – this will add bureaucracy and complexity and has the potential to produce confusion; it will also reduce transparency, increase costs to the public purse and will seem illogical to outside observers.

The Health Protection Agency has also built up an internationally respected body of scientific expertise which should be transferred to Public Health England as part of its core capacity.

That expertise derives from, and is funded by, the research and commercial activity that is an integral part of the agency and critically the staff involved provide a significant part of the agency’s response capacity in incidents. This has been amply demonstrated in many incidents, most recently by the UK response to the Fukushima nuclear reactor incident where the staff developing advice for the UK were those supported by research and commercial activity.

The agency has been able to recruit and retain the highest quality of expert staff because of its reputation, the integration of research and commercial activity into its core business, and the ability of its staff to be influential with the scientific community, with government and with the public.

As a part of a government department these attributes will be at risk in Public Health England. PHE’s ability to compete for research funds will be severely reduced as the major funding bodies such as the Medical Research Council do not fund Government departments. The academic sector cannot fill the gap because, as noted above, it is essential that the research capability is embedded in PHE to be available to directly support the frontline in real time.
In addition it will be far more challenging to engage successfully in commercial activity both in terms of the willingness of prospective clients (including foreign governments) to trade directly with the UK Government and in respect of maintaining the necessary flexibility and responsiveness of structures and support systems within the environment of a Government department. If there is also a perception that expert staff will be constrained in how they communicate and offer advice, both to the public and within the scientific community, by being within a government department of state, then PHE would cease to be an employer of choice for this calibre of expert. This would inevitably reduce the capacity of PHE to deliver its core public health responsibilities and also damage “UK Plc” in terms of its scientific capacity and its international reputation for high quality science and translating research into successful frontline practice.

To summarise, in HPA’s response to the White Paper, we suggest one of the solutions would be for Public Health England to be established as an Executive Agency, which will safeguard both its independence and its expertise. The roles of Public Health England also meet the criteria of an Arms Length Body, as identified in last year’s review of these organisations, strengthening the argument for some independence from a Department of State and making the Executive Agency model appropriate.

These points are explored further in our response and in the responses of many other influential bodies such as the Wellcome Trust and the Faculty of Public Health. To view the HPA’s response to the White Paper, visit: http://www.hpa.org.uk/whitepaperresponse
Memorandum by the HIV Pharmacy Association (HIVPA) (HAUK 48)

We are writing on behalf of the HIV Pharmacy Association (HIVPA) and would be grateful if you would include the attached report as a submission to the Select Committee on HIV and AIDS.

HIVPA has a membership of over 80 clinical pharmacists and pharmacy technicians across the UK. It offers education and networking events to its members to improve personal and professional development for the benefit of the patient and the individual. Our members are core to the medicines management agenda in the HIV specialty, and we believe that we provide a high standard of pharmaceutical care with a legacy of improved outcomes, safer prescribing and cost containment despite ever increasing pressure from new diagnoses. Therefore, we hope that you will consider the attached report, from a pharmacy perspective, recognising the threats and opportunities presented by commissioning reforms.

Heather Leake Date MSc MRPharmS IPresc, Consultant Pharmacist HIV and Sexual Health, Brighton & Sussex University Hospitals NHS Trust, & Honorary Senior Lecturer, Brighton University

David Ogden MSc MRPharmS IPresc, Pharmacy Team Leader – HIV, Infectious Diseases and GUM Services, St. George’s Healthcare NHS Trust


Sharon Byrne, MRPharmS, Principal Pharmacist HIV/GUM, Kingston Hospital NHS Trust & Chair HIV Pharmacy Association

On behalf of the HIV Pharmacy Association

1 Treatment: What impact might the proposed new commissioning reforms have on HIV treatment?

1.1 Currently, HIV treatment is primarily provided by specialist multidisciplinary teams (including pharmacists) in hospital or PCT outpatient clinics and hospital inpatient units (as recommended by BHIVA/BASHH). The drugs used to treat HIV (antiretrovirals [ARVs]), although expensive (approximately £7,000 per patient year for a typical initial regimen) are also one of the most cost-effective healthcare interventions and have resulted in a dramatic fall in HIV-related morbidity and mortality (and consequent improvements in quality of life) since the late 1990s. However, successful HIV treatment requires a high level of adherence to medication (ideally not being more than 1 hour late with a dose any more often than once a month) sustained for many years (currently lifelong).


174 British HIV Association, Royal College of General Practitioners, British Association for Sexual Health and HIV. Briefing paper on extending the role of primary and community care in HIV (draft 2010).
1.2 Regular specialist multidisciplinary input is necessary to optimise treatment uptake and adherence, to maximise health gains for individual patients and to ensure wise stewardship of the public purse. Specialist pharmacists have led developments both in HIV services (e.g. establishing ARV clinics to support patients initiating and changing therapy) and in research (e.g. to evaluate outcomes and devise evidence-based interventions). In addition, HIV Pharmacists play a key role in advising prescribers and patients about many other aspects of drug therapy, including the management of drug interactions, which are commonly seen with ARVs and are frequently complex (with potentially fatal or serious consequences).

1.3 It is currently unclear how the proposed new commissioning reforms will impact HIV treatment and care services, but the proposal that HIV will come under the aegis of the National Commissioning Board is encouraging (compared with the alternative of commissioning by Local Authorities or GP Consortia). The main concerns with any NHS reorganisation are the loss of organisational memory (in this case on the commissioning side) and the potential for services to become fragmented. Given that HIV and Sexual Health/Genitourinary Medicine (GUM) services are frequently integrated or co-located, we are not entirely clear how the changes in Sexual Health commissioning and provision will impact on HIV care.

1.4 For example, if GUM services are commissioned by Local Authorities there does not seem to be any proposed mechanism for ‘joined up working’ between the National Commissioning Board and the GUM Commissioners. This compares unfavourably with the current system, where strong links exist between PCT Public Health Departments (which commission Sexual Health services) and the Regional Specialised Commissioning Boards (which commission HIV services). Also, if Sexual Health Promotion becomes the remit of Local Authorities and more Level 2 Sexual Health services (commissioned by Local Authorities or GP Consortia) are provided in primary care and community settings, what governance arrangements will be established? If these changes result in a reduction in ‘simple’ cases presenting to Level 3 services (GUM clinics) this may threaten the viability of these services, unless the tariff is adjusted to take account of altered case mix. This could have a major negative impact on HIV treatment and care services, as well as HIV prevention. However, the proposals do not yet appear to be sufficiently detailed to answer these questions (and therefore our comments are necessarily limited and speculative at this stage).

1.5 HIV (and Sexual Health) multidisciplinary teams have a strong track record of innovation and of re-engineering services to manage a continually expanding cohort by working differently, for example, by the establishment of email and telephone clinics, by the use of Homecare to supply ARVs to some patients and by promoting HIV training for GPs. People with HIV can have some of their healthcare appropriately managed by their GPs, but specialist input is still required, particularly for prescribing and monitoring ARV therapy (as well as advising on the safe co-prescribing of other agents, including by GPs).

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175 Leake H et al, Optimising therapy – the role of a pharmacist-led antiretroviral clinic. Oral presentation at BHIVA Spring Conference, Warwick, 1997
176 Leake Date H et al, Optimising outcomes – a multidisciplinary approach. Oral presentation at BHIVA Spring Conference, Manchester, 2003
177 Horne R et al. NIHR Programme Grant for Applied Research RP-PG-0109-10047 (grant awarded 2010; programme commencing June 2011)
178 The HIVEd course
2 In what setting can treatment most effectively be delivered?

2.1 We support the recommendations made by BHIVA on the role of primary care, which make it clear that, even though GP involvement in the care of people with HIV is desirable, the HIV management still needs to be overseen by HIV specialist doctors and pharmacists.2 We therefore assume that there are no plans to devolve the prescribing, monitoring and dispensing of ARVs to GPs and community pharmacists, as this would have a catastrophic effect on patient safety and would also increase costs. There are many reasons (and strong evidence) to support these assertions – a few examples are given here for illustrative purposes.

Patient Safety

2.2 In 2002 HIVPA carried out a survey of interventions (defined as ‘any action taken or advice given with the aim of improving patient care’) made by HIV Pharmacy teams on prescriptions from their HIV clinics.179 In a 1 week period in 19 dispensaries 615 interventions were documented on 454 prescriptions (1 intervention per 10 items dispensed). Approximately 45% of the interventions involved at least one ARV.

2.3 More recently, at a large London HIV centre (St. George’s Healthcare NHS Trust), the HIV Pharmacy found an error rate in prescriptions from the HIV Clinic of 8.7%, with a serious prescribing error rate of around 1%.180 None of these errors resulted in patient harm because the specialist pharmacy team detected them before the medicines were dispensed, and the Trust has a robust system to ensure that the learning from such incidents helps to reduce recurrences. Examples of the ‘near misses’ prevented by the Pharmacy team in this study include: subtherapeutic dosing (that could have led to viral resistance development) and overdose (that could have caused toxicity). Other errors, with potentially fatal consequences, have been reported elsewhere.181

2.4 The prescribing error rate would undoubtedly be much higher if GPs were prescribing ARVs and the likelihood of error detection would be greatly diminished if the prescriptions were being dispensed by community pharmacies. This is mainly due to the specialist nature of the treatment (and the relevant training which HIV prescribers and pharmacists have undergone) but also because community pharmacists do not generally have easy access to the patient’s notes and laboratory results (which hospital pharmacists do).

2.5 BHIVA, BASHH and MedFASH have produced detailed guidance on the types of HIV services that should be provided in different settings (eg small outpatient clinic, large tertiary referral centre) and the associated multidisciplinary team members required. We support their recommendations, which include encouraging the development of clinical networks and the integration of specialist pharmacy support within the HIV team.

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179 Leake Date H and Godfrey D, on behalf of HIVPA. Behind the pharmacy door – dispensary-based contributions to HIV patient care. Poster and oral presentation at BHIVA Spring Conference, Cardiff 2002.
2.6 With an ageing cohort (and the associated increase in co-morbidities and polypharmacy) the need for specialist pharmacist advice will increase and be essential for continued patient safety.

Cost

2.7 Drug contract negotiations and purchasing by regional consortia (eg the London HIV Consortium and other Strategic Health Authority procurement specialists) have resulted in significant reductions in ARV costs. Such discounts are not available to community pharmacies (as these are independent contractors), so the cost of treatment would rise considerably if it were being dispensed by them.

3 Cost: Have cost considerations been satisfactorily balanced with public health imperatives in HIV Treatment Policy?

3.1 The personal experiences of HIVPA members have highlighted the impact specialist HIV pharmacists can have on sustained cost containment. We are also aware of parts of the country where a failure to invest in HIV Pharmacy support has contributed to spiralling HIV treatment costs. Appropriate commissioning of HIV Pharmacy Services will reap both financial and public health rewards: with sufficient levels of pharmacy input substantial savings can be made and waste avoided (by optimising arrangements for purchasing, prescribing, dispensing and adherence support). The resulting public health benefit includes better treatment outcomes (preventing the development of viral resistance and reducing infectiousness/HIV transmission).

3.2 One practical example of the way in which pharmacy can save money is by adjusting the amount supplied on a prescription to prevent the patient accumulating more medicines than necessary (whilst also ensuring they have sufficient to last until their next clinic appointment). Data collected by the HIV Pharmacy team at Chelsea & Westminster NHS Foundation Trust (the largest HIV centre in the UK) showed that a pharmacy-led medicines management scheme to prevent oversupply on prescription resulted in a £260,000 saving over a six month period.\(^{182}\) This has only been possible through pharmacy having a close working relationship with the prescribing team as well as the co-operation of the patients in engaging with supply management.

3.3 Another area where we await clarity is the proposed funding arrangements for clinical research. Where multidisciplinary teams are appropriately resourced they can incorporate research into their clinical practice. Benefits of this include participation in commercial clinical trials (and therefore the opportunity for patients to access new treatments, which in some cases will be needed either to achieve virological suppression or to avoid or reverse treatment-related toxicities, and which result in short-term drug budget savings). However it is in the area of non-commercial research funding that the proposed reforms could have the greatest impact and we are concerned that failure to continue the Comprehensive Local Research Networks (CLRNs) would be disastrous.

17 February 2011

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\(^{182}\) Sonecha S. Personal communication – email dated 15/02/11
Supplementary Memorandum by Sharon Byrne, Chair, HIV Pharmacy Association (HAUK 77)

1. We have heard evidence that “some very good things” have been achieved within HIV treatment in recent years, and that care must be taken to maintain them in a time of extensive reform. What elements of existing HIV treatment and care do you think most need to be protected?

We must protect the MDT and the holistic approach that has made HIV medicine the success story of the last ten years. The success has been driven by the high standards of care that is the cornerstone of our service (as laid out in the MedFash standards). Good clinical governance of the standards ensures regular auditing and continued improvements in diagnosis and treatment. The standards ensure training of junior staff in an area of medicine that is still new and in which we are all still learning. This excellent clinical governance and training would be lost if it was run in primary care. At present few people in primary care have the knowledge or skills to take on managing an area of medicine that many have never been involved in.

Although the treatment for the illness may be sometimes seen as simple the disease and its social burden are still complicated. The need to individualise treatment for patients where necessary to achieve success must be protected.

From a public health perspective the follow up of non attenders and patients not taking their medicines correctly is currently looked after by the MDT in a comprehensive way that would not be possible in primary care. The consequences of getting this wrong is three fold (1) from an individual perspective of ill health (2) public health perspective of increased risk of onward transmission (3) increased financial pressure from more expensive second line drugs.

ARV prescribing and screening of the prescription by specialist HIV trained staff must be protected. The HIV pharmacy service provides specialist expertise around drug usage with high quality medicines management and good clinical governance to continue the success mentioned above. A specialist HIV pharmacist reviewing prescriptions prior to dispensing is essential, as non-specialists do not have the necessary knowledge and skills to recognise medication errors, drug interactions or dose adjustments in co-morbidities. We monitor drug usage and ensure cost effective prescribing which would not be possible in primary care. Having the nuclear MDT of specialists, doctors, nurse, pharmacist is key in the provision of safe treatment and care.

Looking at models of care across the globe countries like the USA that do not have universal access to treatment and specialised services rates of treatment success are much less than in the UK, with only 59% of patients with an undetectable viral load compared to 90% in the UK. Preserving this right to seamless and free care must be protected for individual patient health and for the benefit of public health.

2. What can health professionals do to help their HIV-positive patients understand and reduce their risk of infecting others?
The basis of any message is education and support, so not just telling patients why they shouldn’t do something but understanding why they do it in the first place and then providing support to help change behaviour.

As health professionals we can ensure the issue is addressed at each visit and where identified referral is offered to psychological support services and health advisor support.

We must personalise it and tailor advice according to the individual situation.

3. Given the continuing spread of HIV, do you believe that the right balance is being struck in the work that you do between treatment and prevention?

The balance is heavy on treatment that as we have alluded to is very successful and the focus needs to be more on prevention. As discussed prevention of onward transmission is covered in patient consultations but more prevention work needs to be targeted to the HIV negative population.

4. Migrants who do not have the right to remain in UK have to be charged for their HIV treatment and care, yet they can be treated for free for other infectious diseases such as TB. What impact do these rules have on efforts to tackle HIV, from both an individual and public health point of view?

Clearly, creating further barriers to access treatment for this disease that still carries stigma in certain communities is undesirable. The cost of the medicines is so high, that very few individuals who do have a right to remain would be able to afford them. We would support that they should be free for those who need them for the time they are in our communities otherwise it may be a public health risk for onward transmission if their viral load is not controlled on medication.

28 March 2011
Memorandum by HIV Scotland (HAUK 61)

BACKGROUND

HIV Scotland welcomes the initiative in establishing the ‘Select Committee on HIV and AIDS in the United Kingdom’. We note that membership of the Select Committee includes individuals with a long-standing interest in HIV and sexual health. Whilst health and other responsibilities related to HIV are devolved matters, it is important to recognise the common interest across the United Kingdom as well as of those matters reserved to Westminster and with a direct relationship to the interests of people living with HIV throughout the United Kingdom.

HIV Scotland, established in 1994, is the national HIV policy charity for Scotland, and is the umbrella agency for Scotland’s HIV voluntary sector. We want a society which is

- well-informed about HIV
- devoid of HIV-related stigma and discrimination
- dealing with the spread of HIV and providing excellent treatment services

We speak out for people with HIV. HIV Scotland provides knowledge and expertise to help inform and deliver strong policies and effective strategies.

To achieve this, we provide

- expert advice and a voice for HIV in Scotland
- information, training and resources
- signposting to evidence, expertise and community experience
- opportunities to engage with others in shaping policy and practice

EXECUTIVE SUMMARY

Introduction - Rates of HIV infection in Scotland are increasing by, on average, 400 new diagnoses of HIV over each of the last six years. Successes in increased HIV testing, effective treatment by international standards, and pragmatic solutions to otherwise intractable problems, must not silence or distract from our obligation to respond to need. People living with HIV will not thank us if organisational survival and pride take precedence over the promotion of positive change. We must address need, build on evidence of effectiveness, challenge and address difficult issues. People with HIV must be at the heart of what we do.

Lessons learnt - It will assist if we consider lessons learnt in Scotland in the following areas:

1. Key drivers
   a. Leadership at national and community levels
   b. Integrated and combined approaches throughout and across all parts
   c. Cutting across boundaries and acting outwith silos to influence generic structures
   d. Multi-disciplinary and cross-sectoral working to the collective benefit
e. Evidence from a range of sources, including experience of people living with HIV

2. Policy at local and national levels
   a. Pragmatism demonstrated in Scotland’s harm reduction approach to drug use
   b. Incremental and linked strategies for sexual health, HIV and blood-borne viruses
   c. Bold adoption of latest approaches and making most of overarching public policy, eg ‘Better Health, Better Care’ and the ‘Healthy Respect’ demonstration project

3. Action not words
   a. HIV testing in MSM increased 3-fold because clinics implemented policy
   b. National social marketing campaigns in Scotland had Government support, not only financially, but also in taking risks and being genuinely accountable
   c. Standards count for a lot, and Scotland has embarked on development of an integrated set of standards for prevention, recognition/detection, and treatment
   d. Community action, often through voluntary agencies, to reach and support those most vulnerable on account of poverty, discrimination, and risk

What needs to improve – Constant improvement without unnecessary disruption through:

1. Coordination across and between boundaries to ensure best use of resources and shared learning and action – working within territorial limits is ineffective in addressing HIV
2. Greater consistency and equity of provision in all areas of HIV – no individual or community should be disadvantaged by geography, deprivation or identity
3. Maintenance and development of mechanisms to build evidence in surveillance and research – it is essential that established epidemiological information remain strong
4. The greater involvement of people living with HIV with a voice and a role
5. Contextualising HIV fundamentally as a human rights issue given its links and roots

How to achieve the above – Despite analysis of problems, solutions are thin, but include:

1. Scaling up, intensifying and reinvigorating HIV prevention, the key to success in HIV
2. Building a strong business and financial case to support cost effectiveness
3. Engagement of the right expertise from all disciplines to address a global epidemic
4. Development of a new paradigm in HIV prevention which is integrated to testing and treatment

OVERVIEW

Statistically Scotland has recorded on average 400 new HIV diagnoses every year for the last six years, with numbers exceeding the peaks in the mid-1980s. Injecting drug use accounted for 19 of the 360 new cases of HIV in 2010. Sexual transmission is now the most common infection route. Annually, those needing specialist care are likely to increase by between 5% and 13% (150 – 350).
Memorandum by HIV Scotland (HAUK 61)

<table>
<thead>
<tr>
<th>Diagnosed HIV-infected persons living in Scotland</th>
<th>3803</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of HIV-infected persons attending for specialist care and treatment</td>
<td>3254</td>
</tr>
<tr>
<td>Average number of new diagnoses per annum over last six years</td>
<td>400</td>
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</tbody>
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Source: Health Protection Scotland

Policy – key strategic drivers


The **HIV Action Plan** is underpinned by the sexual health strategy and links to the Hepatitis C Action Plan, thus providing direction and impetus to HIV work in Scotland.

In addition to the strategic approach adopted in Scotland, **other key influences** on development are:

- consistent ministerial leadership since 1999;
- combination and integrated approaches to HIV prevention, testing and treatment;
- ability to make links to related issues eg education, rurality, service design;
- multi-disciplinary collaboration.

**Structurally**, devolved arrangements mean that national HIV policy is entirely the responsibility of the Scottish Government, and that delivery is through NHS Scotland, local authorities and Scottish HIV voluntary agencies. Divergence across the United Kingdom in HIV policy and practice already exists. Publication of ‘Healthy Lives, Healthy People’ and the associated creation of Public Health England is unique to England and Wales, and do not directly affect Scotland. The extent to which this change creates greater divergence in both HIV policy and outcomes within the UK remains to be seen.

**Frameworks** within which HIV prevention, testing, treatment and care are delivered within Scotland’s NHS Boards tend to be through Managed Care Networks in Blood Borne Virus, with the West of Scotland’s five NHS Boards operating under a single Sexual Health Network. This means that planning is variable across Scotland, and that, other than the West of Scotland, NHS Boards tend not to work across their own borders. HIV Scotland is of the view that this is a missed opportunity for improving services, reducing duplication, and ensuring the most effective implementation of the HIV Action Plan which was constructed around the creation of Regional Facilitation Teams, now dropped. HIV Scotland welcomes the opportunities in the consultation on development of a national Framework for Sexual Health and Blood-Borne Viruses (including HIV).

The proposed **National Framework** is a further advance in Scotland’s strategic approach. Five overarching outcomes will be delivered on behalf of sexual and reproductive health, HIV, Hepatitis C and Hepatitis B. This strengthens integration and increasing evidence of the benefits of joined-up working. HIV Scotland will respond to the consultation and will work with key partners across sectors to deliver on a shared agenda.
MONITORING

a) How robust is the current system for monitoring the number of people with HIV in the United Kingdom?

Key points –

i. Surveillance of HIV at national levels in Scotland has a good reputation for accuracy and detailed analysis, with good links to front-line services. Effective use is made of the surveillance information in planning at national levels.

ii. Local surveillance at clinic and laboratory level provides regular information which is used in local planning. Capacity at local levels to maintain data is more limited and depends largely upon clinic staff.

iii. There are increasing pressures on Health Protection Scotland staff to provide HIV data and also to contribute to the wider collection of data in Scotland in a fast-moving environment.

iv. It is essential that current capacity be maintained and that when specific projects emerge, that resource implications are considered and provision made to draw on the best from HPS.

v. It should be noted that the HIV Denominator Study is under review, and care should be taken not to lose the undoubted benefits of this long standing resource in Scotland.

SURVEILLANCE

Scotland benefits from a surveillance system at national level which produces comprehensive data on new diagnoses, attributable data through the HIV Denominator Study, and surveillance of CD4 and Viral Load.

Health Protection Scotland, a division of NHS National Services Scotland, has a dedicated team which provides advice, support and information at the heart of Scotland’s health service and with excellent links and partnerships both within the NHS and with the range of agencies engaged in addressing HIV in Scotland.

Reports of new diagnoses of HIV/AIDS from England, Wales, Northern Ireland and Scotland, are pooled by the HPA Centre for Infection at the end of each quarter to produce the current UK data set of reported HIV/AIDS infections.

http://www.hpa.org.uk/web/HPAweb&PAGHPAwebAutoListName/Page/1201094588891

Reports of newly diagnosed HIV antibody positive individuals and AIDS cases have been collated by Health Protection Scotland (formerly the Scottish Centre for Infection and Environmental Health) since the early 1980s.

Data are collected under three main categories –

1. New diagnosis of HIV and AIDS

The main sources of information on newly diagnosed HIV/AIDS infection come from voluntary case reporting of newly diagnosed HIV infections by laboratories (see Surveillance of Attributable HIV Antibody Tests in Scotland) and AIDS diagnoses by clinicians. The General Register Office for Scotland (GROS) reports all deaths that
record AIDS or HIV among the causes of death to HPS. Records of HIV diagnosis, AIDS and death, which are regarded as relating to the same individual, are merged to create one record.

The objectives of the surveillance of new diagnoses of HIV and AIDS are:

a) To monitor trends in diagnosed HIV infection and AIDS cases among the Scottish population;
b) To provide timely and useful information for the targeting of health promotion, the evaluation of preventative measures, and the planning of medical and social services for those affected by HIV;
c) To provide estimates of the national total of HIV infected persons and to assist in estimating future numbers of persons with severe HIV disease who will require care, in combination with other data.

2. Surveillance of attributable HIV antibody tests in Scotland (HIV Denominator Study)

The prevalence of HIV infection, among individuals having a voluntary attributable HIV test in Scotland, is monitored by a surveillance system established in 1988 by the Scottish Centre for Infection and Environmental Health (Health Protection Scotland's predecessor).

Information is derived from a standardised request form used by clinicians requesting an HIV test. In addition to routine information (referral source and specimen details), certain clinical and epidemiological, including risk behaviour, characteristics of the individual are recorded on the form and collated by HPS.

The objectives of the attributable HIV antibody test surveillance system are:

a) To provide timely and useful information on the prevalence of HIV infection among the Scottish population
b) To monitor the trends in prevalence and incidence of, and associated risks for, HIV infection among individuals having a voluntary attributable HIV test in Scotland

The CD4 and Viral Load Surveillance System

Periodic monitoring of CD4 T-lymphocyte (CD4 cell) counts and HIV viral load are part of the routine clinical management of HIV seropositive patients in Scotland. CD4 cell counts and viral load data on all HIV infected individuals receiving specialised care in Scotland are collected and collated by HPS; information from the CD4 and viral load surveillance system is linked to records of HIV diagnosis (see New Diagnoses of HIV and AIDS).

CD4 cell counts give a measure of the degree to which an individual's immune system is 'compromised'. Measures of viral load indicate how actively HIV is replicating. CD4 cell counts and viral load measures, together, are used by clinicians to decide when to start an infected person on antiretroviral therapy and to help them monitor the effectiveness of particular therapeutic regimens.
The objectives of the CD4/viral load surveillance are:

a) To monitor access of HIV infected individuals to specialist follow up services and treatment
b) To monitor the proportion of treated HIV infected patients with undetectable viral load
c) To monitor trends in immunosupression associated with HIV infection
d) To provide estimates of the future numbers of persons with severe HIV disease who will require care (in combination with other data)
e) To provide timely and useful information for the planning of medical services for those affected by HIV.

Source: Health Protection Scotland

STRATEGIC CONTEXT

Surveillance and epidemiology are strongly supported at national levels in Scotland. This is evidenced particularly in the HIV Action Plan for Scotland (2009 – 2014). Actions relevant in this respect include -

**Action 4** - NHS Board plans to maintain and improve prevention, diagnosis and treatment and care services and initiatives will be developed and implemented, using the information gathered from the regional needs assessment.

**Action 6** - An investigation into the reasons why some people living with HIV do not attend specialist clinical services will be undertaken.

**Action 7** - Systems to monitor risk behaviours and new HIV infections among persons at highest risk of acquiring infection will be reviewed and, if appropriate, developed and implemented.

a) Monitoring outwith formal surveillance

Knowledge of our epidemics is key to effective prevention, recognition/diagnosis, and treatment. Surveillance goes beyond the collection and interpretation of national data. It includes also information collected under the auspices of the Social Sciences.

Scotland’s approach to HIV has been informed by a combination of the data and its interpretations from HPS with that drawn from institutions including the Medical Research Council, biomedical institutions, and Scotland’s research community focussed around our Universities. Research in its widest sense has particular strengths.

Voluntary sector agencies play a crucial role in tackling HIV in Scotland. Support for monitoring of activity and trends has been inconsistent. Much of the local information and experience held by Scotland’s voluntary agencies could be very beneficial in planning and learning if it were more comprehensively and consistently gathered. HIV Scotland is currently engaged with agencies to research the data collection and reporting needs of both HIV service providers and funders. This is with a view to improving the flow of information and to enable voluntary agencies to evidence their activity and outcomes.
b) Will the proposed public health reforms impact on this system?

The public health reforms apply only to England and Wales. Given the integral nature of the United Kingdom and in particular the flow of populations across our borders, this and other health reforms in England and Wales are likely, however, to have an effect upon Scotland. Already, the switch in responsibility from the Health Protection Agency to the Department of Health creates a divergent system between the four nations. Reduced capacity in England will affect the quality of reporting across the United Kingdom, particularly in those areas for which the HPA took primary responsibility. As an organisation, HIV Scotland makes requests for data from HPA and there needs to be confidence in the ability of the DoH to respond accurately and suitably. There is a risk that reporting will be affected, which in time could dilute Scotland's monitoring systems.

