SELECT COMMITTEE ON HIV AND AIDS IN THE UNITED KINGDOM

HIV and AIDS in the United Kingdom

Written Evidence

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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 due 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 from 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.1 The 2007 IMD2 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.
3.3 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.

3.4 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.

4.0 Evaluation of HIV Prevention with African Communities

4.1 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.

4.2 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.

4.3 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.

5.0 Targeting HIV Prevention Work

5.1 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

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 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?
• 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. One in seven gay men on the London gay scene has HIV, compared with one in 14 nationally.

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.

• 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

• 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.

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5 According to figures provided by the Terrence Higgins Trust.
6 According to a poll taken by Ipsos MORI for the National AIDS Trust of public understanding of and attitudes to HIV.
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.
Memorandum by the All Party Parliamentary Group on HIV and AIDS (HAUK 104)

- 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?

- 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.

• Significant numbers of people living with HIV are affected by depression and other psychological problems which are exacerbated by problems of stigmatisation.8

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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’.

- There are many examples of good practice where faith communities are engaged in HIV prevention, awareness and support, (for example in Mosques

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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)

1. 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 disproportionably 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
Memorandum by the Association of British Insurers (HAUK 41)

1 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.

2 Executive Summary

2.1 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.

2.2 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

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

1.1 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.

2 Could anything be done to improve monitoring?

2.1 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.

3 What groups in particular are at risk from HIV?

3.1 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 Association of Directors of Public Health (HAUK 36)

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

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

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\textsuperscript{10}. 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\textsuperscript{11}.

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

\textsuperscript{10} HPA ‘HIV in the United Kingdom: 2010 report’
\textsuperscript{11} 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
Memorandum by Professor Virginia Berridge (HAUK 72)

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

1.1 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 to 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
d. Increased level of funding for both social and medical research enabled investigation of the parameters of the syndrome.

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. 12

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.

Memorandum by Professor Virginia Berridge (HAUK 72)

- 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
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.

David Cameron

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.
Memorandum by Mr David Bridle, Managing Director of Boyz magazine (HAUK 13)

Image 3
THT, Proximity
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 0845 121 200 or visit www.thinkHIV.co.uk
Image 6
THT, THIVK You’re Still Negative?

THIVK
YOU’RE STILL NEGATIVE?

THOUSANDS OF GAY MEN HAVE HIV FOR YEARS
WITHOUT KNOWING

THT DIRECT 0845 12 21 200
Image 7
THT, I Did it For Love

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 FOR LOVE

CHAPS
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](http://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.

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.
National Gay Men’s Sex Survey

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
Memorandum by Bristol-Myer's Squibb (HAUK 99)

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
Submitted on an individual basis.

1. 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.
<table>
<thead>
<tr>
<th>Similarities</th>
<th>Differences</th>
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<tr>
<td>A formal tendering process and a 3 year commissioning cycle.</td>
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<tr>
<td>▪ SLHP has a lead commissioning function, clearly defined governance, a performance management framework and clear accountability arrangements</td>
<td></td>
</tr>
<tr>
<td>▪ PLHPP does not.</td>
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| 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 |  |
| ▪ SLHP 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\(^\text{13}\). 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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\(^{13}\) 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

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14 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.15

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 CHIVA16. 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)17 which has been produced by a national association of Paediatric HIV Health Practitioners.

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17 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

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18 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
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\(^{20}\). 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\(^{21}\) 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


\(^{21}\) 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
i) 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)

I. 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-morbidity, 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
Memorandum by the Ministry of Defence (HAUK 95)

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 a 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
HIV campaigns

HIV infection rates in a community depend on sexual behaviour, good testing facilities and attitudes to testing, condom use and disclosure of status. Good creative communications plays a major role in all of these.

Behaviour and attitudes can be significantly influenced by engaging campaigns. Improved testing services and new testing methods need to be well communicated if they are to be accessed by the target groups.
Communication objectives

For the purpose of this submission we are only focusing on our work with Terrence Higgins Trust and the CHAPS partnership to reduce HIV infection in the UK gay community.

In order for any health promotional message to get noticed in the gay press or in gay venues it has to stand out in some way. To then be read it has to be compelling enough to entice the viewer to invest their time in reading further. To be understood the message has to be clear and concise. These factors are all dependent on how the premise is translated into a compelling communication vehicle - the communication strategy.

We always start the creative communication process from the assumption that no one will be at all interested in what the intervention has to say - even though it could affect their health. The reader has to be encouraged to first notice the intervention, then read it and then act upon it. So just placing the premise as a headline on a page with an enticing image is not an option in most circumstances. The exception to this is when the campaign premise is so shocking that it is compelling in its own right. For example “One in seven gay men in London have HIV”.

The first phase of campaign development is to drill down to discover precisely who the target audience are. The narrower the target the more focused we can make the message to appeal to them. For example, in the attached THINK HIV campaign case study (appendix 2), we were only aiming at men who thought they were HIV negative. Then we need to establish precisely how we want readers to react to the message and what course of action we want them to take. For example, in the attached PEP campaign case study (appendix 5), we wanted gay men to realize that PEP treatment should only be sought in an emergency and it isn’t the equivalent to a ‘morning after pill’. Using our insight into the audience and the issue, we then look for an delivery angle and how to make the idea campaignable (i.e. multiple execution). This part of the development process combines both lateral and logical thinking. For example in the attached STI campaign case study (appendix 7), we used the angle of men’s vanity as a reason why they should get tested.