The split in public health responsibility between health and local authority, overlaying as it does upon the abolition of PCTs and Strategic Health Authorities is a further risk to the monitoring arrangements and to public health policy in general. Public health has recently been subject of legislative reform in England and Wales. Change will need to be carefully planned and resourced in order to minimise any adverse effects. Insofar as Local Authorities in England and Wales will have responsibility for public health, there is evidence of strength in their response at a population level in controlling infectious diseases. It is acknowledged that a role exists for Local Authorities in the HIV public health agenda. It is difficult, however, to transfer experience in infection control and risk at population levels to the complex contexts at individual and community of interest levels in which HIV is passed on. Great fragmentation of Public Health in England contrasts with and diverges on a policy of increasing integration and improved coordination in Scotland. It remains to be seen how the proposals will improve public health.

c) Could anything be done to improve monitoring?

In Scotland, implementation of the HIV Action Plan is in progress. As noted above, several actions have an impact upon the monitoring and surveillance of HIV in Scotland.

There is room for improvement even in a system as well developed as is that of the United Kingdom’s Health Protection agencies. This is addressed directly and indirectly in actions under Scotland’s HIV Action Plan. This is not to take away from the strengths of Scotland’s epidemiological information, and of its links to the rest of the UK in this respect. It is clear, however, that a great volume of information is supported by Health Protection Scotland. HIV Scotland frequently draws upon the staff’s expertise for the preparation of reports or for the understanding and interpretation of data. Their work in relation to Action 6 below is an excellent example of expertise, detailed analysis, responsiveness, relevance to the field, and collaboration within Scotland and with other UK colleagues. HIV Scotland is aware, however, that a significant volume of information could be extracted from the HPS data to support enquiries such as the factors, contexts of, and precursors to sero-conversion. Increased capacity is needed for this.

The key is in Action 7 of the “HIV Action Plan” which has initiated the review, development and implementation of recommendations of risk behaviours and new HIV infections in Scotland. Other recommendations affect monitoring arrangements.
Already, under **Action 6** data has been thoroughly revised by a collaboration between HPS, NHS Health Scotland and HIV Scotland on those ‘lost to follow-up in specialist services’. This has provided a ground-breaking information set at a statistical level and corrects some previous misperceptions, and in a new system to flag and act immediately to any loss of follow-up. Work is now underway to relate this to results of qualitative research which will frame recommendations to NHS Boards, Clinics and voluntary agencies.

Monitoring also takes place at regional or Health Board levels, and the recommendation of the HIV Action Plan **Action 4** is set against the background of a local needs assessment informed by the local epidemiology. In NHS Forth Valley, HIV Scotland has worked closely with partners to develop the “Needs Assessment Report: Integrated HIV Prevention in Forth Valley”.

d) **What groups in particular are at risk from HIV?**

The groups particularly at risk from HIV infection in Scotland are –

<table>
<thead>
<tr>
<th>Group</th>
<th>% of all new infections in 2010</th>
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<tbody>
<tr>
<td>men who have sex with men (MSM)</td>
<td>36%</td>
</tr>
<tr>
<td>heterosexual</td>
<td>42%</td>
</tr>
<tr>
<td>injecting drug use</td>
<td>5%</td>
</tr>
</tbody>
</table>

Source: Health Protection Scotland

It should be noted that of all infections acquired in 2010, a total of 48% across all transmission groups were acquired abroad. The majority of new infections acquired within Scotland are through the MSM route. In its report of 23rd February 2011, Health Protection Scotland indicates the following headline statistics-

**Diagnosed HIV-infected persons living in Scotland 3803**

**Number of HIV-infected persons attending for specialist care and treatment 3254**

**Total deaths among HIV-infected persons 1783**

**Deaths among persons known to have been diagnosed with AIDS 1034**

The following breakdown for the year shows that of the 360 cases reported during 2010, 130 (36%) are presumed to have contracted the infection by the MSM route, 151 (42%) through heterosexual contact, and 19 (5%) through injecting drug use. 174 (48%) are presumed to have been infected outwith Scotland. It is expected that all of these figures will rise in due course as the 53 cases (15%) for whom no epidemiological information has as yet been provided are subjected to active follow-up. (Volume 45 No. 2011/08)

Of the 360 cases reported during 2010, 174 (48%) and 2690 (41%) of the 6613 total reports are presumed to have acquired their infection outwith Scotland (Table 4).

It should be noted that of infections acquired within Scotland itself, the majority of cases is by the Men who have Sex with Men route (MSM), estimated at 67%. Of heterosexual transmissions, the majority are acquired abroad.
An increasing number of infections occurring within Scotland have no specific risk factor such as MSM or links to high prevalence areas such as sub-Saharan Africa. These cases often present late, and there are reports of serious complications and death.

Prevalence rates in the main groups indicates current levels of infection –

**Prevalence by transmission route**

<table>
<thead>
<tr>
<th>HIV Prevalence Rate – All Scotland (population 5,450,914)</th>
<th>0.1146 %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Injecting Drug Users</td>
<td>0.5</td>
</tr>
<tr>
<td>Heterosexual (infected UK)</td>
<td>0.1</td>
</tr>
<tr>
<td>Heterosexual (infected Africa/abroad)</td>
<td>7.3</td>
</tr>
<tr>
<td>Pregnant women (Guthrie)</td>
<td>0.09</td>
</tr>
<tr>
<td>Men who have sex with men (MSM)</td>
<td>3.1</td>
</tr>
</tbody>
</table>

Source: Health Protection Scotland

Geographical spread of new infections is indicated in the most recent figures from 2010, reported in Answer (Table 3) –

<table>
<thead>
<tr>
<th>118 Greater Glasgow &amp; Clyde</th>
</tr>
</thead>
<tbody>
<tr>
<td>92 Lothian</td>
</tr>
<tr>
<td>37 Grampian</td>
</tr>
<tr>
<td>28 Lanarkshire</td>
</tr>
<tr>
<td>26 Tayside</td>
</tr>
</tbody>
</table>

Source: Health Protection Scotland

**PREVENTION**

**a) Is Government policy sufficiently focused on HIV prevention?**

Although there is a strong focus in Scotland upon HIV prevention, as outlined below, the critical questions for those with responsibility at national and regional levels relate to –

- Scope
- Intensity
- Effectiveness
- Evidence

Across all of four areas, we need a step change in order to address the growth of HIV, in the context not only of concerns within Scotland and the UK, but crucially at a global level. It is impossible to reduce the rates of new infection, costs of treatment and care, and related poor health without also addressing global imperatives. To this extent, Scotland as part of the UK and in its own right must respond to the clamant need of the young women, drug users and homosexual men who are discriminated against and outlawed by an increasing number of government legislatures, cultural practices and religious institutions.
Memorandum by HIV Scotland (HAUK 61)

Structural barriers internationally and within the UK need to be addressed. It is well established that HIV follows the track of poverty, inequality and discrimination, all of which fuel the epidemic. Human rights and public health are inextricably linked.

These considerations are not limited, however, to the international arena, and policy in all parts of the UK, reserved and devolved, must take account of the impact on people living with HIV and on those vulnerable to the infection, of welfare, economic, immigration, justice, education, and other powers. It is doubtful if the needs of people living with HIV feature large in the factors affecting many decisions, and agencies like HIV Scotland exist to keep HIV to the forefront of our collective social responsibility.

In its HIV Action Plan, the Scottish Government has adopted an integrated model of HIV prevention, diagnosis and treatment to underpin its strategy. This is set out explicitly in the plan’s first summary point, which states that its overall aims are to be achieved through:

- Integrating HIV prevention, diagnosis and treatment and care
- Reducing HIV transmission and undiagnosed HIV through social marketing, education, service provision and guidance; and
- Improving performance management and accountability.

Illustrated thus –

Highly Active HIV Prevention

Coates, Richter et al., 2008

This strategic document is a practical plan highlighting what must happen and who must be involved if the overall aims are to be achieved. It builds on

- the draft proposals developed by the multi-agency HIV Action Plan Group
Memorandum by HIV Scotland (HAUK 61)

- the Treatment and Care Needs Assessment commissioned by the Scottish Government and produced by the Scottish Public Health Network (Scot PHN)
- extensive feedback received from key stakeholders and individuals, including those living with HIV.

Membership of the Group included a range of professionals and experts from across Scotland and represented leadership and expertise from treatment services, prevention, academia, policy, health promotion, and community.

Predating publication and implementation of the HIV Action Plan was the sexual health strategy, "Respect and Responsibility" (Scottish Government, 2005) produced by the Minister for Health as advised in the National Sexual Health and HIV Advisory Committee. This prepared the ground for the HIV Action Plan and already actions were underway at local levels as recommended by “Respect and Responsibility” to review their strategies and actions in light of the 'Review of the HIV Strategy' (Scottish Executive 2001). This committee also receive the report of its MSM sub-group, “HIV Prevention, Report and Recommendations” Clutterbuck, D (2008) MSM Subgroup NSHAC 11:
http://www.scotland.gov.uk/Topics/Health/health/sexualhealth/msmreport/Q/EditMode/on/ForceUpdate/on

Actions 2, 8, 9 and 10 of the HIV Action Plan are specifically relevant to HIV prevention.

Useful links are made from HIV to other action plans and strategies, especially The Hepatitis C Action Plan and Scotland’s drugs strategy “Road to Recovery”.

It should be noted also that Standards in HIV prevention are being developed alongside recognition and diagnosis, and treatment and care. Undertaken by NHS Quality Improvement Scotland (soon to become NHS Healthcare Improvement Scotland) as an action under the HIV Action Plan, this will provide a strong foundation and implementation plan to improve the quality, safety and effectiveness of our interventions under a set of key standards with exacting criteria against which services will be measured.

Planning structures in Scotland will not develop as foreseen in the HIV Action Plan. This is to be regretted as they would have improved accountability, provided a strong basis for equitable provision of prevention, testing and treatment services, and would have facilitated the practical sharing of expertise. Other more local structures are developing, however, with HIV integrated to sexual health and to a greater extent, blood-borne virus planning mechanisms such as Managed Care Networks. This allows HIV strategies and actions to draw upon the learning and capacity of Scotland’s approach to Hepatitis C. At a national level, a National Framework for sexual health, HIV, Hepatitis B and Hepatitis C is to be consulted on with a view to an overarching approach.

b) Have the right groups been targeted in recent prevention campaigns?

The majority of HIV infections acquired within Scotland are through the MSM route. Effort must be focussed therefore on this particular group. Exposure outside the UK accounts in turn for the majority of heterosexual infections diagnosed in Scotland.
Reports of HIV infection: presumed location of exposure is outside UK, 2005-2009
(Health Protection Scotland) (This graph shows that the majority of infections acquired abroad are through the heterosexual route, but that a significant proportion is from MSM)

![Graph showing the proportion of infections acquired through MSM and heterosexual routes from 2005 to 2009.]

Reports of heterosexually acquired HIV infection, Scotland, 2005-2009
(Health Protection Scotland) (This graph illustrates that the majority of heterosexually acquired infections diagnosed in Scotland is in non-UK nationals infected outwith the UK)

![Graph showing the number of heterosexually acquired HIV infections from 2005 to 2009, with a breakdown between UK and non-UK nationals.]

Memorandum by HIV Scotland (HAUK 61)
Depending upon the group being targeted, prevention campaigns take a variety of forms and layers. The information below is intended to demonstrate the range and rationale for HIV prevention in Scotland targeted to specific purposes.

1. **National sexual health campaign** – developed collaboratively and with input from HIV Scotland, ‘Sexual Health Scotland’ was launched in June 2009. It is focussed upon relationships, is positive and encourages a healthy sex life. It was promoted on national radio and cinema adverts, with a strong, highly interactive and engaging website - [http://www.sexualhealthscotland.co.uk/](http://www.sexualhealthscotland.co.uk/)

   This campaign has provided an excellent backdrop to sexual health and HIV and was designed in such a way as to appeal to younger age groups, and related to all sexualities and ethnicities.

2. **Targetting of men who have sex with men** was a commitment under the HIV Action Plan. **Action 8** *The development and implementation of social marketing materials for MSM.* As a result, NHS Health Scotland in partnership with HIV Scotland launched the first national information HIV campaign since the 1980s. This has taken the form of
   b. Literature disseminated through a variety of channels, particularly to areas outwith the main cities, and to generic services and venues. Samples available on request from HIV Scotland.
   c. Professional briefings – informing on current epidemiology and factors to be considered in providing services to men who have sex with men.
   d. Local support to the aims of the national campaign in specific geographical areas of Scotland, using a rolling programme to reinforce messages on the ground and to build on learning.

3. **Development of targeted support for people from areas of high HIV prevalence, especially Africa.** This has been slow as the approach has to be different to broader population approaches or to MSM who have a different social network. It also must avoid the risk of unintended stigmatisation of those living with HIV. Much of the prevention activity is directed therefore through support groups run by Waverley Care - [http://www.waverleycare.org/](http://www.waverleycare.org/) HIV Scotland’s role in this respect has been to work through the African Country Associations to build capacity within the community, and to reinforce the links between prevention and the broader socio-economic factors affecting Africans living in Scotland.

4. **For injecting drug users who form now the lowest transmission group in Scotland,** campaigns are directed through the Hepatitis C campaigns on the basis that if HepC is being adequately addressed, then prevention of HIV transmission through needle sharing will also be addressed. Issues remain, however, for the level of interaction of HIV positive drug users with mainstream services as well as with voluntary HIV services. **About 350 IVDUs are in specialist clinical care in Scotland, and the key need on their part is support in safer sex. It is doubtful if this need is being adequately addressed on their behalf.**

   It is essential that we keep the eye on the ball and maintain vigilance.
c) To what extent have prevention initiatives targeted at injecting drug users been successful?

This has been highly successful. As noted above, the prevention of HIV through the harm reduction policies introduced in the 1980s established a strategy which has been maintained rigorously. Indeed, a ‘defining moment’ for HIV policy and practice was the opening in 1987 of the first needle exchange in Leith (Edinburgh), followed the year afterwards by an official heroin substitute prescribing scheme (Community Drug Problem Service), heralding the start to Scotland’s harm reduction policy which has dramatically reduced HIV infections in Injecting Drug Users.

Arguably, it was prompted and supported by the influence of McLelland, D. 1986 – HIV in Scotland – Report of the Scottish Committee on HIV infection and intravenous drug use, in which he stated, “The prevention of HIV spread should take precedence over the perceived risk of increased drug use.” This was echoed in the ACMD report of 1988.

In a recent personal communication, Professor David Goldberg of HPS wrote of Scotland’s policy,

“In my view it was one of the great public health achievements of the 20th century and although it was successful elsewhere, the Scottish response in the context of very high prevalence was a model of excellent public health practice.”

There are risks, however, to this approach which emanates from unnecessarily polarised debates between methadone treatment and drug free treatment services.

HIV Scotland’s Holyrood 2007 manifesto states that –

“Harm reduction is a major success in Scotland’s proven achievements in reducing and maintaining remarkably low levels of drug related HIV infection. Harm reduction and comprehensive prevention are proven and effective approaches and must remain integral components of prevention strategies”.

When the current strategy was being drafted, HIV Scotland coordinated representation from leading drug abuse experts from primary care, national policy, training, service delivery and prison services to advocate in support of current harm reduction approaches. Our argument was based on a number of considerations.

Most local, national and international drug treatment experts and clinicians have a consensus view that a range of evidence based treatment options should be available to meet the differing needs of a diverse population of drug users seeking help. In particular there is a basic need for services which fall under the general heading of harm minimisation and include maintenance treatment for those with enduring difficulties with addiction problems. This philosophy is enshrined in many documents not least the guidelines on the management of drug users in the UK (September 2007) which was endorsed by all four UK Departments of Health. This document provides a clear framework and a consensus opinion about the correct approach to contemporary drug problems in the United Kingdom. This evidence based guideline underpins the underlying principles of treatment services and refers extensively to the evidence base on all aspects of treatment including methadone maintenance, other substitute treatments such as buprenorphine, detoxification in all its modalities and a wide range of
support services. Further, recommendations from the NICE technical appraisals are integrated into the guidelines.

Observations in the guidelines and NICE appraisals on the relative values of different forms of treatment draw attention to the expensive and complicated nature of rehabilitation and detoxification and the strong evidence base for opiate substitute treatment such as methadone and buprenorphine in not only disengaging drug users from injecting but rehabilitating individuals over many years and supporting them as they grow into a more stable period in later life. It is widely acknowledged that methadone and such treatments are compatible with an otherwise normal lifestyle when delivered sympathetically and with support and that many individuals choose this option after years of attempting abstinence without success.

**Strategic level review** is needed to improve services and life opportunities for individuals with drug problems. Such changes, however, should recognise the value of existing services and listen to those who have benefited from them as well as those for whom other treatment modalities need to be developed. There is a real risk that a shift towards abstinence programmes will weaken the success of harm reduction measures which have kept levels of HIV, Hepatitis C and other health and social harms at their lowest level for many years.

It should be noted that access to **needle exchange in prisons** in Scotland and across the United Kingdom falls short of good practice in other European nations, contradicts recommendations from UNAIDS and WHO, and risks the health of prisoners who inject drugs. Policy is clearly stated in Scotland that needle exchange facilities are integral to drugs policy within prison. There are, however, understandable concerns which will require patience to resolve. Accommodation of concerns, however, ought not to be a permanent block. HIV Scotland urges inclusive UK-wide discussions on the way forward.

d) **How could prevention initiatives be better delivered and evaluated?**

Given the continuing high levels of incidence in Scotland and the UK, taken along with recent reports of increasing incidence in other European countries [http://www.aidsmap.com/HIV-incidence-increasing-among-gay-men-in-Amsterdam/page/1599246/](http://www.aidsmap.com/HIV-incidence-increasing-among-gay-men-in-Amsterdam/page/1599246/) our prevention interventions need to improve. HIV Scotland has drawn attention to what we have called ‘the failure of HIV prevention’. This is not to be taken as a generalised comment on all prevention work. NHS Boards and voluntary sector agencies have worked hard to improve the scope, cover, intensity and quality of HIV prevention. At national levels this has been supported by a number of initiatives. It is clear, however, that across the range of responsibilities both collective and individual, we are allowing HIV slowly to win the battle. We must halt this trend in increasing rates of HIV. The tone is set in the title of Scotland’s most recent campaign, ‘**HIV – Wake Up**’.

One key area in which there must be better approaches is in the engagement of people living with HIV. The Greater Involvement of People Living with HIV (GIPA - [http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf](http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf)) is a principle endorsed at every level, but practised in few. HIV Scotland does not absolve itself from this charge. Action is needed to improve the collective advocacy for people living with HIV. Whilst some efforts have been made, these are generally sporadic and
uncoordinated leading to disillusionment on the part of those who should be ‘on the inside’ and contributing the expertise of those with the experience. Lessons might be learned in this respect from general public engagement approaches as well as from those who have more successfully implemented the GIPA principle.

Other initiatives ought to address the onward transmission of HIV from ‘HIV clusters’ and in targeting much more specifically, groups and settings where HIV transmission is occurring. Links are needed also to other concerns such as mental health, and to training for generic staff.

There is no magic bullet; interventions work in combination and seldom quickly. That it can be achieved, however, is evident not only from the success in Scotland of harm reduction, but also from the experience of other countries. HIV Scotland is involved with partner agencies therefore in the following initiatives –

1. With NHS Health Protection Scotland and others to establish evidence based prevention guidance in MSM and in African populations.
2. With NHS Quality Improvement Scotland to draw up Standards in HIV prevention, testing and treatment, supported by an implementation plan.
3. Learning across the continents – collaborations with African Country Associations, voluntary agencies, Universities etc to draw on experience and learning to inform policy and practice – eg Africa in Scotland, Scotland in Africa conference - [http://www.cas.ed.ac.uk/events/annual_conference](http://www.cas.ed.ac.uk/events/annual_conference), Policy Seminar in Feb 2011 - [http://www.ed.ac.uk/schools-departments/global-health/news-events/events/scotland](http://www.ed.ac.uk/schools-departments/global-health/news-events/events/scotland), and meetings facilitated between high level public figures from Africa and Scottish public (students, associations etc) – eg President Kenneth Kaunda, African High Commissions and late David Katu.
4. Building a policy and practice library within HIV Scotland’s new website.

**TESTING**

a) Are current testing policies adequate across the country?

Improving the earlier detection of HIV is crucial to the success of prevention as well as of treatment.

HIV testing **almost doubled** in Scotland for the five years to 2008. Amongst MSM, for the same period, HIV testing saw a **three-fold increase** with 80% of all tests being undertaken in GUM settings. (Wallace, Gaycon 2010)

Policy switched within GUM clinics at the outset of this period of time, with testing for HIV becoming part of the usual set of checks undertaken as part of a sexual health check-up. In part, lessons were learned from the success of ante-natal testing, such as that most people would consent, uptake was largely dependent upon the commitment and skills of staff, and a culture of testing would emerge. This was backed by HIV Scotland in a national seminar, and in messages communicated through its Healthy Gay Scotland project and partner agencies. Results are evident in the graph below.

The following graph shows that combined policies such as ante-natal testing, opt-out testing in GUM clinics, and community awareness-raising with an emphasis on
challenging stigma, have resulted in reductions in undiagnosed infections. It should be noted, however, that such policies may not necessarily address the need for improved testing among women who are not pregnant, or of gay men who may have additional risk factors in behaviour, psychology, or context.

**Proportion of undiagnosed HIV infections in GUM clinic attendees remaining undiagnosed after their clinic visit, Scotland, 2003-2008** (Health Protection Scotland)

Late testing, defined as having a CD4 lower than 350 remains problematic, and morbidity and mortality which are otherwise preventable, result.

Of the 372 cases who entered monitoring and recorded a CD4 count for the first time between 1 October 2009 and 30 September 2010, 66 (18%) had a count < 200, 66 (18%) a count between 201 and 350, 98 (26%) a count of between 351 and 500, and 121 (33%) a count of > 500. For 21 cases, the count was unrecorded or not known (data not shown). (Answer, HPS, Feb 2011).

The table below demonstrates late diagnosis –

**HIV Detection**

<table>
<thead>
<tr>
<th>Description</th>
<th>Late</th>
</tr>
</thead>
<tbody>
<tr>
<td>Detection Percentage ALL (2010) &lt; 350 ml</td>
<td>36%</td>
</tr>
<tr>
<td>Detection Percentage ALL (2010) &lt; 200 ml</td>
<td>18% (NB was 46% in 2000)</td>
</tr>
<tr>
<td>Detection Percentage MSM (2009) &lt; 200 ml</td>
<td>17% (NB was 35% in 2000)</td>
</tr>
<tr>
<td>Detection Percentage ALL MEN (2009)</td>
<td>13%</td>
</tr>
<tr>
<td>Detection Percentage ALL MEN (2006)</td>
<td>25%</td>
</tr>
<tr>
<td>Detection Percentage ALL MEN (2002)</td>
<td>34%</td>
</tr>
<tr>
<td>Detection Percentage ALL indigenous (2006)</td>
<td>25%</td>
</tr>
<tr>
<td>Detection Percentage ALL indigenous (2001)</td>
<td>33%</td>
</tr>
</tbody>
</table>

(collated from various sources – HPS)
Late diagnosis in heterosexuals and in those of African origin continues to be a particular problem.

More should be done therefore to –
1. promote testing in primary care and A&E settings
2. promote testing to younger gay men who are less likely to test than their heterosexual peers
3. provide testing opportunities outwith the usual clinic hours for those at work, possibly through group specific clinics, eg for gay men or young people
4. reduce the time from arrival in the UK to HIV testing for those with increased risk factors
5. provide information on availability of HIV testing and treatment to minority groups
6. integrate HIV testing to sexual health checks within sexual and reproductive health settings
7. improve sexual health and HIV components of medical and nurse training and education
8. include sexual health and HIV in the health ‘MOT’, provided to men and women
9. include an offer of HIV testing for all new registrations in GP practices
10. promote the benefits of HIV testing to counterbalance arguments ‘not to test’, including the benefits of HIV treatment, safer sex, ongoing mental and physical health
11. variability in testing practice and service quality needs to be equalised, eg in time from test to receiving results. Quality Improvement Scotland Standards in HIV should assist.

b) What can be done to increase take-up rates?
see above
Currently, NHS Quality Improvement Scotland is engaged in drawing up Standards which include standards in HIV recognition and diagnosis. A strong implementation plan will be needed. This significant development, unique within the UK, reinforces integrated approaches to HIV prevention, recognition/detection, and treatment and care

TREATMENT

a) How can the NHS best commission and deliver HIV treatment?

Delivery of HIV treatment in Scotland is through specialist infectious diseases units and GUM clinics. Currently, NHS Quality Improvement Scotland is engaged in drawing up Standards which include standards in HIV Treatment. A strong implementation plan will be developed. It is a model which ought to be emulated elsewhere. This aspect of work is based on Johnman, C. (2009) Treatment and Care Needs Assessment: People Living with HIV. Scottish Public Health Network (Scot PHN). This informative and influential document represents the outcome of the work of a small committee ably chaired and led by Dr John Logan, Consultant in Public Health Medicine, NHS Lanarkshire.

In ‘Answer’ Feb 2011, HPS reports –

During the period 1 October 2009 to 30 September 2010, 3254 HIV infected individuals attended specialist services for monitoring and treatment. This represents 86% of the estimated number of diagnosed cases currently living in Scotland. Of
these, 3154 had a CD4 count recorded, while 3134 were measured for viral load. The majority of cases were from the Lothian (1061, 33%) and Greater Glasgow & Clyde (1036, 32%) areas.

Across Scotland, 80% of cases attending for monitoring are receiving triple therapy or higher (Table 6). Of the 3154 cases recording at least one CD4 count, 239 (8%) had a count <200 cells/mm3, 576 (18%) a count of between 201 and 350, 865 (27%) a count of between 351 and 500, and 1450 (46%) a count of >500. For 24 cases, the count was unrecorded or not known (Table 7). Of the 372 cases who entered monitoring and recorded a CD4 count for the first time between 1 October 2009 and 30 September 2010, 66 (18%) had a count <200, 66 (18%) a count between 201 and 350, 98 (26%) a count of between 351 and 500, and 121 (33%) a count of >500. For 21 cases, the count was unrecorded or not known (data not shown).

Of the 3254 attending between 1 October 2009 and 30 September 2010, 3134 persons had at least one viral load test performed. 2509 (80%) had evidence of reasonable viral control indicated by a viral load measure of <400 copies/ml. Of the 324 cases that entered monitoring for the first time in the same period, 158 (49%) had a viral load <400. For 18 cases, the count was unrecorded or not known.

Time from diagnosis to entering specialist care is equal across all transmission groups, and generally within one month. Rates of uptake of ARVs are equal across all transmission groups.

b) What impact might the proposed new commissioning reforms have on HIV treatment?

N/A in Scotland

c) In what setting can treatment most effectively be delivered?


This must be through a multi-disciplinary team, with clearly identified lead contact for the patient. Links to other specialisms as well as to primary care improve the safety and efficacy of treatment. Management of the patient should be with full patient engagement.

NHS QIS is developing Standards in Treatment for people living with HIV.
COST

The HIV Action Plan states, “By 2012, the number of people living with HIV and requiring specialist care is likely to increase by 5-13% (some 150-350 persons) per year and the average age of individuals living with HIV will increase over time as effective drug regimens sustain and improve their quality of life. Providing treatment and care for all those who require it is one of Scotland’s most pressing HIV challenges”.

The annual cost of HIV treatment per individual is £11,097.

The estimated annual cost of ARV treatment alone for the 2487 individuals on ARVs (HPS) is therefore £27,709,209. Additional costs from inpatient care and HIV-related hospitalisations bring this total person per annum to £13,164 and the total annual cost to £32,820,508.

On this basis alone, the annual increasing cost to Scotland of the treatment of people living with HIV is between £1,660,550 and £3,880,050. The addition of inpatient and hospitalisation costs brings these figures to between £1,974,600 and £4,607,400.

This is likely to escalate as treatment guidelines return to the previously recommended level of CD4 count of 350 and higher.

None of these calculations takes account of the cost of other inpatient/outpatient costs, non-HIV related care, costs in work days lost, or cost in social care. Costs of onward transmission from people living with HIV are not included in this calculation. Costs to health and well-being and to relationships are considerable.

It is estimated that annual UK treatment and care costs could reach £750 million by 2013. Social care costs bring this figure to over £1,000 million. [Mandilia S et al. Rising population cost of treating people living with HIV in the UK, 1997-2013. PLoS One, 5, 12: e15677, 2010 http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3012705/?tool=pubmed]

a) Have cost considerations been satisfactorily balanced with public health imperatives in HIV?

HIV Scotland has undertaken a cost and benefit analysis of early detection and prevention for HIV in Scotland. Based on the ‘Sunrise project’ developed by Bristol-Myers Squibb, it is possible to calculate the cost savings in earlier detection of HIV and its prevention in set ratios of onward transmission.

Taking a CD4 count of <200, against a 20 percentage shift to earlier detection, it is estimated that over a five year period, Scotland could save £4,512,806 in treatment and hospitalisation costs alone.
(NB – this is work in progress, and follow-up required to update statistics for 2010. Report due Spring 2011)

It is concluded therefore that efforts to improve prevention, detection/diagnosis, and treatment are highly cost-effective. Greater financial investment at all levels is required.
b) Is research funding correctly prioritised?

Scotland has a strong track record in HIV related research, which is undertaken in a number of settings and with a number of collaborations. The Chief Scientists office has established a research Advisory Group in response to “Respect and Responsibility” and at the request of the National Sexual Health and HIV Advisory Committee. Priorities are advised from a body of experts from clinical, academic, planning, and HIV Scotland representing the HIV voluntary sector. HIV Scotland can provide a list of current research projects in Scotland.

STIGMA

It is important to try to understand the nature of HIV-related stigma.

Stigma has been defined as the ‘systematic process of devaluation’ (Aggleton et al). With its etymological root in the Greek στιγμα it refers to the mark which differentiated someone from the ‘norm’. Its inextricable link to HIV and AIDS needs to be broken.

Its existence in internal thought processes, our language and actions need to be tackled at these points through the engagement of community, media, leadership and legislators.

Speaking of the People Living with HIV Stigma Index (Scotland) Report http://www.stigmaindex.org/50/analysis/uk.html the Minister for Public Health Shona Robson said,

“I'm pleased to see the publication of the results of The People Living with HIV Stigma Index. One of the key aims of the HIV Action Plan in Scotland is to tackle the stigma and discrimination faced by people living with HIV. It is important to ensure that action taken to combat HIV be approached sensitively to avoid any increase in levels of stigma and the Index will provide us with the evidence needed to tackle this issue.”

Undertaken by people living with HIV themselves, the above Report makes a valuable contribution to the evidence of the reality and impact of stigma on people living with HIV. This model of engagement of people living with HIV in tackling stigma within its own community was pioneered in Scotland in 1997 when, supported by HIV Scotland’s Healthy Gay Scotland project, a group of gay men living with HIV developed a full publicity and web campaign focussed on HIV stigma among gay men themselves.

As is often the case with leprosy, mental health and cancer, it feeds on fear and ignorance, and often comes from family and community, and others close to its target.

Because of the associations of HIV with newly emerging trends over the past ten years, stigma persists well beyond the first wave of fear and ignorance in the 1980s. Increasingly it is perceived as an African (or Western) disease, associated with poverty (or wealth), and linked with gender. These add to the identification of HIV and AIDS with sexuality and drug use.

The multi-layered associations of HIV characterise the stigma and discrimination often experienced by people living with HIV. This makes it difficult to pin down or to deal with
through legislation or education alone, essential as these are. These solutions must be combined with other measures such as human rights and the power of community.

a) What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?

There is probably no more powerful illustration of the impact of stigma than the experience of children and young people infected with the virus. In her most recent research publication in this area, Professor Vivienne Cree of Edinburgh University summarises a key finding thus,

“The infected children and young people were at pains to present themselves, their lives and HIV as ‘normal’. This was in spite of their very troubled backgrounds and current hardships. Being ‘normal’ is a major preoccupation in adolescence. It is also, however, an indication of the wish to avoid stigma.”

From the mouth of one of the children interviewed,

“I want to be like the others.”

The impact on those affected by HIV includes shame, internal blaming, isolation, and secrecy. HIV Scotland is concerned by reports of domestic violence following disclosure of infection, often on the assumption on the part (usually) of the man that his wife or partner has been unfaithful and has infected him.

The workplace can also pose problems for some people living with HIV. Waverley Care, Scotland’s largest HIV charity, has stated that

"At Waverley Care we hear numerous examples of people who have been discriminated against in the workplace because of their HIV but who do not feel strong enough, physically or emotionally to take out a grievance. In some cases it is simply easier to resign. A greater understanding of HIV and its transmission amongst the general population would go a long way to reducing workplace discrimination."

In healthcare settings, inappropriate and irrelevant questions about a patient’s HIV status, or use of procedures which single out people living with HIV unnecessarily, are also reported. For example, universal precautions ought to be taken to protect staff and patients when taking blood. Unfortunately, these procedures are not always followed, and when they are selectively used for people with HIV, it discriminates against the patient, fails to protect the healthcare worker in other situations, and may alert others who notice a difference in usual practice.

Culture and belief can and often are powerful supports to people living with HIV. At its General Assembly in 2006, the report of the Church of Scotland’s HIV and AIDS Project stated that, “The Kirk recognises that HIV stigma and discrimination continue to act as barriers to effective prevention and care within and furth of Scotland; confesses to people living with HIV that the Kirk has been involved in unwitting and unthinking stigmatisation of them; and calls on all Christians in Scotland to overcome ignorance and prejudice about people living with HIV wherever they may be.” Some measure of the success and impetus of the Kirk’s commitment is evident in the £1 million raised in its
congregations for HIV and AIDS work in Scotland and internationally, its Scotland-wide ‘Souper Sunday’ awareness-raising on the first Sunday after World AIDS Day, and a programme of leadership training towards an ‘HIV-competent Church. This contrasts, however, with continuing reports of faith-based stigma and misunderstanding, particularly from some Christian bodies outwith the ‘mainstream’. Others, however, are exemplary in their solidarity with HIV positive people. It is worthy of note that individuals with stigmatising beliefs about HIV are less likely to test for the virus, regardless of personal risk. http://aidsmap.com/People-who-stigmatise-HIV-are-less-likely-to-take-an-HIV-test/page/1528949/

b) Where are problems of stigmatisation most acute?

Based on the above, the problems of stigmatisation are most acute –

- In the home, family and community. HIV positive gay men, for example, often report stigma in the form of rejection, rumour, and isolation from their own peers.
- In the workplace, but also occasionally in schools and colleges.
- In healthcare settings, often through inconsiderate comments or actions
- In church and faith group.

c) What measures are currently taken to tackle HIV stigmatisation? What more should be done?

In general, more should be done by –

- trying to understand stigma and the experiences of people living with HIV
- building a stronger Human Rights approach to HIV that respects dignity
- engaging and involves HIV positive people and draws on Community experience
- taking a multi-faceted and collective approach to tackling stigma
- recognising the difficulties that may arise within particular cultural contexts, including rurality

Services: Measures currently being undertaken specifically on HIV are usually very general. If we consider the areas of concern listed above, most HIV services are for adults and poorly suited to children infected with HIV or affected by the virus. There are notable exceptions, however, in for example NHS paediatric care in Glasgow, Edinburgh and Dundee, and Waverley Care’s long-standing dedicated children’s support services. The HIV Carers based in Glasgow take a distinctive whole family and whole person approach, work with all family members, and liaise where appropriate with social work services. Whilst services need to respond to the needs of the majority of those who ‘come through the door’, this neglect ignores the fact that those living with HIV have identities and lives other than their status or their risk factor, be it sexuality, drug use, country of origin or anything else. To the extent that even agencies at the front line ignore or are uninformed of the real lives of their service users, they fail to address the reality of stigma within home and community.

HIV services must address the needs of the whole person, social and otherwise.
Education in schools and colleges ought to address sexual health and HIV under the Curriculum for Excellence
Workplace: Good examples exist of efforts to inform employers and employees of their duties and responsibilities in relation to HIV and disability generally. Not only legislation but good practice needs to be well understood and implemented. The National AIDS Trust produces information and Guidance on Employment [http://www.nat.org.uk/Living-with-HIV/Useful-information/Employment-advice.aspx](http://www.nat.org.uk/Living-with-HIV/Useful-information/Employment-advice.aspx) Some agencies are able to provide employment support to people living with HIV, and the collaboration between Waverley Care and Terrence Higgins Trust (Scotland) in the Positive Scotland project (Big Lottery funded) is a good though too rare example [http://www.waverleycare.org/content/employabilityandskills/207/](http://www.waverleycare.org/content/employabilityandskills/207/) Local agencies such as Body Positive Tayside and Glasgow’s HIV Carers provide excellent support to people living with HIV so that they are not isolated and on their own in trying to deal with some difficulties. This takes the form of support, eg one-to-one, group support, or advice and referral to welfare rights.


Healthcare settings: A number of approaches might help to reduce stigma and related discrimination in healthcare settings and in turn within the home and family. Provide regular training and online guidance and updates on HIV for all staff. Consider offering support on HIV testing for couples attending together. Provide non-confrontational, confidential ways for people to flag up concerns.

Church and faith groups: Polarisation of views and alienation of people living with HIV or the communities to which they may belong can be avoided. There are numerous examples of excellent practice from faith-based organisations. Faith leaders must inform themselves about the facts related to HIV, and help to dispel the myths and prejudices. Equal treatment and consideration should be shown, and solidarity with people with HIV demonstrated. Links between HIV organisations and churches, mosques or faith groups can be encouraged. In addition to its General Assembly statement, the Church of Scotland has a dedicated HIV and AIDS Programme which aims to break the silence, offer practical support, work in solidarity with sister churches, speak for the voiceless and involve every member.

Specialist HIV agencies, churches and faith groups should work together to inform and support each other’s work. See [http://www.e-alliance.ch/](http://www.e-alliance.ch/)
References


Waverley Care (2011) Employability and Skills. [online] available from http://www.waverleycare.org/content/employabilityandskills/207/
Appendix

HIV voluntary agencies in partnership with HIV Scotland include:

Body Positive Tayside - offers a wide variety of services for people who are HIV positive and/or Hepatitis C positive, or directly personally affected

Gay Men’s Health - involves and empowers gay and bisexual men to promote the health and well-being of all men who have sex with men. This includes men living with or affected by HIV

HIV-AIDS Carers & Family Service Provider Scotland - providing a range of practical and emotional services to carers, families, partners, friends and relatives who are affected or infected by HIV or AIDS

LGBT Youth Scotland - Scotland’s largest youth and community-based lesbian, gay, bisexual and transgender (LGBT) organisation

Positive Help - offers volunteer led practical help to those affected by HIV/AIDS in Edinburgh and Lothian.

Terrence Higgins Trust - the leading and largest HIV and sexual health charity in the UK

Waverley Care - Scotland’s leading charity providing care and support to people living with HIV and Hepatitis C, and to their partners, families and carers.

Glossary & Acronyms

ACMD – Advisory Committee on the Misuse of Drugs
AIDS - Acquired Immunodeficiency Syndrome
AMEHP - African and Minority Ethnic HIV Project
ARVs – antiretroviral drugs
BBV – Blood-borne virus
DoH – Department of Health
GIPA – Greater Involvement of People Living with HIV
GUM – Genito-urinary medicine
HIV – Human Immunodeficiency Virus
HPA – Health Protection Agency
HPS – Health Protection Scotland
IDU – injecting drug use
IVDU – intra-venous drug user
MCN – managed care network
MSM – Men who have sex with men
NAM – National AIDS Manual (aidsmap)
NICE – National Institute for Clinical Excellence
PCTs – Primary Care Trusts
QIS – NHS Quality Improvement Scotland
WHO – World Health Organisation

18 February 2011
Memorandum by International AIDS Vaccine Initiative (IAVI) (HAUK 65)

About IAVI
IAVI is a global not-for-profit, public-private partnership, with offices in the United States, Africa, India and Europe. Our mission is to ensure the development of preventive AIDS vaccines that are not only safe and effective, but also accessible to all people. To that end, IAVI invests the bulk of its resources in the research and clinical assessment of candidate vaccines against strains of HIV that are prevalent in the developing world, where some 95% of new HIV infections occur.\(^{183}\)

Our research and product development teams work with more than 40 academic, commercial and government institutions to develop and evaluate candidate HIV vaccines. So far, IAVI and its partners have designed 17 vaccine candidates, 9 of which have entered human trials in 11 countries in Asia, Africa, Europe and North America. To do this critical work, we, together with local research institutions, have developed a network of sophisticated laboratories and clinics, including in India and in southern and eastern Africa. Our Human Immunobiology Laboratory at Imperial College London is a central hub that co-ordinates the work of the laboratories engaged in informing the design of novel vaccine candidates and in evaluating their ability to prevent HIV infection and AIDS.

IAVI also conducts policy and advocacy programmes to help advance AIDS vaccine R&D worldwide, and supports a comprehensive approach to HIV and AIDS that balances the expansion and strengthening of existing HIV prevention and treatment programmes with targeted investments in new HIV/AIDS prevention tools.

Written submission
We wish to restrict our written submission to questions relating to HIV vaccines and HIV research.

What progress has been made towards an AIDS Vaccine?
An AIDS vaccine is possible

1. Over the past two decades, scientists have learned more about HIV and its disease course than any other virus in history. Today the AIDS vaccine field is capitalising on a steady stream of advances:
   a. A clinical trial completed in Thailand in 2009 (RV144) provided the first demonstration in humans that a vaccine can prevent HIV infection. Two AIDS vaccine candidates, given a few months apart in a so-called prime-boost combination, were found to be about 30% effective at preventing infection with HIV. This result, while too modest to support regulatory approval for the vaccine regimen, has generated considerable excitement within the research field. Researchers around the world are working collaboratively to extract valuable data from the Thai trial data to inform ongoing AIDS vaccine design and development efforts.
   b. In an attempt to understand how peoples’ immune systems may be able to combat HIV, a worldwide search for people who develop special antibodies

\(^{183}\) UNAIDS 2010
capable of neutralising a broad range of HIV variants has yielded promising results. More than a dozen of these special antibodies have been identified (two of them combined could neutralise the vast majority of all HIV variants). Furthermore, these antibodies have revealed a vulnerable site on the surface of HIV that researchers can use to inform vaccine design. The next step is to develop a vaccine that can generate the production of these special antibodies in people before they are exposed to HIV, in order to block the virus from establishing an infection.

c. In an animal model, researchers have been able to significantly improve control of infection with an experimental vaccine against a virus similar to HIV. The lessons learned from these studies are now being applied to design vaccine candidates that target HIV; these will enter clinical trials in the coming years.

2. To advance the development of an AIDS vaccine, researchers are in the process of planning two follow-up studies to RV144 testing the same or similar candidates. A licensure trial in Southeast Asia is tentatively planned in men who have sex with men and potentially other high-risk populations, and an efficacy study is tentatively planned in southern Africa in high-risk heterosexuals. Meanwhile, other promising vaccine candidates are moving forward in the pipeline. The US National Institute of Health is funding a phase Ib trial evaluating the combination of two vaccine candidates (DNA and Ad5). Results are expected in 2013. Also, a trial recently started in the U.S., with a combination of two novel vaccine candidates; testing is anticipated to start in Africa soon. The trial is sponsored by IAVI and carried out with a number of partners in Africa, the US and Europe.

What are the obstacles to success?

3. The recent milestone results in AIDS vaccine development have shown that investments made so far have paid off, as a partially effective vaccine and some promising broadly neutralising antibodies important for further vaccine design could be found. There is no doubt that the scientific challenges we face in bringing a preventive AIDS vaccine to market are vast and hence we must ensure a coordinated global effort to maintain a pipeline of AIDS vaccine candidates that is filled with multiple, diverse and innovative concepts for testing to increase our chances of success. To this end we must stimulate innovation to produce novel AIDS vaccine candidates and new ways of designing, screening, developing and testing them. And we must invest in training a new generation of young and enthusiastic scientists who are willing to dedicate their careers to the discovery of an AIDS vaccine. This global effort requires predictable, sustainable sources of funding.

4. The amount and structure of financing are important determinants of the pace of product development. In global health R&D, financing usually comes in the form of short-term government or philanthropic grants, or contracts that restrict the use of the funds to particular projects or products. This financing structure hampers product development by limiting the degree to which product developers, such as IAVI, can plan for the long term or change direction as the science advances. IAVI identifies and advocates for new financing strategies for global health R&D that permit long-term planning, flexibility and the availability of a reliable stream of resources to speed the development of a safe, effective and accessible AIDS vaccine.
5. G-Finder is a survey that reports on global investment into research and development of new products for 31 neglected diseases, including HIV/AIDS. Latest results from 2009 reveal that although total reported funding for R&D of neglected diseases has increased globally, funding for HIV/AIDS R&D is down slightly (0.9%). The G-Finder survey also showed that much of the increased funding seen in 2009 came from public sources (up 14.0%) but that just over a quarter of this funding was invested internally (26.3%) and that this coincided with a notable shift away from investing in product development towards basic science\textsuperscript{184}.

What can be done in the United Kingdom to facilitate development of a vaccine?

6. The UK is a strong supporter of R&D for AIDS vaccines, both in terms of investments made through DFID’s research strategy and by public and private institutions in the UK research field more broadly. It is important however that this support is sustained and that we do not see an erosion of political commitment for HIV/AIDS issues as seen in other European countries. The UK government has, quite rightly, taken a long-term view and has demonstrated commitment in its portfolio approach to R&D investments, including by funding IAVI. Strong and sustained leadership of this kind is required if we are to eliminate AIDS. The need to sustain this commitment cannot be overemphasised when faced with an unsustainable and growing treatment bill as global HIV incidence remains high and the population of people living with HIV, and hence our pool of infection, grows. Findings from aids2031 show that if we continue on our current trajectory we will spend twice as much on the HIV/AIDS pandemic in 2031, but there will be little to no reduction in new infections\textsuperscript{185}.

7. IAVI praises UK leadership in the global arena. The UK is globally the 3\textsuperscript{rd} largest investor, and in Europe the largest investor\textsuperscript{186}. With the contribution from Europe in AIDS vaccine R&D declining, the UK can further contribute but also call upon other governments in regional and international fora to prioritise HIV prevention, including the development of new prevention modalities, especially an AIDS vaccine, and to

\textsuperscript{184} G-Finder 2010 published by Policy Cures in February 2011
\textsuperscript{185} Critical Choices in Financing the Response to the Global HIV/AIDS Pandemic, Hecht et al, Health Affairs, November 2009
\textsuperscript{186} Funding HIV prevention technologies in 2009, UNAIDS-IAVI-IPM-AVAC resource tracking WG, July 2010
make the response to the pandemic sustainable and to ultimately help to end it. This would help to ensure sustainable and scaled investment in AIDS vaccine R&D, especially towards product development, as translation of academic findings into vaccine products that can be tested, compared and prioritised for large scale development is a priority.

8. While the global community works to expand treatment and care services to those infected with HIV, there is an urgent need to develop new prevention technologies — in particular an AIDS vaccine — to stem the tide of new infections. IAVI worked with the Futures Institute to mathematically model the future trajectory of the AIDS pandemic and the potential impact that a vaccine could have in preventing new HIV infections. A partially effective AIDS vaccine, as part of a comprehensive package of treatment and prevention programmes, could significantly reduce the number of new HIV infections in developing countries. A vaccine with 50% efficacy given to 30% of the adult population could avert 24% of new HIV infections, or approximately 5.6 million new infections, from 2015 to 2030\textsuperscript{187}. Preliminary findings suggest that an AIDS vaccine would be significantly cost saving.

Research
What are the research priorities in the field of HIV and AIDS treatment and prevention?
9. IAVI would like to list its strategic priorities which include:
   • Prioritising the most promising HIV vaccine candidates for efficacy testing in people, which is the only way to assess if a vaccine can work;
   • Making further improvements to vaccine candidates, to achieve higher levels of efficacy (strong robust and long-lasting immune responses that can block or control HIV infection, e.g. through replicating vectors);
   • Designing and developing vaccine candidates that can elicit broadly neutralising antibodies;
   • Ensuring continued engagement of developing countries in the R&D effort, to ensure that vaccine candidates are effective and appropriate for use in those communities, but to also prepare for future access, as well as to contribute to capacity building for biomedical research;
   • Ensuring engagement of the private sector, for instance, more involvement of biotechnology companies to enhance innovation, and greater involvement of the pharmaceutical sector with resources and expertise in late-stage vaccine development, licensure and large scale manufacturing and distribution; and
   • Advocating for sustained and flexible funding to promote long-term product development, and to facilitate adapting research as new knowledge is collected and directing it to the most promising avenues only.

10. In respect to the committee’s question about whether to focus efforts on improving treatment methods that suppress the HIV virus or to develop therapies, such as AIDS vaccines, to eradicate HIV, the answer is that we need both. IAVI supports a comprehensive approach to HIV prevention that includes the scale-up of current HIV prevention strategies, plus the development of new HIV prevention tools, such as microbicides and AIDS vaccines.

\textsuperscript{187} IAVI policy brief 20, August 2009
11. The need for a global comprehensive approach to HIV prevention is compelling. Approximately 33 million people are living with HIV today and despite great efforts in expanding access to treatment only one-third of people living in low- and middle-income countries have access to life saving antiretroviral treatment. Clearly the need to provide treatment to those already HIV infected, and prevention to those at risk, is a moral imperative and IAVI fully supports efforts to expand access to treatment and prevention to those who need it.

12. However current approaches alone, although able to reduce new infections, cannot put an end to the spread of HIV/AIDS. In 2009, 2.7 million new infections occurred and for every 1 person put on treatment, a further 2 became newly infected. According to the aids2031 project, developing countries will need US$ 35 billion a year—three times what is spent now—to address the pandemic in 2031, unless something radically changes the equation. Even with all existing HIV/AIDS prevention and treatment strategies scaled-up to the maximum level feasible, we may only be able to cut the number of new adult HIV infections in half by the year 2031. Even then, more than a million people will still be newly infected each year. Better prevention tools could dramatically reduce that price tag and diminish, and even end, the horrible suffering caused by HIV/AIDS. According to some projections, adding microbicides and pre-exposure prophylaxis to the fully scaled-up implementation of available HIV prevention options could cut HIV infection rates in half. On top of that, a broadly effective vaccine, which unlike the other methods does not rely on the individual’s repeated compliance for efficacy, could eventually finish AIDS off. The history of infectious diseases provides ample evidence of the extraordinary power of vaccines; no other health intervention is more cost effective or has a greater impact on public health than vaccination.

Who are the prime funders of HIV research in the United Kingdom?
Main funders for HIV VACCINE research in the UK:

13. According to The HIV Vaccines and Microbicides Resource Tracking Working Group, the total UK Public Sector Funding for HIV vaccine research in 2009 amounts to US$ 23,602,936. The primary contributors are DFID, the UK MRC and the Wellcome Trust. In comparison, UK funding for the HIV/AIDS response in 2009 was US$ 7.6 billion (DFID was the world's second largest bilateral donor to AIDS programmes, contributing 10.2% of the total disbursements).

How much money will your organisations spend on HIV research in 2010/11? How does this compare to spending in recent years?

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188 UNAIDS 2010
189 UNAIDS 2010
190 Critical Choices in Financing the Response to the Global HIV/AIDS Pandemic, Hecht et al, Health Affairs, November 2009
191 Funding HIV prevention technologies in 2009, UNAIDS-IAVI-IPM-AVAC resource tracking WG, July 2010
14. In 2009, IAVI invested approximately US$ 72.5 million in AIDS vaccine R&D (around 8% of global HIV vaccine R&D spending). Over the coming years, it is essential that IAVI can capitalise on significant progress made over the last 18 months, and scale up its investments in R&D where required to pursue and accelerate the most promising avenues. This however will be a challenging task given the financial downturn and the significant pressure on Research and Development budgets.

What do you think is the appropriate balance between public and private sector funding?

15. Globally, the investment of the private sector in AIDS vaccine R&D has gone down from around 10% to currently 3%. The reason for this very minimal investment by the biotechnology and pharmaceutical sector is the absence of a strong market (the greatest need for an AIDS vaccine is in low- and middle-income countries (LMICs)), combined with too much risk from an R&D perspective (despite promising progress in recent year, the proof of concept for a highly effective AIDS vaccine is still being pursued).

16. The lack of investment by the private sector in AIDS vaccine R&D was one of the main reasons for the initiation of IAVI as a not-for-profit product development partnership (PDP), which combines public and private sector resources. IAVI currently represents fewer than 10% of global investment in AIDS vaccine R&D. IAVI leverages the resources and expertise of both biotechnology and pharmaceutical companies by partnering with this sector and investing in promising technologies and products.

17. Other incentives designed to reduce the risks for the private sector can play a key role in fostering innovation and accelerating development. While it is important to ensure that existing institutions and funding streams receive sustained support, new incentives and facilitation mechanisms to promote innovation can help to push the AIDS vaccine field forward. Furthermore, the resources and expertise of the pharmaceutical sector will become especially critical as AIDS vaccine candidates are being prepared for licensing, large-scale manufacturing and distribution. Possibilities for incentives include milestone payments for R&D progress, fast-track review procedures, an “innovation fund”, such as IAVI has introduced in 2007, to encourage higher-risk projects than would traditionally be funded, new IP incentives, and market guarantees such as Advance Market Commitments (AMCs).

Should the United Kingdom be more prominent in HIV research? Other than providing more money, what can be done to enhance the role of the United Kingdom within HIV research?

18. The UK can take an important leadership role in the global community when it comes to promoting science, technology and innovation (ST&I) for development, and particularly health-related R&D, which is of fundamental importance in the fight against poverty. It is necessary to remove barriers to development—such as disease—to achieve sustained and equitable economic growth. But development also requires building strong economies capable of generating and distributing wealth. Such economic transformation increasingly depends on the ability of countries to use

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192 IAVI annual report 2010
193 Funding HIV prevention technologies in 2009, UNAIDS-IAVI-IPM-AVAC resource tracking WG, July 2010
and generate scientific and technological advances. Thus, building ST&I capacities in developing countries is increasingly seen as an important component of development strategy. The health R&D sector can be a major contributor to development in LMICs, both by developing and facilitating access to new health technologies and by strengthening ST&I capacities through research partnerships. With increased political and financial support, PDPs like IAVI, can contribute to international development in two fundamental ways: by accelerating development of and access to new health tools for diseases of poverty, such as an AIDS vaccine; and by working to strengthen ST&I capacities among LMIC partners. The UK can take a key catalytic role in increasing other donor support for R&D for global health and development.

25 February 2011
Memorandum by the International Centre for Prison Studies (ICPS) \(^{194}\) (HAUK 89)

**HIV/AIDS in the prison setting**

**Introduction**

ICPS is pleased to provide this note on HIV in the prison setting for the Select Committee. The literature on HIV in prisons is voluminous and in this note we are only able to cover the headline points. We would be happy to provide more information if the Committee would find it helpful.

**General background**

HIV has presented severe problems and difficult dilemmas for prisons since the AIDS epidemic began. Rates of HIV infection among people in prison tend to be higher than in the outside population. High rates of other infections such as hepatitis B and C and tuberculosis are also found and make the situation for HIV infected prisoners even more problematic.

The rates are higher in prisons firstly because those most likely to become infected with HIV are from groups which are over-represented in prison; that is marginalised people from disadvantaged backgrounds and those who are involved in drug-taking. Secondly the poor living conditions in many prisons and the behaviour that can take place, such as the injection of drugs and consensual and forced sexual activity, create a risky environment for the spread of HIV. When there is drug-injecting, needles are almost always shared. The National Aids Trust reports that in the UK “45% of men and 65% of women arrive at prison drug dependent, and 40% of these report injecting drug use within the previous month. Injecting equipment is prohibited in prisons, so prisoners who inject drugs are highly likely to share injecting equipment.”\(^{195}\) Tattooing is common in many prisons, often carried out without any measures to prevent disease transmission. Prisoners are most at risk, but the staff are also working in a risky environment.

**The duties of prison administrations**

Governments have a duty of care to people deprived of their liberty. They must provide adequate health care in prisons and take steps to protect detained people from becoming infected. In this context a substantial body of guidelines has been produced by international bodies setting out how prison administrations should respond to HIV/AIDS in the prison setting.

International guidelines were produced by the Office of the United Nations High Commissioner for Human Rights (OHCHR) and UNAIDS in 1996. The guidelines explain their application to prison systems:

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\(^{194}\) The International Centre for Prison Studies assists governments and other relevant agencies to develop appropriate policies on prisons and the use of imprisonment. ICPS has an academic partnership with the University of Essex. The Centre makes the results of its academic research and projects widely available to groups and individuals, both nationally and internationally. These include policy makers, practitioners and administrators, the media and the general public. Such dissemination will help to increase an understanding of the purpose of prison and what can be expected of it. It carries out work on a project or consultancy basis for international agencies, governmental and non-governmental organisations.

Prison authorities should take all necessary measures, including adequate staffing, effective surveillance and appropriate disciplinary measures, to protect prisoners from rape, sexual violence and coercion. Prison authorities should also provide prisoners (and prison staff, as appropriate), with access to HIV-related prevention information, education, voluntary testing and counselling, means of prevention (condoms, bleach and clean injection equipment), treatment and care and voluntary participation of HIV-related clinical trials, as well as ensure confidentiality, and should prohibit mandatory testing, segregation and denial of access to prison facilities, privileges and release programmes for HIV-positive prisoners. Compassionate early release of prisoners living with AIDS should be considered.\footnote{Office of the United Nations High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS (1998) HIV/AIDS and Human Rights: International Guidelines. Second International Consultation on HIV/AIDS and Human Rights, Geneva, 23-25 September 1996. Geneva: OHCHR.}

In 1997 UNAIDS stated \footnote{Prisons and AIDS: UNAIDS point of view, The Joint United Nations Programme on HIV/AIDS, www.unaids.org} [T]he situation [of HIV/AIDS in prisons] is an urgent one. It involves the rights to health, security of person, equality before the law and freedom from inhuman and degrading treatment. It must be urgently addressed for the sake of the health, rights and dignity of prisoners; for the sake of the health and safety of the prison staff; and for the sake of the communities from which the prisoners come and to which they return.\footnote{See, for example, United Nations Office on Drugs and Crime (2006) HIV/AIDS Prevention, Care, Treatment and Support in Prison Settings. New York: UNODC.}

A substantial number of documents have been produced based on these principles setting out in more detail what is required from national prison systems.\footnote{See, for example, United Nations Office on Drugs and Crime (2006) HIV/AIDS Prevention, Care, Treatment and Support in Prison Settings. New York: UNODC.}

### The situation in the UK prison systems

There are three prison systems in the UK, England and Wales, Scotland and Northern Ireland. The Scottish Prison Service and the Prison Service of Northern Ireland are the responsibility of the devolved administrations. Whilst in some countries rates of HIV infection amongst prisoners are high the figures for the UK prison systems have always been relatively low.

A 1997 serosurvey of HIV by the Department of Health established that there was a prevalence of 0.3 per cent amongst adult male prisoners and 1.2 per cent amongst adult female prisoners.\footnote{Department of Health (1998) Prevalence of HIV in England and Wales 1997. London: DH. Para 33.} A survey in Scottish prisons also in 1997 found HIV prevalence of 0.3 per cent amongst adult male prisoners and 0.6 per cent amongst adult women prisoners.\footnote{Scottish Prison Service (2003) Nursing Services Review 2003. Edinburgh: SPS. Section 2.6.}


In answer to a parliamentary question in March 2010 the Minister gave an estimate of the number of prisoners with HIV infection in England and Wales of 163.\footnote{HL Deb 10 Mar 2010: Column 351W.} According to the Survey of Prevalent HIV Infections Diagnosed (SOPHID), in 2009, of the 60,240 adults with HIV infection in England 182 were in prison. 507 adults with HIV infection had been in prison before 2009.
Memorandum by the International Centre for Prison Studies (ICPS)F F (HAUK 89)

The latest report from the Department of Health however notes that ‘Current surveillance systems are inadequate for accurately capturing data on the number of individuals diagnosed with HIV in prison.’\(^{203}\) It is suggested that the survey underestimated the actual figure for HIV infected prisoners. However from January 2011 the Genitourinary Medical Clinical Activity Dataset (GUMCAD) was to gather information on newly diagnosed HIV cases in prison so more reliable figures should become available.\(^{204}\)

**Good practice in dealing with HIV in prisons**

The many guidelines, handbooks, policy documents and manuals on dealing with HIV in prisons agree that the following measures are good practice:

- Education for prisoners and staff on HIV and how to prevent infection
- Preventive measures such as the provision of condoms, bleach, needle-exchange schemes

In the prison services of England and Wales and Scotland some policies are in place that aim at achieving good practice in both these areas. Disinfecting tablets have been available in prisons in Scotland since 1993 and in England and Wales since 2007 (following an earlier attempt in 1995).\(^{205}\) Condoms can be obtained by prisoners from the healthcare services. A guidance note to prison governors and health care managers from the Department of Health and HM Prison Service stated that condoms, dental dams and water-based lubricants must be made available to any prisoner who requests them “if, in their clinical judgement, there is a risk of the transmission of HIV or any other sexually transmitted disease.”\(^{206}\)

A variety of methods are used to ensure information reaches prisoners. There are leaflets, DVDs and music. Most recently playing cards with health messages have been distributed. The most recent leaflets produced for prisoners contain messages about where they can be tested for Hepatitis B and Hepatitis C and HIV.\(^{207}\)

Needle exchange is not currently available in UK prisons although all the evidence from such programmes in other countries suggests they are very effective and the anxieties of prison staff about such programmes have not been borne out. The Scottish Prison Service has been trying to pilot a needle exchange in Aberdeen prison but this has yet to be implemented. According to the National Aids Trust, the ‘prison service in England and Wales are awaiting the outcome of the Scottish experience to judge any change in current policy.’\(^{208}\) The National Aids Trust also reports that an evaluation of policies relating to blood borne virus prevention and control in prison is being conducted by the Department of Health (Offender Health) in partnership with the University of Stirling. The report is not yet available.


The 2009-2010 report from the Department of Health and the Health Protection Agency, Health Protection in Prisons, made the two following recommendations:

There is a need to continue to develop appropriate prison-specific educational materials aimed at raising awareness of bloodborne viruses (BBV) among prisoners. These should also result in increased uptake of voluntary testing by prisoners for hepatitis B, hepatitis C and HIV.

Prisoners should have access to sexual health services in prisons, including access to condoms and lubricant, genitourinary medicine services and the national chlamydia screening programme (NCSP). A mapping exercise of sexual health services will be undertaken to gain a better understanding of service provision in the prison estate, with the aim of developing a sexual health toolkit.

Conclusions
We support these two recommendations. We are also concerned that current changes in the NHS are putting pressure on health service delivery in prisons. Much progress has been made since 2003 when the prison health services became part of the NHS. The policies and practices to control the spread of blood-borne viruses and care for those who are infected have been painstakingly introduced and maintained. There is still more to do. To move backwards now would be damaging and dangerous.

9 May 2011
Memorandum by the International Partnership for Microbicides (IPM) (HAUK 75)

Additional information on Microbicides research and development

Introduction:

The International Partnership for Microbicides (IPM) is pleased to provide some additional supporting information on Microbicides as part of the work of the Lord’s HIV Select Committee and emanating from the session providing evidence on research and development where microbicides were touched on. Below is information on IPM and an Overview of the work to develop Microbicides including information relating to the Caprisa trials referred to in the research and development session which has shown that an antiretroviral (ARV)-based microbicide can work. DFID have been a constant supporter for microbicide research and the work of IPM and awarded £20m in 2009 as part of the DFID Research and Development programme.

Ongoing support is essential to the success of microbicide development. Funding must be secured before clinical trials can be conducted – and just a single efficacy trial alone can cost as much as $120 million. Between 2000 and 2007, global funding for microbicide research and development tripled, with the United States and European donors continually increasing support. There are signs though that support for microbicide research may be flattening. Between 2006 and 2007, the total investment in microbicide research increased 2 percent to US$226.5 million. Such funding levels are well below the annual $280 million amount recommended by microbicide experts to ensure an optimal research effort.

About IPM

IPM’s mission: To prevent HIV transmission by accelerating the development and availability of safe and effective microbicides and other HIV prevention methods for use by women in developing countries.

Founded in 2002 as a product development partnership (PDP), IPM has become an important partner in the microbicide field. By coupling the public sector’s commitment to advancing global public health with the business approach of the private sector, IPM fills a special niche in the microbicide field.

Since IPM’s inception, it has focused its efforts on developing antiretroviral (ARV)-based microbicides and other products in collaboration with our partners:

- leading pharmaceutical and biotechnology companies
- philanthropic foundations
- local research centers in developing countries
- civil society organizations
- academic institutions

Using a “best practices” approach to its work, IPM:

- evaluates promising compounds
Memorandum by the International Partnership for Microbicides (IPM) (HAUK 75)

- designs optimal formulations
- conducts preclinical and clinical trials
- identifies appropriate regulatory pathways for products
- establishes manufacturing and distribution capacity to ensure access to future products

IPM also strategically engages and collaborates with advocates and global health leaders to raise awareness about microbicides and HIV prevention products worldwide.

Through strong working partnerships at the local and national level in developing countries, IPM invests substantial resources in building health research infrastructure in parts of the world where the need for health research is greatest.

**Microbicides Overview**

HIV/AIDS ranks among the world’s most devastating diseases because it has spread rapidly and mainly affects young people in their most productive years. More than 33 million people worldwide are living with HIV/AIDS, and 30 million already have died from AIDS-related causes (UNAIDS/WHO, November 2010). Each day, about 7,000 more women, men and children become infected with HIV, the virus that causes AIDS. Globally, more than 16 million children ages 0-17 years, the majority of whom live in sub-Saharan Africa, have lost their parents because of HIV (UNAIDS/WHO, November 2010).

Women bear a particularly high burden of the epidemic as primary caregivers for the ill and because of their heightened risk of infection because of biological, economic and social vulnerabilities. Based on the latest comprehensive WHO data, HIV/AIDS is the leading cause of death globally in women 15-44 years of age, particularly in sub-Saharan Africa where the epidemic has hit hardest. Heterosexual sex is the primary mode by which HIV spreads in developing countries.

Although a range of prevention strategies exists, they are not enough to stop the spread of HIV — particularly among women. Many women may be unable to persuade their male partners to use condoms or remain faithful. Abstinence is not an option for women who are married, who want children or who are at risk of sexual violence. This is why new prevention strategies that women can use themselves are urgently needed. One such strategy would be microbicides — medical products being developed to protect healthy people from becoming infected with HIV during sex. Some microbicides are being designed only for women as vaginal products, and others would be rectal products that both men and women could use.

The International Partnership for Microbicides (IPM) is among several nonprofit organizations focused on developing microbicides to protect women from becoming infected with HIV during sex with a male partner. Microbicides could come in many forms, including gels used around the time of sex, once-daily gels, films, and vaginal rings that could provide protection for a month or longer. Vaginal microbicides would address one of the central gaps in the existing continuum of prevention options by offering a discreet method women would use to protect themselves against HIV.
How would microbicides work?

In contrast with treatment regimens for HIV/AIDS, which help manage HIV infection after it has already taken hold in the body, microbicides are designed to prevent infection from happening in the first place. In recent years, a number of organizations have been studying a highly potent class of microbicide products containing antiretroviral drugs (ARVs) formulated as gels to be used around the time of sex, as daily gels and films, and as monthly vaginal rings. These microbicides are based on the same types of ARV drugs being used to treat people living with HIV/AIDS and to prevent mother-to-child transmission of the virus. They act specifically against HIV by attacking at one of a number of points in the HIV life cycle. ARV medicines have extended and saved millions of lives across the globe — adapting those drugs to protect healthy adults from becoming infected with HIV could transform the global response to the epidemic. In fact, ARV-based microbicides are following the lead of other life-saving prevention methods that have been successfully adapted from treatments for diseases such as malaria, influenza and pneumonia.

The CAPRISA Trial

New evidence from two recent clinical trials has shown the powerful potential of ARVs to prevent HIV transmission. Results were announced in July 2010 from the first-ever efficacy trial of a vaginal microbicide containing an ARV. That Phase IIB clinical trial, called CAPRISA 004, established proof-of-concept for tenofovir gel. Overall, tenofovir gel reduced the risk of acquiring HIV infection by 39 percent, and it was shown to be safe as tested when used up to 12 hours before sex and again within 12 hours after sex. Tenofovir is an ARV that prevents HIV from making copies of its genetic material once inside the cell by inhibiting the action of the HIV reverse transcriptase enzyme.

Additional research is under way to develop microbicides that attack HIV in various ways, including novel compounds that interfere with the fusion and entry of HIV into the target cell. Another trial, which established proof-of-concept for ARV-based pre-exposure prophylaxis, or PrEP, released promising results in December 2010. The trial demonstrated that taking the daily oral ARV medication Truvada®—an FDA-approved HIV treatment that contains both tenofovir disoproxil fumarate and emtricitabine—while receiving comprehensive HIV prevention services led to a 44 percent reduced risk of becoming infected with HIV-1 in the clinical trial population. This Phase III trial, called iPrEx, was conducted by the US National Institutes of Health with co-funding from the Bill & Melinda Gates Foundation and study medication donated by Gilead Sciences, Inc. In 2006, Gilead granted both IPM and CONRAD rights to develop tenofovir as a topical microbicide for use by women in developing countries.

Some researchers believe that combinations of ARVs in a single microbicide product may improve upon the efficacy of single drugs, but further clinical evaluation is needed. An ideal combination product might be active against independent targets in the viral replication process and have different mechanisms of action.

Formulations, delivery and acceptability

The forms microbicides would take — such as gels, films or vaginal rings — can have a critical impact on their efficacy, cost and acceptability to those who will be using them. An advantage of ARV-based microbicides is that they can be formulated in long-acting delivery
methods that can be applied once a day (gels and films) or used for a month or longer (vaginal rings). Because any of these formulations would be used independently of when sexual activity takes place, they would provide protection against HIV infection even during unanticipated sex.

Although no microbicide has yet been approved for use, an ARV-based microbicide has now been shown to reduce the risk of HIV infection in women. Other ARV drugs that target HIV infection have been identified and are currently undergoing extensive study and testing for use as microbicides. In addition to conducting clinical trials to test the safety and effectiveness of microbicides to prevent HIV infection, IPM and other nonprofit organizations are conducting product acceptability studies to help determine which types of microbicide products women really want and would use.

**How are microbicides tested for safety and efficacy?**

All microbicide candidate products must first go through a rigorous program of laboratory screening and testing to ensure that they have an adequate safety profile before being tested in humans. These intensive preclinical tests can take one to several years to complete. Once a candidate microbicide satisfactorily passes these tests and additional safety tests in animals, it can be advanced through a series of human clinical trials. This process must be followed for any new product before it can be approved for use.

Clinical trials are carried out sequentially: first to determine the safety of the product (no significant side effects occurred) and then to test its efficacy (the ability of the product to prevent HIV infection). The initial safety trials involve small numbers of women who participate under carefully controlled clinical conditions. Larger safety trials, in which the microbicide is administered to a wider range of women over longer periods, are then conducted to gain broader safety data. Only when the safety trials have been completed can efficacy trials be performed to test the ability of the microbicide to prevent HIV infection. These trials involve large numbers of women, and need to be conducted in locations where new HIV infections are occurring at a high rate. This allows researchers to better assess the difference in infection rates between those women who use the active microbicide and those who use a placebo (similar to the microbicide, but not containing any active drug). If significantly fewer women become infected in the group that used the microbicide, then researchers know that the microbicide helps to prevent HIV infection.

Clinical safety trials can take a total of one to two years to complete, while efficacy trials can last three years or longer and involve thousands of volunteers. Therefore, the total product development costs for microbicides can run to hundreds of millions of dollars. Vaginal microbicides would put the power of HIV protection into women’s hands, potentially saving millions of lives around the world. The findings from CAPRISA 004 are encouraging and a true cause for optimism. Additional confirmatory/complimentary trials with tenofovir gel are planned for 2011. A microbicide to reduce the risk of sexual HIV transmission promises to have a significant impact on the epidemic’s future.

**What ethical standards guide clinical trials?**

All clinical trials, including microbicide trials, must be conducted according to international and national regulatory and ethics guidelines to protect the well-being of trial participants and to guarantee the ethical and scientific integrity of the results. Microbicide product developers also adhere to their own guidelines for the conduct of clinical trials (for IPM’s guidelines, visit www.IPMglobal.org). These guidelines are living documents that must
continually integrate new scientific information and discoveries, and be responsive to a changing research and policy landscape.

Informed consent is the cornerstone of ethical trial conduct. Clinical research teams must ensure that all participants in microbicide trials have freely given informed consent based on a clear understanding of the trial, including the risks and benefits of trial participation. The informed consent process must be consistent with International Conference on Harmonisation Good Clinical Practice and local country guidelines. Informed consent is an ongoing process that requires periodic discussions with participants to ensure their continued understanding of the trial.

In addition, as part of the standard of care guidelines for clinical trials, participants are provided with ongoing HIV and sexually transmitted infection (STI) risk-reduction counselling, condoms, pre- and post-HIV test counselling, family planning counselling and treatment for curable STIs that are identified. Participants are also referred for support, care and treatment in the event that they become infected with HIV or require medical attention for any other condition.

How are local communities supported?

Microbicide product developers are committed to implementing clinical trials that have broad support from the communities hosting the trials. Clinical trials may provide long-lasting benefits such as the construction of new research centres, training of local staff to conduct research, educating clinical trial participants about general and women’s health issues, promoting HIV prevention messages within the community and other initiatives that seek to improve the overall health and awareness of communities. In countries where clinical trials are conducted, IPM and other microbicide developers have implemented broad-based programs of community engagement. Information about microbicides and clinical trials is offered to key stakeholders, including local women’s groups, medical professionals, the media, traditional leaders and healers, ministries of health and others. Ongoing training and support for those involved in the clinical testing process — clinical investigators, research scientists, nurses, counsellors, community health workers and project management staff — is also provided.

How will women’s access to microbicides be ensured?

Once developed and approved for use, microbicides must be made widely available and affordable. Historically, it can take decades for the benefits of scientific innovation to reach the developing world. But IPM and the broader microbicide field are committed to expediting widespread availability and access of any effective product, reaching those most in need first. Ensuring access to microbicides is a responsibility that must be shared by trial sponsors, research teams, donors, multilateral and bilateral agencies and national governments.

Conclusion

Lessons learned through years of scientific inquiry have brought the world in 2011 to a milestone in HIV/AIDS research: proof that a topical ARV-based microbicide can reduce the risk of HIV infection. Microbicides will be a critical element in any comprehensive response
Memorandum by the International Partnership for Microbicides (IPM) (HAUK 75)

to HIV/AIDS — one that takes into account the unequal impact of the epidemic on women — and a much needed tool in achieving the United Nation’s Millennium Development Goals. Microbicides will not only help reduce the burden of death and disease among women — and, indirectly, among men and children — they could also support economic development and help eradicate poverty in the developing world.

March 2011
Memorandum by Mr Kevin Kelleher (HAUK 2)

Treatment
a. How can the NHS best commission and deliver HIV treatment?
b. What impact might the proposed new commissioning reforms have on HIV treatment?
c. In what setting can treatment most effectively be delivered?

Cost
a. Have cost considerations been satisfactorily balanced with public health imperatives in HIV:
   (i) prevention policy; and
   (ii) treatment policy?
b. Is research funding correctly prioritised?

Response:

Treatment and Cost:

1. I raise for the committee information that London is unique through the London Specialist Commissioning Group which manages the collected London PCT’s budget on HIV NHS services, it spent £236million in 2009/2010 of which £155million is spent on antiretroviral treatment, £15m on non antiretroviral medication and on high costs diagnostics, £59m was spent on infrastructure and £6m on inpatient care. The estimated budget for 2010/11 is £241million.

2. The LSCG budgeted estimated was £246m (2009/2010) for London and a £9m surplus was returned. In a year where hospitals started to refer people living with HIV to their local GP’s for medication, given this surplus and eventually of payment of medication through the PCT’s why then was this option introduced? Keeping this consolidated arrangement should help to reduce such as duplicating administration, recharging of invoices etc.

3. The cost of treatment and services provided for London as it is managed by the LSCG through the collected PCT budgets suggests that medication and services (provided through the AIDS support grant) is about £8,793.00 per person, per year (2009/2010). This figure consists
of £236million / 28,285 people = £8,343 + £450.00 average ASG cost = £8,793.00. As GP's get more involved this equilibrium should balance it self out, I suggest as one decreases the other will increase. Further saving through the capital investment on infrastructure, price negations and new supply contracts as better rates etc.

4. Any changes should be done through consultation and through an equality impact assessment.

5. The Health Protection Agency suggests that 28,285 people reside within London live with HIV/AIDS a further 2,891 access services within London that resides out of London. The HPA estimates a further 20-25% are infected with HIV but unknown.

6. We ran a survey asking the question “Would you support a Pan London approach, like that of the London Specialist Commission Group collecting together the AIDS Support Grant and additional funding from each London authority to manage as one collective fund to provide HIV social care and support? Of the 65 responses 81% were in favour (19% said No) and (2 didn’t comment. Comments left said:

I. This is better approach than local authority commissioning as they consistently fail to acknowledge that people are more likely to use HIV/Sexual Health services outside of their borough/PCT area due to stigma etc.

As long as learning’s from failings in previous similar Commissioning groups can be avoided from the outset, a Specialist Commission should work well.

II. Comments (2) other

III. Big PAN-arrangements become unwieldy and very bureaucratic.

IV. I can’t answer some questions as I have no background information so don’t know what the Pan London AIDS Support Grant is or the London Specialist Commission Group? http://benefits.tcell.org.uk/forums-keywords/benefits/social-care-rights-responsibilities-entitlements/aids-support-grant-asg and http://www.londonspecialisedcommissioning.nhs.uk/about_us

V. A Pan London approach to social care for HIV positive people is a good idea in theory. However, in my experience there is always too much bitching and back biting between commissioners, PCT’s NHS Services and Voluntary Sector agencies, they are all notoriously bad at working collaboratively. As a result services end up fragmented and ad hoc. So yes a Pan London approach would be good but I do not think the organisations who would potentially be involved are professional enough to view the bigger picture of putting the needs of HIV positive people first.
VI. At last it seems that the views of people with HIV are being listened to. The hit and miss provision currently available is unfair and unjust - I live in Haringey where the incompetent council may talk the talk but simply do not have a clue, for example! I don't know who the LSCG are, but I hope to god they have nothing to do with THT - the 'charity' uniquely responsible for the gobbling up of holistically focused charities that actually did something for people with hiv, and their replacement with the current void in services. THT’s only fig leaf of respectability has been the notion that they are a 'campaigning' charity, yet the fact that the tragic yet curiously farce-like situation with patchy services has been allowed to develop unchallenged by them - and actually with their tacit approval (e.g. the withdrawal of alternative treatments at London Lighthouse for anyone who happened not to have a home in a particular location - although, funnily enough, my hiv virus didn't show a similar preference as to eligible postcodes!!!) is more than sufficient evidence that no one with any association to THT should have anything to do with the AIDS support grant - or anything else connected with hiv for that matter!

VII. Let specialist centres of excellence treat patients such as 56 Dean Street.

VIII. I'm just an ordinary HIV+ Joe who visits my clinic four times a year and takes my pills every night. I haven’t a clue what this survey is about or trying to achieve. What's the London Specialist Group? I've no idea. What does 'a Pan London approach' mean? What is a 'Pan London AIDS support Grant'? When you refer to 'each London authority' are you talking about borough councils or primary care trusts or what? This is a survey devised by people who work in the HIV industry and to which I cannot relate. And one other thing. What are these references to AIDS all about? As far as I'm aware, AIDS is something which affects very few people in London (maybe I'm wrong) and is almost obsolescent. I did have AIDS as defined by having an AIDS-related illness when I was first diagnosed with a low CD4 count, but I don’t have AIDS now and I find the term has very negative connotations. Please stick to HIV. I was told this was a survey 'for those living with or affected by HIV' - not AIDS.

IX. From my point of view the service is running quite well now. There are pitfalls but overall it is a good service. I think it would be better concentrating on improving what we have rather than making yet another change.

X. I am resident in South London and feel that the way the South London HIV Partnership is modelled is brilliant in particular the Hub & Spoke Peer support work stream which has brought on board providers that are actually in direct contact with people on the ground particularly those that are clearly not offered any support by the larger charities. This has resulted in a tremendous improvement in skills, self-esteem and confidence amongst service users. I doubt very much that a Pan-London approach would manage to achieve this and there is a risk that service delivery would be affected by admin costs. Perhaps North, East and West London (if they have not already) should adopt the SLHP model for PLWH in those areas. [http://benefits.tcell.org.uk/forums/south-london-hiv-partnership-funding-and-target-foi-request](http://benefits.tcell.org.uk/forums/south-london-hiv-partnership-funding-and-target-foi-request)

XI. Pan London makes most sense and would reintroduce the notion of moving away from health by post code.
XII. I am flexible about who administers the grant, if it goes ahead as a Pan London thing, but whoever it is, it should not be a collection of transient and ill informed commissioners who never stay in post for more than a year and whose ability to deliver progressive services is hamstrung by their lack of experience, either in commissioning per se, HIV services or the London community. This is what has happened in the commissioning of Pan London HIV prevention work, which has made it very hard for those delivering the work to build on successes and learn from mistakes.

XIII. There has been no accountability for how this money has been spent in the past by local authorities. Street lighting? Mending potholes? Certainly hard to see how it has been spent on providing social care for people with HIV. http://benefits.tcell.org.uk/forums-keywords/benefits/social-care-rights-responsibilities-entitlements/aids-support-grant-asg

XIV. Local authorities have not been held accountable for their spend of the ASG to date. This should change in the first instance before it is agreed to farm it out as a Pan London Fund. Local Authorities should report on their spend, activity and outcomes in the area of HIV Social Care and Support. My concern about it becoming Pan London relates to local equity and the lack of evaluation to date on existing Pan London HIV specific programmes. http://benefits.tcell.org.uk/forums-keywords/benefits/social-care-rights-responsibilities-entitlements/aids-support-grant-asg

XV. I would prefer any approach that preserved the administration of ASG money for HIV/AIDS use only.

XVI. A partnership approach needs to be fostered between the PCT's and User Lead Organisations. Any other way seems to create more bureaucracy.....

XVII. A Pan-London approach would be fairer than allowing individual authorities to make decisions and allow for the targeting of resources where needed.

XVIII. None (2)

XIX. Pan London Consortium has its preferences that are incompatible with people's needs. Each local authority knows the needs of their residents better than the Pan London Consortium. http://benefits.tcell.org.uk/forums/foi-request-london-specialised-commission-hiv-budget-200910-201011-and-201112-known

XX. You need to survey patients in HIV Clinics & GP centres.
7. We analysed the AIDS Support Grant for London (2009/2010), from the responses received, we found that 54% contributed more than the ASG allowance, 12% underspent, 24% just spent the ASG allowance and 10% unanswered (refer spread sheet page 7-9 and graph on page 10). The analysis found just 3% of the ASG budget was used for direct payment, current South London is the only area to consolidate via the South London HIV Partnership. An average spend/cost per person was £450.00 a 42% increase through local contributions and funding locally.

8. I understand that HM Government has made a commitment to keep HIV commissioning as it stands. http://www.theyworkforyou.com/wrans/?id=2011-01-17c.33177.h&s=hiv

10. An analysis of the trading accounts for various HIV/AIDS/LGBT organisations found:

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£ 31,947,383.00  £ -30,988,082.00  £ 959,301.00
Memorandum by Mr Kevin Kelleher (HAUK 2)

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<th>Voluntary Costs</th>
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<tr>
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<td>14.01%</td>
<td>45.67%</td>
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<td>7.38%</td>
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<td>52.50%</td>
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</tbody>
</table>

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Memorandum by Mr Kevin Kelleher (HAUK 2)

February 2011

[Pie chart showing percentage distribution]
Supplementary memorandum by Kevin Kelleher (HAUK 39)

Analysis of DLA, AA, ILF, Direct Payments and Carers

Disability Living Allowance - Cases in payment (5% sample) Caseload (Thousands) : Main Disabling Condition by Gender
Time Series=MAY10

<table>
<thead>
<tr>
<th>Main Disabling Condition</th>
<th>Total</th>
<th>Gender</th>
<th></th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Caseload (Thousands)</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
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<tr>
<td>Total</td>
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<td>1,559.6</td>
<td>1,564.0</td>
<td>1,559.6</td>
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<td>Arthritis</td>
<td>579.2</td>
<td>206.2</td>
<td>373.0</td>
<td>206.2</td>
<td>373.0</td>
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<td>33.4</td>
<td>35.7</td>
<td>33.4</td>
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<tr>
<td>Stroke Related</td>
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<td>61.2</td>
<td>48.9</td>
<td>61.2</td>
<td>48.9</td>
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<td>125.8</td>
<td>230.6</td>
<td>125.8</td>
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<td>266.6</td>
<td>242.9</td>
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<td>38.0</td>
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<td>38.0</td>
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<td>20.3</td>
<td>20.7</td>
<td>20.3</td>
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<td>Malignant Disease</td>
<td>81.5</td>
<td>36.0</td>
<td>45.5</td>
<td>36.0</td>
<td>45.5</td>
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<td>Chest Disease</td>
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<td>44.3</td>
<td>48.6</td>
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</table>

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## Supplementary memorandum by Kevin Kelleher (HAUK 39)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Male (Thousands)</th>
<th>Female (Thousands)</th>
<th>Caseload (Thousands)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Back Ailments</strong></td>
<td>244.6</td>
<td>115.9</td>
<td>128.7</td>
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<tr>
<td><strong>Heart Disease</strong></td>
<td>138.6</td>
<td>84.8</td>
<td>53.8</td>
</tr>
<tr>
<td><strong>Parkinson’s Disease</strong></td>
<td>18.5</td>
<td>10.7</td>
<td>7.8</td>
</tr>
<tr>
<td><strong>Diabetes Mellitus</strong></td>
<td>59.6</td>
<td>31.3</td>
<td>28.3</td>
</tr>
<tr>
<td><strong>Renal Disorders</strong></td>
<td>15.3</td>
<td>7.7</td>
<td>7.6</td>
</tr>
<tr>
<td><strong>AIDS</strong></td>
<td>8.5</td>
<td>6.8</td>
<td>1.7</td>
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<td><strong>Skin Disease</strong></td>
<td>16.2</td>
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<td>8.4</td>
</tr>
<tr>
<td><strong>Frailty</strong></td>
<td>2.9</td>
<td>1.4</td>
<td>1.5</td>
</tr>
<tr>
<td><strong>Multiple Sclerosis</strong></td>
<td>68.0</td>
<td>20.2</td>
<td>47.9</td>
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<tr>
<td><strong>Other</strong></td>
<td>426.0</td>
<td>233.8</td>
<td>192.2</td>
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### CAUTION

The best statistics on benefits are now derived from 100% data sources. However, the 5% sample data still provide some detail not yet available from the 100% data sources. DWP recommends that, where the detail is only available on the 5% sample data, the proportions derived should be applied to the overall 100% total for the benefit. Users should refer to the "Guidance for Users" in the Useful Resources section of this Tabling Tool.

### Definitions and conventions

- "-" Nil or Negligible; "." Not applicable; "." Figures are subject to a high degree of sampling error and should only be used as a guide; Caseload figures are rounded to the nearest hundred and displayed in thousands; Average amounts are shown as pounds per week and rounded to the nearest penny. Totals may not sum due to rounding.

### Source

Department for Work and Pensions, Information Directorate, 5% sample.

### State Pension Age

The age at which women reach State Pension age will gradually increase from 60 to 65 between April 2010 and April 2020. This will introduce a small increase to the number of working age benefit recipients and a small reduction to the number of pension age recipients. Figures from May 2010 onwards reflect this change. For more information see [http://statistics.dwp.gov.uk/asd/espa.pdf](http://statistics.dwp.gov.uk/asd/espa.pdf)

### Notes

- **Caseload (Thousands)**: Totals show the number of people in receipt of an allowance, and excludes people with entitlement where the payment has been suspended, for example if they are in hospital.
- **Main Disabling Condition**: Where more than one disability is present only the main disabling condition is recorded. "Other" includes 25 medical conditions, including "Obesity" from February 2010 (for claims to benefit from October 2008 onwards). Previously, "Obesity" was included within "Mental Health Causes".
No, of People supported by The Independent Living Fund by Main Disabling Condition

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<th>Disability description</th>
<th>number of users</th>
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<td>Severe learning disability</td>
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<tr>
<td>Cerebral Palsy</td>
<td>3130</td>
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<tr>
<td>Multiple Sclerosis</td>
<td>2224</td>
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<tr>
<td>Other</td>
<td>1604</td>
</tr>
<tr>
<td>Down's syndrome</td>
<td>1199</td>
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<tr>
<td>Spinal injury</td>
<td>1183</td>
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<tr>
<td>Brain damage (inc head injury)</td>
<td>902</td>
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<tr>
<td>Learning disability</td>
<td>667</td>
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<tr>
<td>Cerebro-vascular (inc stroke)</td>
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<tr>
<td>Arthritis (osteo-rheumatoid-still's dis)</td>
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<tr>
<td>Muscular Dystrophy or Atrophy</td>
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<tr>
<td>Epilepsy</td>
<td>423</td>
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<tr>
<td>Spina bifida</td>
<td>351</td>
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<tr>
<td>Autism</td>
<td>171</td>
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<tr>
<td>Friedreich's ataxia</td>
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<tr>
<td>Mental illness</td>
<td>108</td>
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<td>Learning disability with autism</td>
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<td>Polio damage</td>
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<td>Huntington's Disease</td>
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<tr>
<td>Aids related disease</td>
<td>86</td>
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<tr>
<td>Parkinson's disease</td>
<td>85</td>
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<tr>
<td>Dementia (inc Alzheimer's)</td>
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</tr>
<tr>
<td>Cardio-vascular(inc heart disease)</td>
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<tr>
<td>Cancers-tumours</td>
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<td>Hydrocephalus</td>
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<td>Osteoporosis</td>
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</table>
### Supplementary memorandum by Kevin Kelleher (HAUK 39)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Count</th>
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<tr>
<td>Physical malformation limbs-Thalidomide</td>
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<td>Quadriplegic</td>
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<td>ME</td>
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<tr>
<td>Diabetes</td>
<td>7</td>
</tr>
<tr>
<td>Blood disease (inc leukaemia)</td>
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<tr>
<td>Visual impairment</td>
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<tr>
<td>ADHD</td>
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<td>Lupus</td>
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### Attendance Allowance - all entitled cases Caseload (Thousands) : Main Disabling Condition by Gender of claimant

**Time Series=MAY10**

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<th>Male</th>
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<td>Caseload (Thousands)</td>
<td>Caseload (Thousands)</td>
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<tr>
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**Definitions and Conventions:** "-" Nil or Negligible; "." Not applicable; Caseload figures are rounded to the nearest ten. Some additional disclosure control has also been applied. Average amounts are shown as pounds per week and rounded to the nearest penny. Totals may not sum due to rounding.

**Source:** DWP Information Directorate: Work and Pensions Longitudinal Study.

**State Pension Age:** The age at which women reach State Pension age will gradually increase from 60 to 65 between April 2010 and April 2020. This will introduce a small increase to the number of working age benefit recipients and a small reduction to the number of pension age recipients. Figures from May 2010 onwards reflect this change. For more information see [http://statistics.dwp.gov.uk/asd/espa.pdf](http://statistics.dwp.gov.uk/asd/espa.pdf)

**Notes:**
- **Caseload (Thousands)**: Totals show both the number of people in receipt of an allowance and those with entitlement where the payment has been suspended, for example if they are in hospital.
- **Main Disabling Condition**: Where more than one disability is present only the main disabling condition is recorded. "Other" includes 25 medical conditions, including "Obesity" from February 2010 (for claims to benefit from October 2008 onwards). Previously, "Obesity" was included within "Mental Health Causes"
### Supplementary memorandum by Kevin Kelleher (HAUK 39)

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| | 37.64% | 10.49% | 7.38% | 21.23% | 1.57% | 19.86% | 0.92% | 0.09% | 0.82% | 100.00% |

Denotes information obtained from NHS statistic database

| London Councils - Direct Payments | 4495 | 2311 | 1250 | 4646 | 2494 | 1327 | 182 | 21193 |
| London Councils - Personnel Budgets | 529 | 357 | 76 | 3962 | 169 | 2 |
| London Councils - One off’s | 2169 |
| Totals | 5024 | 2668 | 1326 | 8608 | 2494 | 1496 | 2169 | 0 | 184 | 21193 |
| Differential | -6182 | -454 | -872 | 2288 | 2028 | -4418 | 1895 | -26 | -61 | -8578 |

Wales Information not held
Northern Ireland (December 2009) 1890
http://www.dhsspsni.gov.uk/index/stats_research/stats-cib/statistics_and_research-cib-work_areas/statistics_and_research-adultworkarea/statistics_and_research_directpayments.htm

Scotland 33,000,000 | 1424 | 785 | 100 | 708 | 3017 | 10938.02 | 334 |
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### Supplementary memorandum by Kevin Kelleher (HAUK 39)

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**Abbreviations.**

- **No. - Number**: Denotes additional income from Primary Care Trust
- **DOH - Dept. of Health**: Denotes FOI response relates to how the income is spent for that financial year
- **DWP - Dept. Work Pensions**: Denotes additional through the allocation of Dept. for Schools and Families (Aim High)
- **Bold**: Denotes no response to FOI request

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### Supplementary memorandum by Kevin Kelleher (HAUK 39)

<table>
<thead>
<tr>
<th>Category</th>
<th>Total No.</th>
<th>No. of Authorities asked</th>
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**Pie Chart**

- Total No.
- No. of Authorities asked

**Graph**

- No response
- Spent over Carers Allowance
- Spent under Carers Allowance
- Spent same / close to Carers Allowance
Letter from LASS (HAUK 23)

We are pleased to be able to provide evidence to the Select Committee and would be delighted to be invited to the House of Lords to elaborate on the evidence presented here.

One of the key areas we would like to draw the Select Committee’s attention to is our local advert to promote HIV testing. It is in 15 languages and could easily be adapted and used in other areas of the country. At the cost of around £2000 to produce it is far cheaper than any national campaign and could provide the basis of nationally led but locally sourced awareness. This can be viewed on LASS website – www.lass.org.uk. It would be very beneficial to add high profile public figures to this – giving the message it is better to know one’s HIV status – this would have a significant impact on many people and communities, and encourage more people to get tested.

One general point that we want to make is that there is great benefit from using community volunteers in HIV testing, prevention and also supporting people living with or affected by HIV. However, it is important that volunteers are correctly trained, supported, managed well and kept current of developments and local needs and concerns – all of which many voluntary sector organisations do very well.

Our final general point relates to the proposed public health reforms and funding. There is already evidence that current cuts are beginning to reduce the capacity of the voluntary HIV sector to provide innovative and cost efficient solutions local in the longer term. Some HIV organisations have already closed and others have had to reduce services. At LASS we are proud of our innovative and solution focussed approach. People living with HIV in Leicester have formed their own group – LhivE supported by LASS and this group will also be making a submission. We have also established a social enterprise and worked with Leicester University to develop data base to capture outcomes achieved through care, support advice and advocacy.

A strong lead from this consultation will benefit the voluntary sector and communities greatly. Our more detailed comments and evidence follows below.

1. Monitoring

1.1. The current monitoring systems are not robust. The information available for local use is often 2 years out of date. Sophid data relies on hospital diagnosis and does not capture people diagnosed and treated by GP or tests carried out in the community. A simple on-line means to record tests, available to all providers of HIV testing including community providers, should be put in place and would be effective and efficient. It would need to include the means to track individuals and some ownership by individuals would be helpful with an explanation of how the data is used and how individuals benefit from submitting data and can help others and reduce onward transmission.

1.2. The public health reforms will have an impact on this due to the proposal to diversify the commissioning of services, which will de-centralise the monitoring and reporting. It is likely to be more challenging to record, track, corroborate and collate the data – resulting in inaccuracies.

1.3. Potential improvements could include:
Centralised and simplified reporting, with all sites which provide testing able to report.
Coordinated tracking of people who are diagnosed at community sites to ensure that they are connected into the required medical systems and support. Pre-requisites for this are strong and clearly defined pathways and training for all clinical and other support staff.

1.4. Locally our target population for HIV testing (the ‘at risk group’) is everyone who has unprotected sex. Leicester is a very diverse city with communities from many different places and cultures. We know there is high prevalence in the Sub-Saharan African and the MSM (Men who have sex with Men) communities. There are also rising HIV rates in over 50’s and in women so we don’t discriminate but we do target communities in most need of our messages. One of the things we also have to consider is that it is common to see friends and “couples” from different communities, including among young people. So people in these relationships will also be more at risk if their partner is from a high prevalence community.

2. **Prevention**

2.1. The government policy is not sufficiently focused on HIV prevention and nor is the public health white paper. The public health reforms are not strong enough in relation to raising awareness about HIV or other STIs. Talking about sexual health needs to become the norm if we are to address the public health issues of HIV transmission and reduce the numbers of newly infected people in the UK. The emphasis in the white paper on individual’s taking responsibility for their own health will need considerable investment if this is to work to include sexual health (not just obesity, smoking etc.) and we believe this work needs the support of people in communities on the ground in positions such as the health trainers. At LASS we have evidence of benefits of involving individuals who live with HIV in prevention and awareness campaigns. Since we began training of volunteers and services users in prevention, testing and awareness raising this has contributed to giving 4 former volunteers and service users the skills levels to be appointed as members of staff, however only on a part time and temporary basis until the end of March 2011, due to funding uncertainties.

2.2. Any centrally created prevention campaign needs to have a strong message, e.g. ‘Know your HIV Status’ encouraging people to get tested and know if they have HIV or not. This can be adapted for local and perhaps regional community work – so that particular groups and communities do not feel stigmatised, but focused work can be done where the prevalence is higher. We are still dealing with the stigma created by the ‘tombstone campaign of the 80s. So any national blanket coverage media campaigns need to be carefully designed and considered with consultation across the different regions.

2.3. In our experience the needle exchange scheme with drug users has been very effective in keeping HIV infection among injecting drug users low.

2.4. We have some suggestions and examples of improving prevention initiatives:

- We are currently leading the East Midlands regional partnership for NAHIP, working with the different African communities in Leicestershire, Nottinghamshire and Derbyshire and now developing work with Northamptonshire. This work uses nationally created resources but allows us to tailor our delivery and approach to the local needs.
- A key element of our prevention approach is to empower the local communities with strong HIV awareness and community testing skills, so that they can cascade this within their community. Our focus is about the benefits of knowing HIV status: if people know they will either be diagnosed (if they have HIV) or will be more motivated to maintain a negative status. The communities we work with want to develop a poster campaign with photos of people who have been tested wearing
badges saying: "I know my HIV status". Of course they don’t have to disclose to everyone what that is.

- This approach takes time and requires training, co-ordination, management and support, however much of it can be delivered by volunteers, with the correct support and training. Ideally paying local people as trainers as a step up from volunteering would enhance the concepts of the Big Society while delivering a far cheaper campaign than a blanket TV or film would.
- There needs to be consistent and factual information for all school children, young people and students about HIV etc. This is an area where we find significant gaps and discrepancies across education providers.
- Evaluation of prevention initiatives needs to be based on outcomes. The concept we have is to consider the following within our HIV and sexual health awareness and prevention:
  - Diagnosed – people living with HIV have the skills and confidence to work together to live well and prevent onward transmission.
  - Affected – culturally and age appropriate support, advice and information is available to carers, partners and family members who support an HIV positive person.
  - Undiagnosed – targeting the ‘at risk’ populations to increase access to testing and decrease the time between infection and diagnosis.
  - At risk – sexually active or close to 1st sexual encounter – to give people the skills, knowledge and confidence to take responsibility for their sexual health and risk taking.

So we focus our work within these categories as necessary. We deliver community HIV testing as well as signposting people on to other services for this – e.g. GU medicine and other sexual health clinics. It would be helpful to be able to evaluate the true outcomes of our work and to know whether people access testing at GUM because of the prevention and awareness messages we deliver.

- We know from the work we do in different communities that the young people in particular are pulled between their parents culture and beliefs and what they see on TV, advertising etc. This needs to be considered in any prevention work – addressing parent’s concerns as well as the mixed messages that young people are getting.

3. **Testing**

3.1. Testing policies and indeed strategy are not robust and do not reflect the need to reduce onward transmission. There needs to be a considerable investment in testing as a community intervention that also raises awareness and knowledge about HIV. Initial HIV testing does not need to be clinical, unless the person is symptomatic.

3.2. We deliver a community based testing service, covered by trained staff and volunteers. We have delivered more than 350 tests since we started the service in June 2009, with 4 new diagnoses. The people who were newly diagnosed were immediately taken to GUM for a second test and could also access our support services together with a mentor, and to talk to someone who is HIV positive themselves, to help them through the initial stages of diagnosis. The saving to the NHS is estimated to be £250,000 per new positive diagnosis. We estimate that the cost of LASS providing a test is approximately £22, including training and supporting a team of volunteers, as well as the subsidiary costs. The testing volunteers are also able to cascade their knowledge and understanding about HIV and the benefits of testing to their communities. This approach therefore offers a double benefit. More than
60% of the tests have been for men, and approximately 50% for people from BME communities in Leicester.

4. **Treatment**
4.1. There needs to be consistency in the tariffs paid for medical support within the hospital system. In one hospital in Leicester regular follow up and treatment through the Infectious Diseases Unit clinic is funded at a different rate to the clinic in the GUM. Not all follow up needs to be in medical/hospital settings. The specialist dietician provides community clinics here in our voluntary community base and we would like to have the opportunity to house other specialist medical staff for ‘clinic style appointments and check ups’ where medical equipment is not needed. There is currently not enough innovation in the health service to make this possible.

4.2. We are already training volunteer mentors to support people living with HIV in attending their medical appointments and to support with medication management on a day to day social care basis. This could be taken much further through non-medical approaches to the routine check ups. There will always be a need for medical services for people with complications, who are newly diagnosed or who are changing their drugs. What we are making a case for is a wider range of options for routine treatment and checkups including use of non-medical premises. This could extend to other health and well being checks and support also taking place in community settings – such as cholesterol testing, blood pressure checks etc.

4.3. We have a plan for a well being centre but as yet changes in health and social care funding have not provided an opportunity to take this forward. Volunteers and community staff such as health trainers still need appropriate training, support, supervision and management so while a community based service will be significantly cheaper it will not be free.

4.4. We are concerned that the proposed commissioning arrangements that will split health funding through GPs, national funding and local public health will make the commissioning of treatment far more complex for voluntary organisations. We will potentially be applying for funds from a wide range of sources, – although we recognise this does also give an opportunity to standardise hospital treatment payments across the country. We are also concerned that many GPs do not have any knowledge or experience with HIV, so will not know or understand that an HIV positive person may need more than just clinical support for their HIV and may have other related issues (e.g. mental health needs). In our experience many GPs do not know about many voluntary sector services and support (including mental health) so are unlikely to consider them in their commissioning of services.

5. **Cost**
5.1. More emphasis and money needs to be allocated to coordinated local and targeted prevention and awareness projects to really address the problems of onward transmission and to de-stigmatising HIV. There is also a need for more research into the effects of prevention strategies and longer term research on the role of HIV community testing as an approach to prevention and awareness raising. More work is needed in schools and colleges and we could learn some lessons on youth peer education from Africa and replicate the successful ones here. Often due to British cultural taboos around sex and relationships we fail to build on lessons from other countries.
6. **Stigma**

6.1. Stigma is still a very significant factor in HIV diagnosis and disclosure and this impacts on onward transmission and failure to present for an HIV test. Individuals within the medical professions are also known to stereotype and stigmatise further by not recognising HIV and not referring people for tests.

6.2. We generally need to educate the population to include sexual health as part of their health lifestyles and this will need a considerable change in attitudes and a new focus for public health.

6.3. The historic tombstone campaign has contributed to fear and stigma within communities as already mentioned. It also created complacency in some groups and communities as they consider themselves ‘not at risk’ due to the stereotyping within the campaign.

6.4. People living with HIV are in a very difficult situation regarding their own disclosure and while some of this may be self stigma some of it is created by these messages – e.g. see press on teacher who won employment tribunal for being unfairly dismissed for being HIV+.

Stigma about HIV also results in people presenting late for tests – when they are already quite ill – which has a significant cost implication for their care and support, and also in denial – which can mean that people don’t take their medication as necessary – again with the potential for a high cost to the health service. This is why the root of prevention needs to be the concept of everyone knowing their HIV status and taking responsibility for their own sexual health and well-being.

We trust the above information is of use and would be happy to answer any further questions.

16 February 2011
Memorandum by London Specialised Commissioning Group (HAUK 51)

Introduction

1. The London Specialised Commissioning Group (SCG) collaboratively commissions a range of specialised and other services on behalf of the 31 PCTs in London. In respect of HIV care and treatment, we commission for around 30,000 Londoners cared for in the capital. The SCG also hosts the London Sexual Health Programme which works to strengthen sexual health commissioning across London. The Programme, together with the Health Protection Agency (HPA) has pioneered the ‘Late Diagnoses Toolkit’ to assist London PCTs meet the aim of reducing late HIV diagnosis. This is an outcome measure proposed in the National Public Health Outcomes Framework.

2. The London SCG works closely with national bodies such as the HPA, British HIV Association (BHIVA), British Association for Sexual health and HIV (BASHH), the Halve It Campaign and has a strong Patient and Public Engagement work stream. In preparing this submission we have worked with a wide range of expert bodies. This submission focuses on our experience as a commissioning organisation with public health expertise, responsible for leading and supporting work around improving outcomes for patients and reducing onward transmission of HIV.

3. Given the effectiveness of therapy, most patients - if diagnosed early - are thought to have a near normal life expectancy. As patient populations are ageing, this also means that care needs beyond long term effective viral suppression are likely to change with increased incidence and prevalence of common chronic conditions such as diabetes, coronary heart disease and chronic kidney disease. Particular attention needs to be given to the development of treatment and care structures that can meet the holistic needs of HIV infected individuals.

4. The UK HIV epidemiology shows a distinct epidemiological pattern with high prevalence of infection in urban centres. London accounts for just under half of the England burden of HIV. This unequal distribution needs to be considered in the review of evidence and future prevention, testing and treatment strategies.

Monitoring

a. How robust is the current system?

5. From a public health and epidemiological perspective, the HPA’s Centre for Infection is the main focus for the collection and analysis of epidemiological information regarding people with HIV in the UK. The systems are internationally renowned for their completeness, particularly in relation to clinical outcomes for patients. Important clinical information is also captured in a number of cohort and research studies such as the UK Collaborative HIV Cohort Study (CHIC), the HIV Resistance Database, the Collaborative HIV in Children Study (CHIPS) and National Study of HIV in Pregnancy and Childhood (NSHPC). Links have been made across these studies to streamline data collection where possible and maximise the analysis opportunities of these rich data sources.

6. The London SCG works in partnership with the HPA and researchers carrying out cohort studies to utilise epidemiological and outcomes data for commissioning and demonstrating improvements in clinical outcomes. These data sources are the only way to effectively overcome some of the data barriers that exist in relation to HIV commissioning.
7. Care is commissioned on a 'year of care' basis in London and SOPHID data is used to confirm patient numbers in the absence of NHS number. The HPA is the only organisation with permission to collect all patient identifiers and consequently they are able to produce an HIV care census, ensuring 'one patient, one record' across all providers. Data relating to pregnancy and paediatric cases is reported through the NSHPC and CHIPs and is used in a similar way.

8. As far as we are aware, the London collaboration is the first internationally to use epidemiological (HPA) data in this way to underpin commissioning and to demonstrate the clinical outcomes achieved for patients:

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<td><strong>Outcome 1:</strong> Time interval between HIV diagnosis and date of first CD4 count at the same centre. This is used as a proxy for date of the first appointment with a clinician.</td>
<td>To ensure patients newly diagnosed with HIV are promptly integrated in to HIV care.</td>
<td>100% of newly diagnosed patients receive a CD4 cell count within 28 days</td>
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<td><strong>Outcome 2:</strong> Viral load &lt;50 and still on therapy 1 year after therapy first started.</td>
<td>To monitor the effectiveness of ART after one year treatment.</td>
<td>85% of patients who started treatment have a viral load &lt;50 copies.</td>
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<td><strong>Outcome 3:</strong> Patients to have CD4 ≥200 after 1 year or more at centre.</td>
<td>To monitor immune status of patients after one year or more of HIV clinical care.</td>
<td>90% of patients in care should have a CD4 ≥200</td>
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<td><strong>Outcome 4:</strong> Proportion of patients still alive by 1, 2, 3 years from HIV diagnosis, stratified by CD4 count at diagnosis.</td>
<td>To identify early death among patients recently diagnosed and receiving HIV care.</td>
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b. Will the proposed public health reforms impact on this system?

9. The potential impact is difficult to quantify at this stage but it is important that robust HIV surveillance systems are maintained to ensure that outcomes for patients continue to be monitored and to support effective commissioning. The proposed changes could provide an opportunity to further enhance the excellent work that the HPA do, in particular supporting local and regional prevention and service commissioning with enhanced epidemiological profiles for high prevalence areas.

c. Could anything be done to improve reporting?

10. Further coordination and analysis of existing HIV epidemiological data systems could improve reporting on the outcomes for people with HIV. Further development of the partnerships between epidemiologists, researchers, clinicians, patients and commissioners has the potential to harness academic data for greater clinical and patient benefit.

11. At present, reporting to the HPA is voluntary. Making HIV surveillance reporting contractually mandatory with set deadlines, would help further improve the quality and completeness of the national HIV dataset. Furthermore, this could also improve the timeliness of SOPHID analysis which is inevitably delayed until all providers have submitted complete data before analysis can
begin. Given the dependence on SOPHID to drive payment for care and treatment, it in the interests of both care providers and commissioners for more timely SOPHID data publication.

12. Improving timeliness of SOPHID data would also require improvements in analysis and data systems. A move to Electronic Patient Records and potentially to a real-time electronic HIV Registry would help improve both individual clinical management of patients and epidemiological data. This may also enable future submissions from primary care or third sector organisations that play an increasing role in diagnosing HIV and providing levels of care and support to patients.

13. Improvements in monitoring the care and outcomes for people with HIV could also be secured by reconsidering the rules on pseudo-anonymisation of patient data. As a result of legislation, additional steps have been put in place to protect patient confidentiality for HIV and sexual health patients. As a result, NHS numbers are not used for these patients but a system of generating other patient identifiers has developed (Soundex coding). All patients in the NHS enjoy and expect the highest levels of data protection and confidentiality and it should be considered whether an alternative system for HIV is still required. The potential consequences of having a different and limited system of patient identifiers in HIV means that

- Patients may have HIV records which are separate from their other medical records. This may have an implication for care, particularly out of hours or in an emergency
- Patients who may be particularly unwell or whose care may not be adequate can not be identified through case management approaches used in other long term conditions. It is not currently possible to identify patients with multiple admissions across providers in order to assess and respond appropriately to care needs to help keep people well.
- Additional administration is incurred for commissioners, researchers and epidemiologists in matching data across complex systems and making assumptions about activity levels
- Invoicing and payment is complicated by the inability of commissioners to validate patient level activity with an NHS number

14. In light of recent policy drivers (e.g. expansion of HIV testing outside GUM settings) and the changing and complex care needs of the population, there are currently very limited HIV testing-related and health information systems outside the HPA, in particular in primary care and community settings where the majority of patient contact with health services occurs. Activity information on the expansion of HIV testing monitoring into non-specialist health service settings will be crucial to monitor progress with the expansion of HIV testing. There is currently little HIV related NHS information to support local planning and commissioning of high quality, sustainable HIV long-term condition service models integrated in existing health services.

d. What groups in particular are at risk from HIV

15. HIV in the UK is predominantly an issue for two major groups: men who have sex with men (MSM) and Black-Africans. So far there is little evidence of significant heterosexual UK acquisition/transmissions at population level, however there may be some degree of underestimation in high prevalence areas.

Prevention

a. Is Government policy sufficiently focused on HIV prevention?

16. Effective treatment has transformed HIV from a fatal disease to a long-term chronic illness. If diagnosed early, it is expected that most patients can expect a near normal life expectancy, however it is estimated that the prevention of one new HIV infection would save the public purse between £280,000 and £360,000 in direct lifetime healthcare costs.
17. HIV prevention in the UK over the past decade has been largely led by community organisations, with a focus on behavioural prevention interventions. Interventions have been commissioned nationally by the DH or regionally by local health authorities and PCTs. The commissioning model has tended to focus on outputs rather than outcomes and has been variable across geographical areas. There has been insufficient work to evaluate the impact of such programmes and we would suggest that current programmes – particularly those funded by the DH - need to be reviewed and reformed in light of emerging evidence.

b. Have the right groups been targeted in recent prevention campaigns?

18. It is right to target prevention campaigns at MSM and Black Africans, but it is also important to note that many individuals who fall into these broad epidemiological categories are also members of the wider public, who do not often self-identify as such e.g. outwardly heterosexual men who meet other men for sex via the internet. These individuals are unlikely to encounter the safer sex and HIV prevention messages intended for them as members of an “at risk” group. Consequently, it is arguable that a population-wide HIV education would be helpful, complemented by targeted interventions for specific at-risk groups.

19. In addition, the inclusion of teaching about HIV and same sex relationships within Sex and Relationships Education in schools would do much to ensure that every citizen has a strong, basic awareness of HIV transmission, safer sex and risk minimisation.

c. To what extent have prevention initiatives targeted at injecting drug users been successful?

20. Needle exchange schemes have been successful in reducing transmission of HIV. However, more work needs to be done to provide sexual health promotion to injecting drug users. In particular, work needs to be prioritised for on-street sex workers who are known to have a higher level of STIs including HIV and often drug dependencies than off-street sex workers.

d. How could prevention initiatives be better delivered and evaluated?

21. The delivery of HIV prevention should be a priority at both a local and national level. Currently HIV prevention and HIV treatment and care services are commissioned separately. This separation leads to lack of clarity as to where the responsibility lies in driving some prevention programmes at a time of financial constraint. It is unclear how the government’s proposed reforms will impact on HIV prevention, although it appears that funding for sexual health services and HIV/STI prevention will be commissioned through local authorities, whilst HIV treatment and testing will be commissioned through the NHS Commissioning Board. The Public Health White Paper proposals could perpetuate a split in the prevention-testing-treatment-care pathway.

Testing

a. Are current testing policies adequate across the country?
b. What can be done to increase take-up rates?

22. Please refer to the submission of the ‘Halve It’ Coalition
Treatment

a. How can the NHS best commission and deliver HIV treatment?
23. The London experience supports the commissioning of HIV care and treatment at scale. These benefits could be improved further by a national approach led by Public Health England and NHS Commissioning Board.

24. Pan-London commissioning of HIV care and treatment services has been based on a collaborative approach and has resulted in significant benefits and successes for all partners. For patients, a pan London approach has safeguarded open access, confidential services. SCG level commissioning has delivered more equitable access for patients to high quality care and treatment as a result of a common service specification and pan London procurement of antiretroviral therapy. A pan London approach has reduced variation in prescribing practice and allows for comparison of clinical outcomes.

25. For clinicians, a pan London approach to HIV commissioning has supported clinical engagement in planning and monitoring processes. Clinicians have been able to influence HIV commissioning at all levels, including recent developments in clinically-led therapeutic tendering for drugs. This will continue to be important as clinicians ensure commissioning attention is focused on the emerging clinical needs of patients. The collaborative approach has supported peer review and benchmarking which has stimulated improvement and innovation. The London HIV Consortium has led the way internationally on the measurement and performance of key HIV clinical outcomes, and this was reported in December 2010 by the HPA.

26. For commissioners (and arguably tax-payers), a pan London approach has secured considerable efficiencies and economies of scale. Pan London procurement of ARVs, benchmarking of prescribing trends and home delivery performance of drugs has helped maximise efficiencies in the care and treatment budget for the last few years. Commissioning, contracting and performance management is undertaken once by a central team, rather than by every PCT or sector, creating economies of scale and securing the same high standard of care beyond PCT or sector boundaries. Given the limited opportunity for demand management in HIV and open access to services, the financial risk sharing assists PCTs in financial management and planning.

27. Contracting transaction costs could be further reduced through national commissioning of HIV care and treatment. Single contracts with providers of HIV care treatment that covered all their patients, irrespective of residence could reduce the work involved for providers in recovering appropriate income for care provided. Single service specifications, outcome measures and CQUINs could also ensure equitable quality across an open access service.

28. Further clarification on entitlement to HIV care and treatment (not just testing) for those not ordinarily resident in the UK would also be welcomed.

b. What impact might the proposed new commissioning reforms have on HIV treatment?
29. Services are best commissioned in line with agreed clinical standards and with both clinical and user engagement. The London SCG’s work around HIV and sexual health commissioning has secured high levels on engagement and this helps ensure that the QIPP agendas can be delivered in an effective way.

30. The proposal for Public Health England and the NHS Commissioning Board to take a leadership role in HIV care and treatment is to be welcomed. This will ensure that reducing HIV
transmission, improving outcomes for patients and reducing HIV prejudice and stigma will remain a priority even in areas of low prevalence where HIV risks being marginalised as a public health issue.

31. A national framework for HIV (including prevention, medical care and treatment and other services) would help build on the positive outcomes of regional commissioning arrangements in respect of quality, equity of access, economies of scale and streamlined commissioning processes. In such a system, managing the interface with local arrangements will remain important for local accountability. The HIV care pathway includes prevention, social care and voluntary sector support services which at present are commissioned at a local level to respond to local needs. There is an opportunity to look at the interfaces between the national arrangements to maximise the impact of limited resources and responsiveness to local need whilst avoiding duplication and fragmentation of pathways.

32. For example, in London, commissioning of HIV prevention activity has been separate from care and treatment commissioning. It has included pan-London programmes as well as local programmes across 31 PCTs. Experience shows that this approach may not optimise the opportunity to link prevention to care and treatment interventions, to maximise purchasing power by pooling a number of relatively small budgets and by reducing transaction costs by commissioning once. The proposed reforms provide an opportunity to assess the benefits of a Public Health England led prevention strategy.

33. Finally, Specialised Services have been committed to a process of designating services against agreed clinical, patient, service and cost criteria and this process should continue in order to effectively plan for safe and sustainable specialist services.

34. In what setting can treatment most effectively be delivered?

35. Engagement of GPs is required to reduce undiagnosed HIV and to support the co-management needs of an ageing cohort of HIV patients with other common chronic conditions. Work currently led by BHIVA to develop the role of primary care in HIV care is to be welcomed as this will ensure that HIV patients receive the best possible care for non HIV related health needs. This development will require support to primary care to develop their skills and capacity in caring for HIV patients. Work will also need to be undertaken to help reassure patients of the role of primary care in meeting their needs. Consideration should be given to provision of free prescriptions for people with HIV. HIV is a long term condition without cure and patient surveys suggest that HIV patients experience economic and social deprivation, as well as prejudice and stigma. Both HIV and its treatment have consequences for patients in relation to additional co-morbidities and drug-to-drug interactions. Giving HIV patients access to free prescriptions could help overcome major barriers to primary care engagement.
Cost

a. Have cost considerations been satisfactorily balanced with public health imperatives

36. Increasing incidence and prevalence of HIV is a major financial risk for the NHS, with the costs of providing HIV treatment and care to an increasing cohort of HIV patients is c. £250 million annually across London. This will continue to rise, especially in high prevalence areas in the UK. Late diagnosis is an additional concern where the associated costs are up to 15 times the costs of an earlier diagnosis, and there is a high rate of death within the first year of treatment. Whilst in the long term, reduced late diagnosis benefits individuals and is likely to be cost saving, in the short term HIV costs and treatment will increase as these individuals will immediately start therapy, which accounts for around 60 - 70% of total outpatient care and treatment costs.

b. Prevention policy

37. There is a need for review of the prevention policies in light of the current context. The additional and unseen costs that exist alongside HIV treatment are the care costs for long term co-morbidities (e.g. cancer, lymphoma, and disability following opportunistic disease), social care, time off work and the cost of benefits that are not included in standard ‘treatment and care’ costings. Prompt diagnosis and effective treatment can reduce (almost halt) onward transmission. Testing guidelines to reduce undiagnosed HIV and prevent onward transmission (and therefore reduce cost) should form part of any future HIV prevention strategy. If all patients diagnosed HIV positive in 2008 had been diagnosed earlier and prevented from transmitting HIV to one additional person (through effective treatment) then the annual saving would be in excess of £50 million.

c. Is research funding correctly prioritised?

38. There is a relative paucity of practical prevention intervention research in the UK. Much of the current prevention research evidence stems from a North American context, or predates the ART experience (ECDC 2009, HDA 2006, NICE 2006). The quality and accuracy of UK prevention interventions must be improved in line with the increasing evidence there is a clear need to review research priorities with a view to evidence based synergistic (behavioural and biomedical) prevention interventions.

Stigma

39. Please refer to the evidence submission of the National AIDS Trust (NAT)

18 February 2011
3. The Committee has received evidence that the balance of spending between prevention and treatment is disproportionate. Do you agree with this assessment?
   a. Is it the case that resources must be balanced between the two? Would more spending on prevention require additional resources, or are there efficiencies within treatment spending which can be achieved to boost funding for prevention activities?

Preventing HIV infection rather than treating it is to be preferred and investment should support this ambition. However, to assess the balance of spend between HIV prevention and HIV treatment requires clarity about what is meant by and included in both ‘prevention’ and ‘treatment’.

An effective HIV prevention strategy needs to involve a range of primary and secondary prevention activity. These interventions need to be aimed at different audiences, from the general public to specific at risk groups. Interventions include those aimed at:
   • helping individuals to protect themselves against contracting HIV (e.g. education campaigns, condom distribution)
   • helping HIV positive people to reduce the risk of onward transmission of HIV (e.g. behavioural interventions, effective therapy)
   • preventing development of HIV in those who have been exposed to infection (e.g. post exposure prophylaxis)
   • preventing HIV positive people from becoming unwell, developing opportunistic infections and AIDS defining illnesses (e.g. effective treatment)

Interventions such as information and education campaigns, behavioural interventions and condom schemes all play an important part in HIV prevention. However, medical interventions such as HIV testing, pre and post exposure prophylaxis, sperm washing and effective HIV treatment all make a vital contribution to HIV prevention.

For example, reducing mother to child transmission of HIV has been one of the major success stories in preventing HIV infection. The combination of universal opt-out testing, treatment in pregnancy, obstetric management and bottle feeding reduces the risk of infection from 25% to around 1%. Data collected by the National Study for HIV in Pregnancy and Childhood shows that in 2010, over 75% of pregnant HIV positive women were diagnosed before their pregnancy (compared to 35% in 2001). Consequently, 97% of women are on combination antiretroviral treatment during pregnancy (compared to 65% in 2001), and 38% of women could have a vaginal delivery (compared to 11% in 2001).

The prevention contribution of treatment cannot be underestimated. Effective treatment reduces virus to undetectable levels. In 2008, a consensus statement of HIV experts was published in the Bulletin of Swiss Medicines suggesting that in HIV infected individuals on effective treatment and without sexually transmitted infections, there is “no relevant risk of transmission”.

Effectiveness of treatment depends on a range of factors including access and adherence. HIV care services, voluntary organisations and social care all play a role in ensuring HIV infected
individuals are able to take treatment effectively and take measures to prevent onward transmission.

As HIV infections continue in the UK, it is important that work is undertaken to establish a more robust evidence base for successful interventions in HIV prevention. This would ensure the UK has a relevant evidence based prevention strategy upon which appropriate investment in programme can be based.

Funding prevention and treatment should remain a priority. Efficiencies may be possible in both HIV care and treatment. This will depend on evolving models of care which recognise HIV as a long term condition. Any changes in the way care is delivered will need to protect effectiveness of treatment, dealing with issues of drug interactions, tolerability, toxicity and adherence. The efficacy of treatment as prevention (both for the individual in terms of staying well and as a public health intervention to reduce transmission) will represent a cost pressure. To be effective, treatment needs to be strictly adhered to and will be life long. In this context, efficiencies in the treatment budget will depend on continued improvement in the cost of antiretroviral therapy to the NHS.

4. How, in your experience, has the relationship between commissioners and clinical staff operated? To what extent is commissioning practice informed by the experience of clinical staff?

Good engagement between commissioners and clinicians is essential to securing excellence for patients. In London, commissioning of care and treatment services is very much shaped by clinical and patient engagement. Extensive clinical engagement has been achieved through the London HIV Consortium arrangements. The Consortium and sub groups (Drugs and Treatment, Audit and Outcomes, Patient and Public Engagement) bring together clinicians, commissioners and patients to influence commissioning and delivery of care. Clinicians chair the sub groups of the Consortium structure and doctors, nurses and pharmacists are represented throughout these structures.

From an operational point of view, Lead Clinicians have been identified at all providers as a key point of contact for HIV contracts. Now, a lead clinician from every provider attends annual contract negotiations and monitoring meetings. Clinical engagement and leadership has been critical to recent developments in procurement of antiretroviral therapy in London as part of the QIPP process.

London is progressing a review of HIV services to ensure the model of care meets the changing needs of patients. An Expert Advisory Group (EAG) has been established with clinical representation and is chaired by a local clinician and former chair of the British HIV Association. A Clinical Working Group reports to the EAG and brings together HIV doctors and nurses to develop standards of care and advice on specifications for future service developments.

Effective commissioning and delivery depends not only on commissioners and clinical engagement but also patient engagement. Patient engagement in London is well developed with a Patient and Public Engagement Sub group of the Consortium as well as clinic level patient forums and a range of patient-led and advocacy organisations. This serves to enhance the clinical engagement processes (as the shared focus of commissioners and clinicians is on
excellence for patients) and to ensure that patient experience, concerns and preferences are at the centre of how new ways of delivering services are developed.

The London experience demonstrates how mature and effective engagement relationships can be achieved where the right conditions exist. These are

- Clinicians who understand how commissioning works
- Patient engagement at all levels
- Commissioners with expertise and experience in how HIV services work
- Investment in engagement processes

8 June 2011
Memorandum by Dr Sheena McCormack: Senior Clinical Scientist, Medical Research Council Clinical Trials Unit; Reader in Clinical Epidemiology, Imperial College; Consultant HIV/GU Physician, Chelsea & Westminster NHS Foundation Trust (HAUK 56)

Individual submission by Dr Sheena McCormack MSc FRCP

Summary

HIV/AIDS is now a chronic manageable condition, but every year the number of new cases adds to the overall burden, and this is not sustainable for the NHS or globally. The effectiveness of antiretroviral microbicides and oral prophylaxis has recently been shown to prevent HIV in randomised placebo controlled clinical trials, and Government policy must refocus to take account of these developments. An effective vaccine is much further away from implementation. More stringent evaluation and monitoring of behavioural interventions is needed to ensure they are effective in reducing the proportion presenting late in disease.

Monitoring

1.1 The current systems for monitoring new infections, and people known to be living with HIV in the UK, are robust. Their completeness depends on how successful the testing strategies are in identifying those infected, and there is room for improvement in the area of testing (see 3.3).

1.2 Data on new infections are collected through laboratory and clinic surveillance systems, including unlinked anonymous population sampling which provides a useful estimate of those unaware of their HIV positive status. Data on those living with HIV are collected annually outside London and biannually within London through SOPHID (Survey On Prevalent HIV Infections Diagnosed) and collated through the Health Protection Agency (HPA).

1.3 These systems are complemented by research funded national datasets on which more detailed analyses can be conducted, such as (1) the UK CHIC dataset which combines data from multiple HIV clinic cohorts capturing 90% of the individuals in England that are HIV positive; and (2) the UK HIV Drug Resistance Database which is the largest database in the world linking clinical data to viral genotypes that are resistant to antiretroviral drugs.

1.4 It is key that the surveillance of new infections and those living with HIV continues, as well as the research funding for UK CHIC and the UK HIV Drug Resistance Database, in order to evaluate the effectiveness of policy change at a population level. The surveillance systems might be threatened by the disbanding of the Health Protection Agency and creation of Public Health England.

1.5 The following groups are at risk from HIV in UK

- Men who have sex with men (MSM), particularly the young (<25) many of whom lack awareness about the serious nature of HIV and how it is transmitted, and possibly those in the age range of 40-50 who previously practised safe sex but have now tired of it
Memorandum by Dr Sheena McCormack: Senior Clinical Scientist, Medical Research Council Clinical Trials Unit; Reader in Clinical Epidemiology, Imperial College; Consultant HIV/GU Physician, Chelsea & Westminster NHS Foundation Trust (HAUK 56)

- Individuals whose sexual networks include people from countries with HIV prevalence >5%

1.6 Globally, the highest rates of new infections are reported in young women (15-35) in Sub-Saharan Africa (SSA).

**Prevention**

2.1 *Prevention needs to be at the forefront of Government policy*, as the number of new infections diagnosed each year, particularly those acquired in UK, remains unacceptably high. Treatment and monitoring of care are managed well in UK through the British HIV Association and British Association for Sexual Health and HIV, but the costs will continue to escalate with the increase in cases and ever improving life-span. Prevention is the only way to control this. Fortunately, *evidence is gathering for the effectiveness of biomedical interventions* in preventing HIV. It is critical that the Government refocuses policy accordingly.

2.2 Two randomised placebo controlled clinical trials reported a reduction in HIV incidence with the use of *antiretroviral drugs in HIV negative individuals* in 2010. CAPRISA 004 observed a 39% reduction (95% CI: 6-60%) in women using two doses of a vaginal gel (*microbicide*) containing 1% tenofovir applied before and after sex¹, and iPrEx reported a 44% reduction (95% CI: 15-63%) in MSM using a daily tablet of a drug (*oral PrEp*) containing a combination of tenofovir and emtricitabine². Both trials demonstrated that adherence was much lower when measured by the level of drug in the blood or genital tract, than when measured by self-reported use. This suggests that the biological efficacy is much higher than the observed effectiveness, and that *further work is required to improve adherence*. Our expectation, based on preceding work conducted by the UK Government funded Microbicides Development Programme, is that adherence to a single pre-sex dose will be in the region of 90% and stable over time³. This is considerably better than the two dose strategy for which adherence was around 70% and fell over time¹. A single dose would clearly be more cost-effective. The most critical work to inform delivery of this promising intervention is to assess the effectiveness of a single dose of 1% tenofovir vaginal gel in a placebo-controlled trial.

2.3 There is also promising evidence from an *HIV vaccine* trial using a combination of two products, which led to a reduction in HIV of 31% (95% CI: 1-51%)⁴. Although this barely excludes chance as the explanation, the protection was consistent over time, and maximum during the first 12 months when the immune responses were stronger. This is encouraging, and we can anticipate that at least one further efficacy trial will follow. The US NIH funded HIV vaccine trials network is working closely with industry, and is in the strongest position to launch such a trial in the next 5 years. It will be important to prepare for confirmation of protection with this strategy, by optimising the delivery and accelerating the schedule for combination products. This is the focus of the research in UK in collaboration with our European and African colleagues.

2.4 The third biomedical initiative to reduce the burden of HIV, is to *scale up testing and offer immediate treatment* to all those found to be positive, regardless of the individual need. The theory is that treatment will control viral replication, thereby reducing the risk of onward transmission. This is attractive as the HIV positive pool is smaller than the ‘at risk’
pool and has a biological marker to ease identification. Research is underway to evaluate the feasibility of this approach in several countries in SSA.

2.5 The work to scale up testing and improve the strategies should continue, but it is important to identify realistic outcome measures. The ultimate outcomes are to decrease the number of new infections and the fraction presenting late. These are relevant for national campaigns. It is more challenging to identify appropriate outcomes that could substitute for these to assess local and regional campaigns, or to optimise interventions in pilot studies.

2.6 Development and delivery of new initiatives, both behavioural and biomedical, should involve the target communities. This could be done using participatory methodology. Integrating qualitative methods (Focus Group Discussions, In depth interviews, formative ethnographic research etc) in the assessment assists the development process; the evaluation and feedback to maintain the quality of the intervention; and the interpretation of quantitative outcomes. Therefore a multi-disciplinary approach to the implementation of new initiatives is recommended.

2.7 It is clear from epidemiological studies that changes in sexual behaviour played an important role in controlling the epidemic. However, effectiveness in terms of a reduction in HIV incidence (new cases) has rarely been demonstrated in controlled trials of behavioural interventions. There is no common explanation for this, but the results reported emphasise the value of using biomedical outcomes in combination with qualitative data in the evaluation of behavioural interventions, due to the unreliability and bias in self-reported sexual behaviour.

Testing

3.1 Opt-out testing policies are working well in Ante-natal (95% agree) and moderately well in Sexual health clinics (77% agree). There has been some success with outreach services targeting communities that were not previously accessing testing services, and the proportion of MSM that have never tested is small (5-10%). However, in 2009 half the adults diagnosed with HIV presented late enough in the course of their infection to meet the criteria for treatment within 3 months of diagnosis, so current testing policies are not adequate. Late presentation is most marked in the heterosexual group and could be due to reduced awareness, increased stigma or other socio-cultural barriers to testing.

3.2 Disclosure to sexual partners so that they are tested is a highly effective strategy. When individuals are unable to do disclose directly, specialist clinics will contact partners on their behalf.

3.3 More research and operational monitoring are needed if we are to improve HIV testing in UK. We need (1) a better understanding of the barriers; (2) to determine the optimal frequency of testing according to risk profile; (3) to ensure that realistic targets set for testing are met; and (4) to improve the chances of avoiding risk after receiving a negative result.

Treatment
4.1 Commissioning and delivery of treatment should be central for reasons of efficiency and to maintain the highest quality of care. HIV/AIDS is one of the four most costly conditions, because of the cost of the drugs. Centralising the service allows procurement to be competitive, ensuring the treatment of choice is as economical as possible. Treatment and management continues to evolve with emergent drug toxicities, co-infections, and an ageing cohort.

4.2 If the reforms result in GP consortia commissioning services, this is likely to lead to an overall increase cost of HIV/AIDS care, and there is a danger that the quality of care could deteriorate, not least of all because the other sexual health needs of these patients will no longer be met if care is diverted away from specialist multi-disciplinary clinics; this could increase the chance of onward transmission. The quality of data collected could deteriorate if reports are submitted outside specialist clinics with the appropriate software and links to national systems for monitoring the epidemic.

4.3 The coordination and monitoring of treatment and care is best organised through the specialist clinics, although it could be delivered under their supervision through community partnerships.

Cost

5.1 HIV is a global infection. We are fortunate that the burden in UK is light relative to other European countries, the US, and especially SSA. In the early phase of the epidemic, research for HIV/AIDS was ring fenced and this approach succeeded in establishing a network of academics in UK able to compete for national and international awards. Subsequently, UK research has remained competitive in basic science and in global health trials, and has proved cost effective by continuing to build on established research infrastructure with African partners. However, it has become increasingly difficult to identify donors in UK and in Europe that have sufficiently large sums needed for clinical trials of biomedical interventions for HIV prevention, such as microbicides and vaccines. Joint funding initiatives such as the collaboration between the Medical Research Council, the Department for International Development and the Wellcome Trust have gone some way to addressing this gap, and are to be encouraged. It would be helpful if Government policy facilitated more interaction between donors that typically fund research and donors that typically fund development both in UK and in Europe. This would ease the transition of promising interventions from research through implementation into service provision.

5.2 For UK research, it will be important to prioritise funding

- to optimise and evaluate the use of antiretrovirals in HIV negative individuals, and to determine the cost effectiveness of this intervention with a view to service provision
- to address the issues around testing referred to in 3.2, and determine the feasibility and acceptability of scaling up testing and offering immediate treatment
- to optimise treatment regimens and laboratory monitoring
Stigma

6.1 Fear of stigma inhibits individuals from testing, thus contributing to late presentation and onward transmission whilst ignorant of HIV status. It inhibits individuals from disclosing their status to sexual partners, to their GPs, and to their families which in turn limits the support available for care in the community. Stigma can also inhibit individuals from accessing care.

6.2 In heterosexual communities, especially Black African, and to a lesser extent in MSM.

6.3 The services provided in specialist clinics and through community organisations tackle stigma by raising awareness, and through one to one/group counselling to support disclosure. Over the last 15 years HIV has evolved from a fatal disease to a chronic manageable condition, and this in itself has helped to reduce stigma for those infected, and to facilitate disclosure because of the medical benefit to partners of knowing their HIV status.

6.4 Stigma is more challenging in the Black African communities, where HIV infection may complicate immigration status. The majority of this community regularly attends religious services, and the African HIV Policy Network has successfully engaged with Faith Leaders to raise awareness of HIV, improve attitudes and encourage compassion.

References


18 February 2011
Memorandum by John McKernaghan, Manager, The Bruswick Centre (HAUK 18)

Monitoring

a. How robust is the current system for monitoring the number of people with HIV in the United Kingdom?

It currently only tracks those receiving treatment but does not consider those who are not accessing treatment, for example those who may not be presenting as they are required to pay for treatment but can’t afford to (‘failed’ asylum seekers for example.

The time lag can be problematic in terms of service planning. This is of particular concern if cuts to services are implemented.

b. Will the proposed public health reforms impact on the this system

c. Could anything be done to improve monitoring

d. What groups in particular are at risk from HIV?

Men who have sex with men (younger men and those with lower educational qualifications)
Black Africans (Black African women in particular)
People with lower educational qualifications

Prevention

a. Is Government policy sufficiently focused on HIV prevention

This has improved with the introduction of CHAPS and NAHIP but this can be a bit South East/London focused and this doesn’t help prevention work in the regions. There is inconsistency in different areas of the country with some PCT areas doing great work while others are shamefully letting their men who have sex with men and Black African populations down.

Not sure how Local Authorities will be able to manage, work with and deliver HIV prevention work given how up tight they are currently in their responses to prevention work at public sex environments for example. Unless this is addressed this could impede prevention work.
b. Have the right groups been targeted in recent prevention campaigns?

Some good campaigns have taken place but again they tend to have a London-centric approach. This is particularly the case with the CHAPS campaigns. Moreover the campaigns often don’t hit locally and therefore local population loose out.

c. To what extent have prevention initiative targeted at injecting drug users been successful?

The needle exchange schemes are something to be immensely proud of. Local experience has shown that drugs.

d. How could prevention initiatives be better delivered and evaluated?

- Engagement with the communities most at risk
- More acknowledgement of and involvement with local partners
- Involvement of the voluntary sector and ensure it is sustained to deliver prevention initiatives
- Encourage CHAPS and NAHIP to be more involved with local partners (i.e. not stopping at regional level)

**Testing**

a. Are current testing policies adequate across the country?

- Too inconsistent, some areas have rapid testing some don’t. Some clinical testing sites will offer same day testing others won’t (this has particular issues for cross charging between PCTs and NHS Trusts).
- Quality, consistency and purpose of rapid community testing needs to be assured and improved.
- Clinician hostility to community testing needs to be addressed

b. What can be done to increase take-up rates?

- See above
- Deliver a national programme of community based testing
- Train and support voluntary sector providers to deliver this locally

**Treatment**

a. How can the NHS best commission and deliver HIV treatment?

- Look at competitive tendering of services to set very clearly what is offered/expected from an HIV treatment service.
- GPs have limited experience and knowledge of HIV and may not be best placed to commission HIV treatment services.
- Get the views of other stakeholders including service users/patients

b. What impact might the proposed new commissioning reforms have on HIV treatment?
Memorandum by John McKernaghan, Manager, The Bruswick Centre (HAUK 18)

Loss of knowledge and expertise
Uncertainty
Opportunity to improve services

c. In what setting can treatment most effectively be delivered?

Depends what service users need, could be delivered in a variety of settings and does not need to be limited to clinical settings.

Cost
a. Have cost considerations been satisfactorily balanced with public health imperatives in HIV?

(i) Prevention policy –
(ii) Treatment policy -

b. Is research funding correctly prioritized?

Stigma
a. What impact does stigmatization of those with HIV have on those infected and on addressing HIV as a public health problem?
Prevents people from testing
Mental ill-health
Lack of care and self-care management
Risk taking behaviours
Criminalisation of ‘reckless’ HIV transmission has reinforced stigma
People not belonging to groups at risk unlikely to see HIV prevention as an issue for them and may engage in risk taking behavior

b. Where are problems of stigmatisation most acute?
Judicial system – criminalization of HIV transmission
Media
Public attitudes
Amongst groups most affected

c. What measures are currently taken to tackle HIV stigmatisation? What more can be done?
Limited measures being undertaken
More education and awareness raising to challenge the deeply embedded stigma including this in school education as part of a longer term challenging of stigma
Ensure HIV specifically mentioned under Hate Crime
Stop prosecutions for ‘reckless’ transmission of HIV
Ensure all public health messages including sexual health messages talk of self responsibility

February 2011
Is research funding correctly prioritised?

1. Scientists in the UK have made substantial contributions to our basic understanding of HIV, how it interacts with the immune system, the pathogenesis of AIDS, and the development on therapies and preventions. Examples are the identification of CD4 as the primary receptor for the virus, the role of the killer CD8 T cell response in the partial control of HIV in infected patients, identification of innate cellular mechanisms that confer resistance to HIV infection, development of a mathematical model that measured the life span of infected cells explaining how drug therapy works. In addition, UK scientists have contributed significantly to the development of candidate vaccines and locally applied microbicides, which are in clinical trials. UK virologists have contributed to understanding the nature of HIV and its origins. UK scientists play prominent roles in major international meetings, contribute to strategy development for the Global Enterprise for HIV Vaccine, and serve on scientific advisory boards for HIV/AIDS treatment, microbicide and vaccine programmes in developing countries.

2. Compared to the United States however, UK expenditure on HIV/AIDS research is very small. This is also true of the EC as a whole and it is a cause for some concern in US funding circles that Europe is not pulling its weight. The NIH expenditure on HIV research is approximately $3 billion per year, 10% of the total NIH budget. This includes $598 million for HIV vaccine research. Examples of US NIH led initiatives are the HIV Vaccine Trials Network (HVTN) based in Seattle, The Vaccine Research Center (VRC) at the NIH and the Center for HIV AIDS Vaccine Immunology (CHAVI), each funded at more than $30m per year. These large initiatives reach out beyond the USA itself, particularly to Africa. In parallel, the Bill and Melinda Gates Foundation spends $76.8 million per year on its AIDS Vaccine programmes, some of which funds European scientists. There is nothing approaching this scale of funding from European agencies or charities. The total funding for AIDS vaccine research in EU countries is $65 million; UK expenditure on vaccine-related AIDS research is $26.3 million (figures from the AVAC-IAVI-IPM-UNAIDS Resource Tracking Working Group). Total UK HIV research is more than $50m, but is a long way below expenditure in the USA after adjustment for GNP (7:1).

3. In the UK, the MRC spends a total of £28.8m per annum on HIV research. This includes large programmes in its two African Units, the MRC Clinical Trials Unit, the MRC Human Immunology Unit in Oxford (though that is changing its priorities with a change of Director), the Virology Centre at UCL, large international clinical trials in partnership with DFID and EDCTP, a variety of Programme Grants and some small project grants. Approximately half the MRC spend on HIV is relevant to vaccine development. In addition, the Wellcome Trust funds the UK HIV Vaccine Centre (UK HVC), the early treatment trial SPARTAC and some large programme grants (now being reassessed under their new investigator funding schemes). In addition the Wellcome Trust also has overseas HIV research programmes that include Africa Centre in South Africa and some AIDS research in Kenya.
4. Despite the relatively low level of funding compared to the USA, the research programmes and Units supported by MRC and WT are highly competitive internationally and the UK scientists involved punch above their weight. However, our contribution to the global effort is quite small.

5. There are programmes in European countries that are generally on a similar or smaller scale to those in the UK, including high quality programmes in France, Germany, Italy, Switzerland, Spain, the Netherlands and Sweden. The European Union Framework Programmes contributed €130m to FP6. An example of EU funding is the European framework vaccine initiative Eurovac which has links with Aventis Pasteur. The European and Developing Countries Clinical Trials Partnership (EDCTP), with an original budget of approximately €150m pa, builds research infrastructure appropriate for clinical trials on HIV, TB and Malaria treatment and vaccine trials.

6. European Pharmaceutical companies, such as GSK, Roche, Novartis, have been prominent in antiretroviral drug development. The introduction of these effective drugs by American and European Pharmaceutical companies has been a spectacular success, one of the unsung achievements of the HIV era. The advances include the almost total prevention of mother to child transmission of HIV and long term survival of infected patients. This success illustrates how discoveries in academic laboratories (including discovery of the virus, the function of the virus genes, crystal structures of virus proteins) can be exploited by industry to develop drugs. Clinical academic centres collaborated in proving drug efficacy and rolling out the treatments in short time. Following various pressures many of these drugs have been made available to developing countries at reduced cost. However, although the drugs treat very effectively, they do not cure. Eradication of the virus in those infected is a challenge for the future.

7. Vaccine development has not been so straightforward. The Pharmaceutical industry has been involved but much of the leadership has come from academia, particularly in the USA. It is clear that there are huge scientific obstacles to overcome before a successful vaccine can be made. A prophylactic AIDS vaccine is no longer a very attractive target for Pharma — huge outlay, high risk of failure and impoverished markets. The battle has therefore been taken up by the public and charitable sector, primarily the NIH and BMGF, with rather peripheral involvement from the major Pharmaceutical companies. Some European research groups, six in the UK, work very productively with NIH or BMGF funding within large consortia, which are often led from the USA. The EU funded Eurovac programme, in partnership with the Gates Foundation, has made a significant contribution to vaccine development and some of the concepts being widely tested (eg prime-boost strategies, peptide antigens) originated in the UK. Recently there has been some cautious optimism that there is a way to make a vaccine. An efficacy trial in Thailand that combined two previously suboptimal vaccines gave 30% protection, the first positive protective effect seen with a candidate AIDS vaccine. This observation needs repeating and if confirmed is not enough protection to license as a vaccine, but it does generate optimism that a vaccine is possible particularly if the immunogen is improved. This is an aim of several of the academic consortia, including the Wellcome Trust funded UK HIV Vaccine Trials Consortium (UKHVTC), led from Imperial College London, that is developing and trialing an improved version of the vaccine that was tested in Thailand.

8. There is also optimism in the basic science that will underpin future vaccine design. Recent research has revealed a lot of new information about the nature of the virus that is transmitted from one person to another, the very first immune responses, how the virus can
evades those responses, the influence of host genetics on virus control and the slow
development of neutralizing antibodies. A very detailed molecular understanding of what
makes a good antibody is emerging. It needs to target particular parts of the virus envelope
protein and may need a lot of mutation as the immune response progresses, a normal but
semi-random process. These findings suggest ways of making vaccines that elicit strongly
neutralizing antibodies that can deal with the diversity of HIV. Although there is a lot to do
to make that a reality the path to an effective neutralizing antibody vaccine is becoming
clearer. Also, in parallel, the alternative approach of stimulating T cell immunity with a
vaccine is being advanced with new approaches aimed at dealing with the virus diversity and
preventing virus escape from vaccine stimulated immune responses. The majority of the
vaccine development work is being done in the United States but there are significant
European and UK contributions, often by groups working within US-funded consortia.

9. For HIV vaccine development, the non-human primate (NHP; rhesus and cynomolgus
macaques) model has been invaluable for developing ideas and the model will be absolutely
essential in the future. First line testing of vaccine concepts in NHP can identify those worth
taking in to the large, expensive and time consuming human vaccine trials. Equally important
the NHP studies can identify those that are unlikely to work. However, recent legislation in
Europe, though welcome on humane grounds, is pricing European science out of this field
while the USA with much better funding available and lower animal costs, is expanding this
critical area of research. Some small-scale preclinical vaccine work is still possible in the UK,
but later development of any vaccine candidates originating in the UK will inevitably have to
involve collaboration with the USA.

10. The priorities for HIV/AIDS research are not controversial. Basic understanding of
the virus and the immune responses to the virus are central. Prevention programmes are
vital everywhere, but are a particular priority in developing countries. Mother to child
transmission can be reduced from 20-40% to <5% by selective drug use. For sexual
transmission, current prevention programmes include, education, needle exchange, male
circumcision, anti-retroviral drug prophylaxis, development of new microbicides and vaccine
development. Vaccine discovery must have a very high priority because no other measures
can ultimately control the pandemic. Treatment priorities include examination of the benefits
of treatment very early in infection and the ambitious aim of eliminating the virus in those
infected, possibly involving aggressive drug treatment and harnessing the immune system.
Steady improvement of current long-term drug maintenance therapy is also a priority. The
existing initiatives to provide low cost effective treatment strategies for resource poor
countries need to be sustained and expanded. However, monitoring for drug resistance will
be critical and, as for all previous therapies involving antibiotics, resistance could become a
major issue in the future.

11. Is the balance of UK research funding for HIV/AIDS right? As a recent council
member of the MRC, I am fully aware of the pressures that it is under from all directions.
There are similar multiple calls on the NIHR and the Wellcome Trust. It is extremely
unlikely therefore that the MRC could double its expenditure on HIV from 4.8% of its total
budget to 10%, which would match the NIH. However, some increase in funding would be
desirable to maintain the best research in the UK and to ensure that research funds coming
in from the USA can at least be partnered by local resourcing. But this may not be possible
at the present time. The balance of priorities in MRC funding may be difficult to change,
given the present budget constraints, but this might be a good time to review of all UK
funding, checking the balance between basic, preventative and therapeutic HIV research
against the global priorities, as for instance spelt out in the Global HIV Vaccine Enterprise
Strategic Plan, published in 2010 (http://www.hivvaccineenterprise.org). It is also vital that the MRC and other agencies can remain responsive to very high quality applications that can advance the science in new directions. What might also be effective would be pressure on the EU to increase its commitment so that it could fully fund high quality HIV research programmes, units and international consortia that would complement some of the highly successful NIH and Gates initiatives.

(Professor Sir Andrew McMichael FRS, F Acad Med Sci. is Director of the Weatherall Institute of Molecular Medicine in the University of Oxford. He is currently one of the scientific leaders of the NIH funded Center for HIV AIDS Vaccine Immunology (CHAVI), which funds most of his own HIV vaccine research. He is on the scientific advisory board of two Gates Foundation consortia for HIV vaccine development and for the South African AIDS Vaccine Initiative. He was Director of the MRC Human Immunology Unit in Oxford between 1998 and 2009 and a member of MRC Council between 2005 and 2010).

February 2011
Memorandum by Medical Foundation for AIDS & Sexual Health (MedFASH) (HAUK 63)

1.0 Medical Foundation for AIDS & Sexual Health (MedFASH)

1.1 The Medical Foundation for AIDS & Sexual Health (MedFASH) is a charity dedicated to the pursuit of excellence in the healthcare of people affected by HIV, sexually transmitted infections and related conditions. We work by informing and supporting health professionals and policy-makers. Over the last decade we have undertaken a range of national projects to develop standards, guidance and educational materials and in 2008, for the Independent Advisory Group on Sexual Health and HIV, we carried out a review of the (then) national sexual health and HIV strategy, focusing particularly on how to overcome barriers to implementation.

1.2 We have long had an interest in promoting and supporting high quality HIV prevention, treatment and care, and we have a particular commitment to increasing rates of HIV testing and diagnosis. We welcomed the opportunity to submit oral evidence at the Select Committee’s session of 8 February and are pleased to supplement that through this written submission.

1.3 Our evidence follows the questions issued by the Committee and focuses especially on those topics where we have the most expertise or concern. We would be happy to provide further information. Copies of MedFASH publications can be found on our website or supplied on request. Our full contact details are at the end of this memorandum.

2.0 Monitoring

a. How robust is the current system for monitoring the number of people with HIV in the UK?

2.1 The UK should be proud of its systems for monitoring and surveillance of HIV which are among the most robust in the world. The quality of data available, and the expertise of the Health Protection Agency (HPA) which manages the systems and interprets the data, are recognised and valued across the HIV sector in this country and internationally.

2.2 MedFASH recently worked in partnership with the HPA to develop guidance on increasing the uptake and effectiveness of HIV testing\(^{209}\), commissioned by the European Centre for Communicable Disease Control (ECDC). This guidance aims to inform the development, monitoring and evaluation of national HIV testing strategies or programmes in the countries of the European Union and the European Economic Area. It states that monitoring and evaluation (M&E) of an HIV testing programme “relies on the collection of good quality data and timely dissemination of results to key stakeholders. A well designed M&E system will inform policies, improve the quality and effectiveness of interventions and therefore guide future allocation of resources. National surveillance data, including new diagnoses, the proportion of individuals who present late and an estimate of the number of undiagnosed infections, are important for monitoring the impact of a programme. Expanding testing in new settings will require robust M&E to ensure high-quality HIV

testing reaches the populations most at risk.” It was clear from working on this project that even such basic information is not currently available in all European countries, whereas the planning of programmes and policies in the UK is able to benefit from the availability of considerably more sophisticated data at both national and local level.

b. Will the proposed public health reforms impact on this system?

2.3 To support future planning and monitoring, it is essential that the capacity and skills of the HPA are retained if its functions transfer to Public Health England. We also believe that the ability of the HPA to speak with an independent voice in interpreting reported data and drawing out recommendations for action is valuable and should be retained. This is particularly important in view of the stigma attached to HIV which tends to promote the dissemination of misinformation or silence – neither of which make for well-informed policy-making or programme planning.

c. Could anything be done to improve monitoring?

2.4 We would like to see the availability of more information on HIV testing and diagnosis in settings beyond GUM and antenatal services, including information about the use, take-up, effectiveness and cost-effectiveness of rapid point-of-care tests which are increasingly being used outside traditional settings. We welcome the recent development and ongoing roll-out by the HPA of the Recent HIV Infection Testing Algorithm (RITA) which should improve our understanding of current transmission dynamics and, potentially, of the effectiveness of prevention efforts.

2.5 There is currently inadequate information about the prevalence of HIV infection in prisons. The last survey of blood borne viruses (BBVs) in prisons (which also measured undiagnosed infection) was in 1997. Commissioners are hampered by this lack of information on which to base needs assessment to inform commissioning.

d. What groups in particular are at risk from HIV?

2.6 Men who have sex with men (MSM) are the group at the highest risk of acquiring HIV in the UK. People from, or with links to, countries of high HIV prevalence, especially in sub-Saharan Africa are also more likely to have HIV and there is evidence of transmission within the UK among these populations.

3.0 Prevention

a. Is Government policy sufficiently focused on HIV prevention?

3.1 We very much welcome the inclusion of an indicator for late diagnosis of HIV in the proposals for a Public Health Outcomes Framework currently out for consultation. Improvements in relation to this outcome indicator should reduce not only morbidity and short-term mortality among those diagnosed with HIV but also the transmission of HIV infection by those who would have remained undiagnosed for longer (such a reduction occurring through behaviour change and/or the impact of antiretroviral therapy on infectiousness). Retaining this indicator in the final published framework will therefore be a significant plank in Government policy on prevention.

3.2 However, there is uncertainty as to how HIV prevention will otherwise be prioritised or ensured, at national or local level. With the majority of HIV spending necessarily allocated to HIV treatment and care so as to ensure access to antiretroviral therapy
at the optimum time for all who need it, prevention activities in the community have often been a ‘soft target’ for spending cuts when budgets are tight. This is a false economy, given the cost of each new infection that we fail to prevent (estimated at £280,000-360,000 lifetime costs). Nevertheless, it is a real and current risk in the push for cost savings, especially in the transitional period before new NHS commissioning structures come into place and before the proposed new sexual health strategy is drafted. A strong steer from Government is needed to local authorities (LAs) and Directors of Public Health that HIV prevention is an essential part of local public health.

b. Have the right groups been targeted in recent prevention campaigns?

3.3 Broadly, the decision to target MSM and African communities is appropriate in response to the prevalence of infection and risk in those groups. However, it is important to ensure that the broader population and young people in particular are aware of the facts about HIV, the potential risks and how to avoid them, and the need for understanding of communities affected in order to reduce the stigma that can impact negatively on prevention. Recent surveys seem to suggest that general population knowledge levels about HIV are declining. Messages about HIV for the general population need to be credible and appropriate, and contextualised with other sexual health messages. Campaigns should complement comprehensive sex and relationships education for all young people in schools and those excluded from school.

3.4 It should be recognised that people living with HIV, and the communities most affected, can play an important role in HIV prevention, as can professionals providing care for people with HIV. Prevention campaigns should be multi-faceted and multi-sectoral, informing and engaging these partners in prevention.

c. To what extent have prevention initiatives targeted at injecting drug users been successful?

3.5 The UK’s record of early and more recent implementation of drug treatment and harm reduction measures including needle exchange schemes has enabled it keep HIV prevalence relatively low among injecting drug users (IDUs), although rates vary from 0.6% in Scotland to 4.1% in London. This is in contrast to some other European countries and the USA where HIV infection quickly became concentrated among IDUs. However surveillance data suggest that there has been increased HIV transmission among IDUs in the UK in recent years, the prevalence of other blood borne viruses in this population is high (about a half have been infected with hepatitis C), and a fifth continue to share injecting equipment. History has shown that HIV can spread very rapidly among drug injecting populations and it is therefore important not to be complacent and to ensure the continuing provision of needle exchange and other harm reduction measures despite the current financial pressures.

d. How could prevention initiatives be better delivered and evaluated?

3.6 Sustained investment in prevention is needed. The continuation of national prevention activities is important but this is not sufficient in itself and needs to be

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complemented by prevention at local level, with better synergy between them. Some prevention could be more effectively commissioned across a number of local areas, especially for those whose lifestyle means they are best targeted away from where they live.

3.7 Support for people living with HIV as agents of HIV prevention should be a core function of HIV treatment and care services. This will include advice on the impact of ART on HIV transmission. For individuals most at risk, especially MSM, it will also be important to ensure that targeted campaigns and other prevention interventions keep abreast of new prevention technologies (eg pre-exposure prophylaxis) as they develop, to exploit their potential in an effective and cost effective way.

3.8 While there are still significant gaps in the evidence, there is also a need better to disseminate what is already known about the effectiveness and cost-effectiveness of prevention. To further build the evidence base, investment in prevention activities should be sufficient to allow for their evaluation and the sharing of this learning.

3.9 To support the delivery of effective and cost-effective local HIV prevention, we hope to see the publication of a prevention framework for sexual health and HIV, as was recently in development by the Department of Health.

4.0 Testing

a. Are current testing policies adequate across the country?

4.1 A quarter of people living with HIV remain undiagnosed. Over half of those diagnosed receive their diagnosis late (at a stage of disease progression when treatment should already have started). Despite a number of national initiatives to increase rates of detection and diagnosis in recent years (letters from the UK Chief Medical Officers212, UK national HIV testing guidelines213, educational packs and booklets for health professionals214,215,216), there remains geographical variation in rates of late diagnosis and testing practice is inconsistent and insufficient. Some local pilots217 have shown that increasing testing in non-traditional healthcare and community settings is feasible and acceptable, but existing policies alone do not seem to provide sufficient incentives, sanctions, or even professional awareness, to promote major changes in practice.

4.2 For this reason, we very much welcome the proposed indicator for late diagnosis of HIV in the draft Public Health Outcomes Framework, and believe that it must be retained as a lever for commissioning to scale up HIV testing. We also look forward
to the forthcoming NICE public health guidance on increasing the uptake of HIV testing in MSM and black Africans and hope mechanisms will be put in place to increase the likelihood of it significantly impacting on commissioning and service delivery.

b. What can be done to increase take-up rates?

4.3 We believe the principles and practical steps outlined in the guidance, written by MedFASH with the HPA for ECDC, on increasing the uptake and effectiveness of HIV testing provide a good point of reference. The core principles set out within this for the development of national HIV testing strategies include showing political commitment, reducing stigma, involving affected communities and all major stakeholders in the development and implementation of HIV testing strategies, and making HIV testing an integral part of other relevant national strategies and programmes (eg on drug and alcohol use, prison healthcare, tuberculosis).

4.4 Increasing HIV testing needs to be a priority at national and local level, with leadership and clear accountability for improvement. It should be included in joint strategic needs assessments and local strategies, and incentivised through mechanisms such as QIPP and CQUIN. It will be important to increase the evidence base for cost-effectiveness of testing and, in order to ensure sustainability and maximum cost-effectiveness, to integrate HIV testing into normal procedures in new settings (such as medical admissions units or general practice) rather than using additional personnel.

4.5 There is evidence that uptake of testing (eg in antenatal settings) can vary widely according to the individual healthcare workers offering the test. In one of the recent DH-funded pilot studies, in a hospital setting where HIV testing was recommended as routine, clinicians still appeared to be targeting testing rather than offering it to all, and were failing to identify the majority of undiagnosed infections. Testing uptake thus often depends on the offer of testing being made, and changing the attitudes and practice of healthcare professionals in a position to offer testing is key. They need education, appropriate to their profession and working context, to reduce the fear and stigma associated with HIV, raise awareness of undiagnosed infection, lower the threshold of suspicion for diagnostic testing, normalise the offer of an HIV test as part of good medical practice and present the failure to test as potentially negligent. Probably the single medical setting with the biggest potential to reduce undiagnosed HIV infection is general practice, as most individuals have a GP. GPs are in a position to offer testing based on clinical presentation (eg symptoms of indicator conditions), on assessment of risk (eg sexual behaviour or country of origin) or as part of routine screening (eg for all newly registering patients, especially if local HIV prevalence is high).

4.6 To complement this, population groups at highest risk of HIV also need information and education to raise awareness of risk and the prevalence of undiagnosed infection as well as the benefits of treatment and where to seek advice and get tested. Testing in outreach settings to reach populations who are reluctant to seek or accept HIV testing in mainstream health services is also needed.

5.0  Treatment  

a. How can the NHS best commission and deliver HIV treatment?  
b. What impact might the proposed new commissioning reforms have on HIV treatment?  
c. In what setting can treatment most effectively be delivered?  

5.1 Our answer addresses all three questions. As a fast changing service which needs to link with a range of other medical specialties and involve a broad multidisciplinary team, it is important for HIV treatment and care to be commissioned by commissioners who have an understanding of the particularities of HIV. This means not only the purely clinical aspects of care, but also the impact of social factors such as stigma and social exclusion which have implications for psychosocial support.  

5.2 As a relatively high cost low volume service, to which patients may travel considerable distances, HIV treatment and care is not an appropriate candidate for commissioning at a very local level eg by individual PCTs or GP Commissioning Consortia (GPCC). In the current NHS structure, cross-PCT commissioning at regional level, such as through specialised commissioning consortia, allows for economies of scale, sharing of risk and standardisation of care quality.  

5.3 We agree with the leading medical specialist associations for HIV that HIV treatment and care should be provided through managed networks. Networks support the implementation of standards and the provision of patient-centred care by facilitating the development of shared protocols and referral pathways, mapping and redesigning services to meet needs more effectively and eliminate waste, and providing a framework for the training and professional development of staff. Networks also have the potential to make equitable the opportunity to participate in clinical trials of improved treatments.  

5.4 Networks should also provide a context for the greater involvement of general practice in sharing the management of HIV with specialist centres. This is becoming increasingly necessary as the numbers of people living with HIV grows year on year, and also increasingly feasible as the routine management of those who are stable on treatment requires fewer visits to the specialist centre.  

5.5 For the reasons outlined above, we support the recommendation that HIV treatment and care should be commissioned in the forthcoming NHS structure by the NHS Commissioning Board (NCB). We hope there will be a mechanism for this to happen at a sub-national level, so as to be close enough for commissioning to be informed by an understanding of local needs and service configurations.  

5.6 A major risk of the reforms is that commissioning will become fragmented. It is essential that links are maintained and strengthened between services providing HIV prevention, HIV testing and HIV treatment and care, as well as with other sexual health services. Commissioning needs to ensure that this happens. Much HIV prevention should take place within HIV treatment services, supporting people living.
with HIV to prevent onward transmission of infection. Pathways into HIV specialist care from testing services in community settings, primary care and other medical specialties should be smooth with rapid access to emotional support and partner notification as well as clinical assessment. Ongoing sexual healthcare including STI screening is also important for people attending HIV services, as is access to psychological support (within the acute setting and/or in the community) and mental health services. Links to other medical specialties for HIV-associated conditions and co-morbidities (eg hepatology, respiratory medicine) are also important, as is the provision of social care integrated with healthcare for those who need it. All this highlights the need for coordinated commissioning between the NCB, LAs and GPCC to ensure coordinated care for people living with HIV.

6.0 Cost

a. Have cost considerations been satisfactorily balanced with public health imperatives in HIV:

(i) prevention policy; and

(ii) treatment policy?

6.1 In the case of HIV, setting cost considerations in the balance against public health imperatives creates a false dichotomy. Preventing new HIV infections and reducing the morbidity and mortality associated with late diagnosis provides benefit for both the public health and the public purse. It is estimated that the prevention of one new HIV infection would save the public purse between £280,000 and £360,000 in direct lifetime healthcare costs and that, had all of the UK-acquired infections newly diagnosed in 2008 been prevented, there would have been a saving of approximately £1.1 billion in direct healthcare costs. On top of this, there is also a saving in other costs to society (eg social care, welfare benefits) and in the cost of further infections prevented. There is thus a strong case for investment in prevention as ‘investment to save’.

6.2 However, investment in HIV prevention has to date been patchy, especially at local level. While we would welcome more economic analysis, we believe prevention should be more consistently prioritised. This includes community-based prevention and behavioural interventions in a range of settings, as well as HIV testing because of its impact on HIV transmission (through behaviour change and reduced infectiousness on treatment).

6.3 Similarly, we believe that ensuring access to high quality treatment and care for all is an appropriate use of financial resources. Failure to provide ART when needed, along with psychological and social support that may help adherence to treatment (and thus its effectiveness), leads to greater costs arising from emergency care and hospital admissions for the individual as well as the increased risk of HIV transmission and the cost of further infections.

6.4 We believe the current policy of restricting access to free HIV treatment for people of uncertain immigration status is not only unethical but also misguided in terms of the cost benefit because, for the reasons outlined above, the public health risks and

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the costs to society are likely to be higher if treatment is withheld than if it were made available.

b. Is research funding correctly prioritised?

6.5 We are not in a position to give expert comment on this question. However, we regret that there is no longer an identifiable HIV and sexual health research strategy informed by multidisciplinary advice from a range of experts working in the sector, as there was until the demise of the DH/MRC Sexual Health and HIV Research Strategy Committee.

7.0 Stigma

a. What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?
b. Where are problems of stigmatisation most acute?
c. What measures are currently taken to tackle HIV stigmatisation? What more should be done?

7.1 HIV-related stigma is recognised worldwide as a barrier to effective prevention, testing and access to treatment. It promotes silence, secrecy, fear, misinformation and worse.

7.2 For individuals living with HIV, stigma makes it harder to disclose their status to family, sexual partners or their community and they risk rejection, ostracism and even violence if they do. Adherence to treatment may be difficult, whether because of the need to hide medication or because of psychological difficulties such as depression\(^{222}\) exacerbated by stigma.

7.3 From a public health point of view, stigma inhibits uptake of HIV testing (and thus the potential preventive impact of testing) and the ability to negotiate safer sex. For some women, fear of disclosure of their HIV status leads them to risk transmission of HIV to their child through breastfeeding rather than prompting suspicions by bottle feeding. While stigma can be rife in many populations, particularly acute difficulties have been reported in some African communities.

7.4 Stigma needs to be countered among a wide range of professionals including those whose role brings them into contact with people living with HIV, those in education and other public services including the police and criminal justice system, and those working in the media. Equalities legislation is helpful in outlawing HIV-related discrimination. We believe that normalisation of HIV testing will reduce stigma among both health professionals and the public over time, as should the normalisation of safer sexual behaviour including condom use.

7.5.1 Tackling stigma requires openness, visibility and leadership. The establishment of the Select Committee in the House of Lords is a positive step in this direction and we hope to see further ongoing political leadership and cross-governmental action to combat stigma at national and local level.

25 February 2011

Supplementary Memorandum by Ruth Lowbury, Chief Executive, Medical Foundation for AIDS and Sexual Health (MedFASH) (HAUK 66)

Following our oral evidence at the session of 8 February 2011, the Select Committee asked MedFASH to provide written answers to the following supplementary questions. This submission is additional to our first submission of written evidence.

1. A HIV outpatient funding tariff is being developed by the Department of Health, with the involvement of many clinicians within the HIV community. Can you explain how this will work and what advantages it will bring?

1.1 MedFASH has not been directly involved in the development of the HIV outpatient tariff and we are therefore not best placed to explain it in any detail. We are generally in favour of the tariff as it should allow equity in resource provision throughout England. We also welcome the attempt to include in the tariff an element of psychological care (for the proportion of patients who need it) as well as medical and nursing care. However, it is important that this (and any other) draft tariff should have adequate road testing before implementation as there is a wide range of complexity and cost at different stages of disease.

2. How confident are you, following reforms to bodies such as the Independent Advisory Group on Sexual Health and HIV, that there will be sufficient channels in place to provide independent advice on HIV to the Government?

2.1 My memberships, in an individual capacity, of the Independent Advisory Group (IAG) on Sexual Health and HIV and of the Expert Advisory Group on AIDS have had the support of my employer, and I can therefore respond to this question on behalf of MedFASH.

2.2 The IAG enabled Ministers and officials to benefit at low cost from the independent advice of leading experts from a broad spectrum of disciplines and sectors across sexual health and HIV. The Group’s membership remained constant for the length of individuals’ terms of office, allowing the development of mutual understanding over time and the ability for the Group as a whole to offer well-rounded and non-partisan advice. While the DH’s commitment to ensure it receives ongoing advice from the field through a new stakeholder group is welcome, it is doubtful whether a smaller group consisting of changing representatives of stakeholder organisations will be able to offer such wide or considered advice, and it is likely to be more difficult for members to lift themselves above the special interests of the organisations they are there to represent.

2.3 The IAG was very productive, publishing annual reports and authoritative papers which provided an independent point of reference for Government as well as for policy-makers and professionals at national and local levels. We have not seen the terms of reference for the new stakeholder group(s). If they do not include the scope to publish advice, we would be concerned that the impact will inevitably be diminished.
2.4 We understand the new stakeholder group will be smaller than the IAG but will presumably still have a remit to advise across the different aspects of sexual health and HIV. The membership list has not to our knowledge been published, but as regards the Select Committee’s question about HIV advice, it will be important to be reassured that there is sufficient representation on the group to provide input informed by the diversity of HIV-affected populations and needs, and by experience of the range of issues relating to HIV prevention, testing, treatment and care including social care and psychological support.

2.5 We welcome the retention of the Expert Advisory Group on AIDS (EAGA) and trust that its new status as a Departmental Expert Committee will not prevent it continuing to offer independent scientific and public health advice to guide policy.

a. **What contribution could organisations such as yours make to HIV and AIDS policy development? How involved are you at present?**

2.6 MedFASH has a track record of contributing actively to policy and strategy development, notably through the review of the national sexual health and HIV strategy which we undertook for and with the IAG. Our report made recommendations for improving sexual health and the delivery of sexual health services, many of which remain relevant. We were also commissioned to produce a consultative paper for the IAG/DH conference in February 2010 to inform strategic planning on sexual health and HIV. Our longstanding working relationship with the DH, including the delivery of several major national projects, has enabled us to develop an understanding of the process of national policy development and the barriers to its implementation.

2.7 We have expertise in a range of sexual health issues and extensive multidisciplinary professional networks. We work closely with specialists and their representative associations in GUM and HIV, sexual and reproductive health, general practice and other medical specialties. We also collaborate with HIV and sexual health commissioners, other leading charities and service user groups. Our project work is characterised by the engagement of a wide range of stakeholders and we are recognised for our ability to facilitate consensus between them and to produce high quality outputs to support their work.

2.8 We trust our expertise and skills in HIV and sexual health policy will continue to be valued and used, particularly as the DH develops its new sexual health strategy. We are disappointed not to have been invited to join the DH’s new sexual health stakeholder group.

2.9 We continue to contribute independently to initiatives which seek to influence policy on HIV, for example the Halve It campaign. We also work with other charities and medical specialist societies to offer independent suggestions for policy development and provide authoritative responses to consultation.

2.10 In an independent capacity I remain a member of EAGA, an unpaid role in which I am supported by MedFASH.
3. **What do you think should be the conclusion of the review, announced by the Government, into the ban on those with HIV working in “exposure-prone” fields of medicine?**

3.1 MedFASH recognises that if an HIV-infected individual is on antiretroviral therapy with a consistently undetectable viral load, the risk of transmitting infection is extremely small, and it is right that the current policy should be reviewed on the basis of the latest evidence. We do not have an established position on what the review’s conclusion should be, but we believe it is paramount to ensure patient safety while going as far as the evidence permits to enable healthcare workers to pursue their chosen career. (It should be noted that the ban is actually on performing certain exposure-prone procedures rather than working in certain fields of medicine per se, although this has the effect of excluding some career paths such as surgery or dentistry.)

4. **Do you have any specific examples of cases where those infected with HIV were not tested in a timely fashion, leading to expensive inpatient treatment at a later stage of their infection?**

4.1 While we have heard anecdotally of many such examples, Select Committee witnesses who provide clinical or support services to people with HIV will be better placed than MedFASH to answer this question.

28 February 2011
1. The Medical Research Council (MRC) is one of the main agencies through which the Government encourages scientific research into HIV/AIDS. The MRC receives its funding through the Department for Business, Innovation and Skills and the annual spend specifically on HIV research in 2009/10 was approximately £29 million.

2. This submission aims to respond to the questions from the Committee which relate to cost, and specifically the prioritisation of research funding.

3. The MRC has a long history in supporting research in this area. In 1983 the MRC established a working party on AIDS and has supported research into HIV/AIDS since that time. The MRC’s research activities address the two biggest challenges; (i) protection from HIV transmission and (ii) treatment of those affected.

4. Research supported by the MRC includes protection studies ranging from design and development of vaccines against HIV, development of microbicides to inhibit sexual transmission of the virus, through to behavioural intervention studies to understand how to work with high risk communities to modify behaviour. Other research supported by the MRC aims to provide policy makers with information to guide service planning and public health action.

5. Our research on treatment is primarily aimed at better understanding how to manage antiretroviral therapy and discovering the optimum combinations of drugs for patients at different stages of disease.

6. A list of research studies relating to HIV in the UK from the MRC’s current portfolio is shown at Annex 1. The clinical studies supported, are underpinned by a number of more ‘basic’ studies aimed at understanding the biology of the virus or the immunology of the viral host interaction; epidemiological longitudinal surveillance studies/ databases and cohorts which have been supported (in full or in part) by MRC are shown at Annex 2.

7. Sexual Health and HIV in the UK
The MRC has worked closely with the UK Health Departments. From 1986-2008 the DH Policy Research Programme (PRP) provided funds (in 2008 this was approx £1m) to MRC, specifically for epidemiological, social and behavioural research, initially under the aegis of the Committee for the Epidemiological Study of AIDS (CESA). Following the publication of a ten year National Strategy for Sexual Health and HIV for England in July 2001 and similar policy developments in Scotland and Wales, a new body, the Sexual Health and HIV Research Strategy Committee (SHHRSC) was established in 2002 to include research that could better address the broader sexual health research priorities arising from these new national strategies for sexual health and HIV. Studies supported through the SHHRSC are indicated in the Review of the National Strategy for Sexual Health and HIV. This includes support for the National


Survey of Sexual Attitudes and Lifestyles (NATSAL) 1990 (funded by the Wellcome Trust), NATSAL 2000 (funded by the MRC/SHHRSC) and NATSAL 2010 (funded by MRC, WT ESRC and SHHRSC).

8. International Partnerships
The current research portfolio in HIV includes a diversity of research, both UK focussed and with a global health perspective. The MRC supports studies on HIV in the MRC Unit, The Gambia, and in partnership with the Uganda Virus Research Institute a joint the MRC/UVRI Research Unit on AIDS in Uganda. Approximately one third of the MRC’s current annual research spend on HIV relates to developing country / global health issues. There can be important feedback to the UK from international research, for example health practice models in sub-Saharan Africa, where almost two-thirds of all people with HIV live, helped inform those of the UK, MRC fellow Dr Audrey Prost and colleagues at University College London used experience from Kenya, to inform models for voluntary counselling and testing for HIV226, in the UK.

9. The MRC has a longstanding partnership with the Department for International Development (DFID) which has provided support for activities both in prevention and treatment. For example the Microbicides Development Programme is a partnership between the UK and Sub-Saharan Africa to develop vaginal microbicides for the prevention of transmission of HIV infection. The MRC/DFID DART trial227 one of the largest trials in Africa to evaluate two strategic approaches for the management of Antiretroviral Therapies (ART) provided robust evidence that ART can be delivered safely, without routine laboratory monitoring for toxic effects, but that differences in the progression of the disease suggested a role for monitoring CD4-cell count from the second year of treatment to guide the switch to second-line treatment.

10. The MRC also actively boosts HIV/AIDS research through partnerships with North America, Europe and Africa. For example, the MRC is a major player in the European and Developing Countries Clinical Trials Partnership (EDCTP)229 which involves 16 European countries and 46 sub-Saharan African countries, and aims to develop new clinical interventions to fight HIV/AIDS, malaria and TB. Since 2003, the MRC has contributed over £12m to this initiative (over and above the spend figure quoted above, first paragraph), a third of which focuses on HIV/AIDS.


229 http://www.edctp.org/
ANNEX I

Currently funded research within the MRC portfolio pertinent to UK includes topics such as

- Aspects of CD8+ T cell and NK cell recognition that impact on MHC class I associations with HIV-1 disease progression
- Assessing the impact of HIV-1 in the black Caribbean community in south London
- Correlating gene expression changes and innate immune responses with protective SIV vaccination in cynomolgus macaques
- Development of a universal HIV-1 vaccine
- Development of therapeutic vaccination strategies for the treatment of HIV-1 infection
- Direct Control of Human Gene Expression by HIV Proteins
- Edinburgh HIV Brain & Tissue Resource
- Experience and outcome of pregnancy among women living with HIV in the UK: impact of ethnicity and African region of origin
- Experiences of female migrant sex workers from Eastern Europe and effect of multiple vulnerabilities on risk of STIs/HIV
- Functional Properties of Cytotoxic T Cells that Suppress HIV: "The Good And The Bad"
- HIV-Host Interactions
- Humoral immunity to Human Immunodeficiency Virus (HIV)
- Identification of and molecular characterisation of a HIV restriction factor Lv2
- Incidence, prevalence and outcome of extensive virologic failure in over 60,000 patients with HIV (PLATO II)
- Incidence, prevalence, harms and intervention effects for problem and injecting drug use: crime, morbidity & mortality
- Infection of CD8 lymphocytes by HIV-1 in the aetiology of AIDS
- Inferring HIV transmission networks from time-resolved viral phylogenies for epidemiological modelling
- Interactions between HIV-1 and iron
- Is the treatment of HIV causing irreversible mitochondrial damage leading to long-term health consequences?
- Modelling the determinants and implications of the disparate trends in HCV and HIV amongst injecting drug users
- Modulation of TB-HIV drug interaction by host genetic influences
- National Phylogenetic Study of Current HIV Transmission in England
- Novel interventions in HIV-1 infection
- Pregnancy outcomes in HIV infected women in the United Kingdom
- Regulation of translation of human immunodeficiency virus type-I RNA by the viral Gag protein
- Role of ESCRT-I and ESCRT-II in HIV-I budding
- Role of the secretory pathway in HIV-I egress from T cells
- Sexual Attitudes and Lifestyles of London’s Eastern Europeans: SALLEE
- Sexual and reproductive health programme
- Structural Traps as RNA Therapeutics
- The extent of channelling bias when assessing the impact of antiretrovirals on cardiovascular events in HIV-positive patients
- The Impact of T Cell Immunity on HIV-1 Diversity
• The modulation of macrophage apoptosis during S. pneumoniae infection by HIV-1 or antiretroviral agents.
• The role of Nef in the downregulation of CD4 in the pathogenesis of HIV.
• The uses and outcomes of treatment of HIV infection in the UK
• What Constitutes a Protective CTL Response in HIV-1 Infection?

Link to MRC online portfolio http://www.mrc.ac.uk/ResearchPortfolio/index.htm
ANNEX 2

Longitudinal surveillance studies/ databases and cohorts with MRC support

We also support a number of research programmes not specifically assigned to the HIV portfolio including the third round of The National Survey of Sexual Attitudes and Lifestyles 2010 (Natsal 2010) (approx £5.5m over 5 yrs) where MRC is the main funding partner with Wellcome Trust, ESRC and SHHRSC.

Other longitudinal cohorts/collaborations

- **CASCADE Concerted Action on Seroconversion to AIDS and Death in Europe**
  This is collaboration between the investigators of 23 cohorts of persons with well-estimated dates of HIV seroconversion. Seroconverters are enrolled into the individual cohorts locally and nationally and are typically followed up life-long, national contributor is UK Register of HIV Seroconverters

- **COHERE** Collaboration of Observational HIV Epidemiological Research Europe
  To conduct epidemiological research on the prognosis and outcome of HIV-infected people from across Europe including pregnant mothers, children, and adults. To focus on scientific questions requiring a large sample size of patients which the contributing cohorts cannot answer individually.

- **NSHPC** National Study of HIV in Pregnancy and Childhood ()
  Information is collected on maternal demographics, ART, pregnancy outcome and infant's infection status

- **ART CC** ART Cohort Collaboration
  The ART Cohort Collaboration, which includes 19 cohort studies from Europe and North America, was established to estimate prognosis of HIV-1 infected, treatment naive patients initiating highly active antiretroviral therapy (ART).

- **HIV Drug Resistance Database**
  The UK HIV Drug Resistance Database was set up in 2001 as a central repository for resistance tests performed as part of routine clinical care throughout the UK. Over 51,000 test results have been received and organised, around 90% are in the form of viral gene sequences.

- **UK CHIC** UK Collaborative HIV Cohort
  Investigates the clinical outcomes, response to treatment and epidemic dynamics of HIV-1 in the UK. Currently, the database contains more than 34,000 records of patients who have attended for care at one of a number of HIV clinics around the UK

- **DHICE** Databases for HIV: Integration, Collaboration and Engagement
  A multi-agency initiative, involving the National Health Service (NHS), the Health Protection Agency (HPA), Medical Research Council Clinical Trials Unit (MRC CTU), academia and the patient community, to develop a UK platform for integrated clinical and research data in the HIV field.
- **Edinburgh HIV Brain & Tissue Resource**
  
The purpose of this brain and tissue bank, set up in 1990, is to retain, store and make available for research use, post mortem tissue samples from individuals who have died of HIV/AIDS. All the samples are authorised and ethically approved for research.

18 February 2011
Memorandum by Metro Centre Ltd (HAUK 21)

Preamble

The Metro Centre Ltd is a medium sized charity providing support for LGBT people, HIV prevention and support, and sexual health promotion locally, regionally, Pan-London, nationally and internationally. With a head office in Greenwich for nearly 30 years, the organisation currently employs over 100 people and 80 active volunteers, with an annual turnover of £2.5 million.

1. Monitoring

How robust is the current system for monitoring people with HIV in England?

1.1 The Metro Centre is not best placed to comment on this question, except to say that the Health Protection Agency (HPA) plays a significant role in this area. The Metro Centre utilizes HPA data regularly, to inform service development and ensure strategic approaches that are based on evidence.

Will the proposed health reforms impact on this system?

1.2 While the Metro Centre is not able to comment on whether the proposed health reforms will have an impact on the current monitoring system, it does believe that the proposed health reforms will have an impact on the voluntary sector engaged in HIV prevention and support, and is able to provide comment on this if required.

Could anything be done to improve monitoring?

1.3 The Metro Centre is not best placed to comment on this aspect of monitoring.

2. What groups in particular are at risk from HIV?

2.1 See question 2 below.

3. Prevention

Is the Government significantly focused on HIV prevention? Have the right groups been targeted?

3.1 While the Metro Centre believes that the right groups have been targeted, it also believes that the government’s focus on HIV prevention has been somewhat patchy.

3.2 The DH funded HIV testing pilots commissioned over 2008-09 were a good example of a centralized approach to gathering evidence which could build best practice in relation to HIV testing. The Metro Centre was one of 7 organisations funded nationally to conduct a pilot, and the Metro Centre pilot assisted in establishing that community testing clinics for African communities were feasible and acceptable, and that positivity rates at community testing clinics were higher than other testing sites.
3.3 On the other hand, while London has high and growing incidence of HIV amongst gay men and African communities, the spend on HIV prevention has not matched the epidemiology. At the beginning of 2011, there are significant concerns that this spend could decrease significantly, ensuring that HIV prevention activity would reduce even further.

3.4 There are parts of London as well where spend on HIV prevention has been slashed, and in some cases has virtually disappeared. Despite having a growing number of gay men and African people becoming infected with HIV, NHS Bexley has withdrawn all funds from the Pan London HIV Prevention Programme (PLHPP), withdrawn all funding from local charities for gay men’s HIV prevention, and not commissioned any HIV prevention for African communities.

3.5 The Metro Centre also believes that government does not have sole responsibility for HIV prevention. Clearly, the voluntary sector has a significant role, and not just when it is funded by government. The Metro Centre has recently secured funds from the TIDES Foundation and the MAC AIDS Fund to deliver HIV testing to African communities in Woolwich. Private enterprise must be tapped as well to support HIV prevention strategies.

4. Have the right groups been targeted in recent prevention campaigns?

4.1 The Metro Centre believes that in most instances the right groups have been targeted for HIV prevention. Current epidemiology would indicate that gay men and African people are most at risk of infection, particularly in certain parts of the UK, and these two groups should remain the focus of preventative and HIV testing activity.

4.2 While the right groups have been targeted, the Metro Centre does not believe that the right methods have been adopted to target these groups. While small media definitely has a role in providing information, it is not possible to measure any discernable behavior shift through the over-use of mass media. Campaigning therefore that focuses on these approaches cannot be proven to be successful.

4.3 On the other hand, preventative approaches that are more ‘narrowcast’, that is based on intensive, interpersonal one-to-one interventions can be measured, and can be proven to be successful, or not. The Metro Centre focuses on counselling, mentoring and Health Trainer intervention, often built around a HIV negative test result, as its primary prevention methods, and has developed outcome measurement tools, most notably the BASK Inventory, to measure changes in behavior, attitudes, skills and knowledge.

4.4 The BASK Inventory measures an individuals behavior, attitudes, skills and knowledge at the beginning of the intervention, mid-term, at the end of the intervention, and 6-12 months after the end of the intervention. These measures can be applied individually, and as an aggregate. Included below is a table which demonstrates the aggregate BASK scores for 67 gay men who undertook the HIV prevention mentoring program between June 2008 and May 2010, at the 4 intervals of the intervention, indicating significant positive shifts in all four domains.
5. **To what extent have prevention initiatives targeted at injecting drug users been successful?**

5.1 The Metro Centre has no informed knowledge to be able to comment on this question.

6. **How could prevention campaigns be better delivered and evaluated?**

6.1 The Metro Centre believes that HIV prevention should not be framed in terms of ‘campaigns’. A ‘campaign’ implies some short term, often mass media, intervention, which is not focused on creating long term sustainable change.

6.2 As noted above, the Metro Centre believes that HIV prevention strategies and activity should be focused on measurable, one-to-one, interpersonal interventions, delivered in the right setting at the right time. These are the hallmarks of the Metro Centre’s own mentoring, counselling, HIV testing and Health Trainer interventions.

6.3 As an example, the Metro Centre has developed the ATOM approach to preventing HIV amongst African communities in South London. The premise of the African Testing Outreach and Mentoring (ATOM) approach is that the provision of a rapid, free and confidential HIV test in a community setting, when coupled with pre-test one-to-one outreach, and immediate post-test interventions in the event of a negative result, provide the best opportunity to reduce HIV infection. Research has indicated that the moment of a negative HIV test result is an important time to support individuals to remain negative. The Metro Centre signposts all HIV negative results to its innovative Africasafe and Harboursafe mentoring programs, commissioned by the Kings Fund. ATOM as a preventative approach is intensive and one-to-one, and most importantly, with the use of the BASK Inventory, measurable.
Testing

7. Are current testing policies adequate and could more be done to increase take-up rates?

7.1 The Metro Centre believes that more could be done to increase take-up rates of HIV testing.

7.2 Over the past two years the Metro Centre has observed a significant reduction in the number of HIV testing sites across South London. This is of particular concern because the areas covered, specifically Lewisham, Southwark, Lambeth and Greenwich, have the highest rates of HIV infection in the UK. In 2009, there were at least five different community HIV testing sites for African communities in Woolwich, Brixton, Kennington, Vauxhall and Peckham. At the beginning of 2011 only one of these remains (Peckham). Two of these clinics were pilots (Brixton and Vauxhall) but they were not funded beyond the pilot period.

7.3 The following are some of the strategies that could be adopted to increase uptake of HIV testing:

- HIV tests should remain free, confidential and accessible in a range of settings, to ensure that communities have a suite of options from which to choose;
- The recommendations of the DH funded HIV testing pilots commissioned over 2008-09 should be implemented;
- Community HIV testing options should be expanded, particularly for African communities;
- Rapid HIV test technology should be the norm in all settings;
- Peer-led option for delivering HIV tests should be implemented, following the success of the gay men’s community testing pilot for the DH;
- HIV tests should where appropriate be tied to other tests to either reduce stigma or increase uptake. For instance, providing a HIV test as part of a full STI screen can increase uptake. As well, providing a HIV test as part of a holistic health screen (BMI, cholesterol, hypertension, diabetes etc) can also increase uptake;
- Those geographic areas with highest incidence, in particular parts of South London, should have significant investment in building a suite of community, statutory and GP based HIV testing options; and
- Specifically for African communities, the impact of stigma in declining a HIV test should be measured, and strategies developed and implemented to address issues related to stigma.

Treatment

8. How can the NHS best commission and deliver HIV treatment?

8.1 While the Metro Centre is mostly concerned with HIV prevention, it is commissioned as well to provide some supports to people living with HIV. The Metro Centre believes that treatment for people living with HIV should be conceptualized as ‘treatment and support’, and that integrated pathways should be developed between treatment and support providers.
8.2 The South London HIV Partnership (SLHP) is a good example of Local Authorities working with Health Authorities to provide integrated pathways between treatment and support for people living with HIV. The Metro Centre is commissioned as part of the SLHP to provide service coordination between all workstreams of the Partnership, including counselling, advice and advocacy, HIV support and peer support. The whole Partnership works very closely with all GU Clinics across South London, and has developed formal agreements with most of these GUs for referral and support. The Metro Centre believes that the model adopted by SLHP is feasible, effective, acceptable to service users and most importantly, duplicable.

8.3 The Metro Centre also believes that the voluntary sector has largely remained untapped in relation to health maintenance support for people living with HIV, and that this option should be piloted in various sites around the UK.

9. **How will proposed commissioning reforms impact on HIV treatment?**

9.1 The Metro Centre is already beginning to see the impacts of commissioning reforms on HIV treatment and support.

9.2 Over 2008-10 the Metro Centre has been commissioned within SLHP to provide service coordination through the First Point service.

9.3 As of February 2011, the Metro Centre remains unaware as to whether the SLHP will continue to commission service across 2011-12, and has therefore had to deliver vulnerability to redundancy notices to 5 full time staff. Formal notice of redundancy will need to be delivered on 28 February 2011.

9.4 This commissioning uncertainty for the SLHP is occurring despite the fact that evaluation has demonstrated that across the board the SLHP is an effective, feasible and acceptable HIV support intervention.

**In what setting can treatment be most effectively delivered?**

9.5 See above.

9.6 In the same way that prevention activity and HIV testing should be offered in a range of settings to promote a range of entry points for service users, treatment activity should adopt the same approach. This applies particularly to an increasing role for the voluntary sector.
Cost

10. Have cost considerations been satisfactorily balanced with public health imperatives in HIV:

    Prevention policy; and
    Treatment policy?

10.1 The Metro Centre believes that more work needs to be done on the cost effectiveness of HIV prevention strategies, particularly when balanced against treatment strategies.

10.2 The Metro Centre has a clear understanding of the costs of its own prevention activities, and has compared these costs with the life time costs of HIV infection available from the HIV Consortium and the Health Protection Agency (HPA).

10.3 Using HIV Consortium data, the Metro Centre estimates that 1 person prevented from not becoming HIV+ through a personalised BASK outreach intervention saves £8,784 in the first year.

10.4 Using HPA data, the Metro Centre estimates that the lifetime costs of treating one person infected with HIV in Greenwich are greater than the annual costs of conducting personalised, intensive HIV prevention with over 500 gay men.

Is research funding correctly prioritized?

10.5 The Metro Centre does not have a significant response to this question, except to say that the voluntary sector, particularly in partnership with the statutory and private sectors, has an increasing role to play in relation to research related to HIV prevention.

Stigma

11. What impact does the stigmatisation of HIV have on those infected?

11.1 The effects of stigma are specific and widespread, acutely damaging to health and in the UK are significantly borne by those communities most affected by HIV, gay men and African communities.

Where are problems of stigmatisation most acute?

11.2 Problems of stigmatization are most acute in areas of high prevalence of HIV, and both before infection and after. Stigma plays a significant role in some individuals and communities not seeking or undertaking a HIV test and it plays a role in marginalizing individuals from treatment and support after diagnosis.

What measures can be taken to tackle stigmatisation?

11.3 The Metro Centre believes that stigma is best tackled in partnership with the communities who are most impacted by HIV, and on a service by service basis.
11.4 For example, the Metro Centre provides HIV testing clinics for African communities, and has worked with African people to build, implement and review these clinics. The ATOM approach described above attempted to tackle stigma by recruiting community members to promote the clinics and provide outreach, and by designing the clinics so that they were not perceived by the community to be solely for the purpose of HIV testing. Various of the Metro Centre’s HIV testing clinics were premised on the ‘embedding’ of a HIV test within a broader health screen, so that attendees at the Clinics were not stigmatized as arriving only for a HIV test.

11.5 The Metro Centre believes that the voluntary sector, working in partnership across services, is best placed to design interventions which tackle stigma.

February 2011
Memorandum by Mildmay UK (HAUK 11)

1. We are writing from Mildmay UK regarding treatment for and the impact of stigma upon those infected with HIV in the United Kingdom.

2. Mildmay was established as a specialist voluntary sector service back in 1988 when the only treatment available for patients infected with HIV/AIDS was palliative. With the changing demographics of people infected with HIV, and the greatly increased longevity and reduction in deaths attributed to the introduction of anti-retroviral therapy, the provision of treatment at Mildmay has been transformed. It has changed from being a centre for palliative care for those with HIV to being a rehabilitation centre for people living with HIV. We are concerned at recent proposed changes to the health care funding, which could leave the unique group of patients for which we have care of exceedingly vulnerable.

3. The majority of our work consists of complex assessment and rehabilitation amongst those with advanced HIV disease and AIDS diagnosis particularly those who have been diagnosed with neurocognitive impairment. The group of patients we care for are poorly served by current services, in that a number of them do not fit easily into standardised models of care. Rehabilitation of patients with cognitive impairment is often not best delivered in a traditional acute hospital in patient setting. This unit has developed considerable expertise in enabling these patients with neuro cognitive impairment to be rehabilitated and returned to the community. Currently 45% of our patients return to independent living in communities. Often they then require fewer health and social care interventions as a consequence thereby reducing care costs and improving their quality of life. We also treat patients with complex social situations, significant mental health problems and those dealing with acceptance and adjustment to their diagnosis often in the presence of significant social stigma. These patients often do not engage well with traditional services and hence our belief that specialised services are essential for such patients.

4. Currently a number of London PCT’s commission our services, and amidst uncertainty about funding within the health sector, voluntary sector organisations such as ours are vulnerable to decreases in funding, with potential consequent increasing rates of death and disability in a small but significant number of very vulnerable patients.

5. We are concerned about the impact of the loss of specialised commissioning managers, and are concerned about the capacity for “consortia of consortia” to be able to engage in a commissioning relationship to enable sufficient up front funding to enable this unit to be able to keep its doors open in anticipation of spot purchase needs of individuals within pressurised budgets.

6. We would seek to advocate for all specialised services such as ourselves to come within the National Commissioning Framework envisaged in the 20/80 allocation of funding outlined in the legislation.

11 February 2011
Memorandum by Dr T R Moss, Consultant, Genito-Urinary Physician and Mrs A J Woodland, Prison Nurse (HAUK 25)

HIV/AIDS and the prison population

‘In what setting can treatment most effectively be delivered?’

We would be pleased if your committee might consider the following experience and observation.

This relates to the potential for HIV positive prisoners to become stigmatised. We would also ask the committee to explore whether the development of multiple drug class resistance to anti-retroviral medication whilst in custody has been observed in other areas of the United Kingdom?

These concerns are based on ten years of experience of designing and providing a prison based, holistic Genito-Urinary Medicine (GUM) Service delivered by a coordinated interdisciplinary team. This consisted of a Specialist Prison Nurse with extensive specialist training in GU/HIV care, working with a visiting NHS Consultant GU Physician. Each team member’s skills were complementary, covering physical, psychological and social needs.

Prison is a community, which differs markedly from a community that most people would conceptualise. It is extremely difficult to implement the community health care model into the individual Institution. Each prison receives the appropriate category of prisoners for that establishment. Therefore each prison is individually managed. No two prisons are the same. Further, prisoners themselves behave and function differently in the custodial setting in comparison with the outside community.

The combination and concentration of high-risk behaviours in this population: IVDU, alcohol abuse, literacy issues, increased mental health issues and extremely chaotic lifestyles are cumulative factors, which create these substantial differences.

It is the combination of these factors, which make the prison population so vulnerable to all sexually transmitted infections and HIV/AIDS.

We have become aware that there are small but increasing numbers of prisoners who enter prison whilst taking combination anti-retroviral therapy. Those who are well controlled may begin their sentence with an undetectable viral load and a reconstituted immune system.

We have observed that the carousel movement of prisoners from one institution to another may interrupt anti-retroviral therapy. This is known to rapidly lead to virus mutation leading to the development of drug resistance. Access to expert, continuous care, with monitoring for drug resistance, by Specialist Physician and Specialist Nurse allows the introduction of alternative and expensive anti-retroviral therapeutic regimes where indicated. Such continuity of care is difficult to maintain throughout a prison sentence due to inevitable transfers.

Our experience leads us to advocate that ‘in-house’ Genito-Urinary Medicine clinics promote adherence to therapy and thus maintain the efficacy of combination of drug
Memorandum by Dr T R Moss, Consultant, Genito-Urinary Physician and Mrs A J Woodland, Prison Nurse (HAUK 25)

...treatment. It also supports psychological health and well being. The continuity of care establishes a positive therapeutic clinician-prisoner relationship. It is also the only means by which the stigma of this disease may be avoided by preservation of confidentiality.

Absolute confidentiality is the basic tenet of effective diagnosis, management and control of all STI's. Prisoners who are referred to hospital GU departments must be accompanied by prison escorting staff. There is a security requirement that prison officers remain present throughout the confidential consultation and intimate examination. This necessity is understood and is not contested. The security requirement, however, clearly compromises each patient's confidentiality. It is necessary for the hospital based, Specialist Physician to provide written reports to prison health care staff. The computerisation of prison health care records may further compromise confidentiality. Quite simply, if a prisoner attends a hospital department we cannot, for the above reasons, maintain those levels of absolute clinical discretion, which forms the foundation of HIV medicine. This is a further deterrent to continuity of care and absolute compliance with therapy.

Within our civilian population most newly diagnosed HIV infections are acquired by heterosexual intercourse (ratio approximately 2:1; hetero-sexual: MSM). It is therefore observed that prisoners may return to civilian life with multiple resistant HIV presenting a serious risk to any future sexual partner and to the Nation’s Public Health. Onward transmission of HIV increases with a rising viral load. The subsequently infected partner/s will be host to the same drug resistant, viral type. Further onward transmission becomes inevitable. We would therefore hope that your committee would address the very limited availability of ‘in-house’ GU/HIV Specialist prison services.

We are sorry to record that our own ten years of service provision ceased 28/08/2010.

This communication records our own personal, professional observations and concerns. They do not relate to any policy of prison or hospital employer.

February 2011