Another communication consideration is what would be the best platforms or media to reach the audiences. Different messages and different audience groups often require different approaches via media that best suits them. Social media networks have been explored recently but HIV prevention doesn’t always generate the interest within the target groups that have been expected or sought. The gay press tends to still be the most targeted medium to reach the audience, but a lot of men who are not ‘out’ or do not frequent the gay scene may only come across health messages online (e.g., a web banner on Gaydar). So we believe that campaigns need to combine all media options and that the mix of these options will vary according to the specific message and the target audience.

Once the communication angle has been established, we develop an appropriate visual styling that will not only attract the target audience, but will stand out in the visually ‘noisy’ gay press. We also attempt to introduce different styling from previous campaigns so they are distinctive and will not be confused.
Communication issues

Avoiding victimisation and criminalisation of gay men with HIV
All our campaigns carefully avoid any messages that may be deemed offensive by HIV positive men. If the message is perceived as persecuting, stigmatising, criminalising or ostracising positive men this could in turn reduce their self esteem which in turn could lead to them engaging in sexual risk taking and encourage non-disclosure. But also, Terrence Higgins Trust and other HIV/AIDS charities invest significant resources into supporting people living with HIV and a significant source of funding derives from donations from people living with HIV as well as from their friends and families. So their health promotional messages must be acceptable to this group.

Reaching a diverse audience of gay men
The demographics in the gay community are diverse. Men of all ages. Men from all socio-economic backgrounds. Men from different geographic locations where there are differing attitudes to homosexuality and differing clinical facilities. Men from different cultures in which there is HIV stigma and differing attitudes to sexual orientation. Men from different educational backgrounds. Men whose first language is not English. Men on the gay scene. Men who don’t seem to be that worried about HIV and of course men with HIV.

This diversity of mindsets creates significant communication challenges. HIV-related campaigns either have to be personalised to empathise with specific groups or ‘tribes’ which can be a strain on the limited budgets. Or their messages have to be appropriate to all audiences without having to be ‘dumbed down’ in the process.

Safe sex message fatigue in the gay community
For over 30 years the gay community has constantly been bombarded with safe sex messages and so inevitably there is a degree of fatigue and arguably the message can becomes wallpaper. Sexual health campaigns therefore have to be smarter, more engaging and more compelling than ever if they are to be read, remembered and ultimately influence behaviour and attitudes.
Memorandum by Felton Communication (HAUK 84)

Didactic versus nudge
Terrence Higgins Trust and the CHAPS partnership have always had strict rules to ensure their intervention are not didactic in nature. For over 10 years we have been adopting what is now labelled “nudge” approach. The downside of this methodology is that the press has often criticised our clients and ourselves for not providing clear instructions for gay men to follow. There is often a fine line between telling people what to do and suggesting a course of action or a change in behaviour that might benefit them.

In the pursuit of non-didactic interventions, we fear that there have been occasions when perhaps a clearer ‘call to action’ was needed to improve the effectiveness of the message.

Authority versus a trusted friend
There is no doubt that Terrence Higgins Trust is pre-eminent in the HIV and sexual health sector in the UK and especially in the gay community. So an intervention with their logo on it will provide a sense of gravitas that the advice or information contained is credible and can be trusted. The flip side of this is that as Terrence Higgins Trust has grown over the past almost 30 years their status as “one of us” in the gay community may have become blurred. This means that for some groups of men, especially some on the gay scene, the messages may be viewed as being from an institutional source and therefore government derived.

It is therefore critical that Terrence Higgins Trust and other larger HIV charities strive for the right balance of authority by ensuring that their expectations are realistic and their tone of voice remains real.

Partnership issues
Another factor that adds to the difficulty of developing truly compelling and effective campaigns is the inevitable politics that is present within any partnership. In the case of CHAPS, where each partner can have different approaches to health promotion, there will be differences of opinion on our proposed communication methodologies as well as creative strategies. Though this can be helpful it can also affect feedback and support of a particular conceptual strategies to the extent of dumbing down the messaging. Fortunately, the focus groups that are set up with target audiences to test all our campaigns highlight any unintended messaging and determine in advance whether the concepts are likely to be effective.
Appendix 1 - The bottom line
HIV transmission campaign

“Truly outstanding. Witty yet informative communications that were intended to catch the audience off-guard long enough for them to take in the important messages of the campaign.”

Judge’s statement in awarding the campaign a CIB

Rectums are absorbent. That's a fact that gay men have to contend with when having unprotected anal sex. Over 25 years, however, they'd been bombarded with messages about safe sex and the dangers of the HIV virus. When Terrence Higgins Trust asked us to run a campaign to raise awareness of HIV transmission during unprotected anal sex, we knew we had to try a different tack.

After three rounds of pre-testing with focus groups which included HIV positive gay men, we settled on arse-shaped imagery: two eggs; two sponges; a peach. Each communicated a simple message: about fragility; absorbency; and STIs. Each was designed to stand apart from the typical cluttered adverts seen in the gay press. Each had enough tongue-in-cheek humour to attract attention, without being patronising.

We placed the ads in a variety of gay publications. We also produced an anal care booklet, anal care workshop flyers and a sponge gimmick shaped like a bottom, distributed by outreach workers at gay venues across the UK.

Research carried out after the campaign was overwhelmingly positive. Respondents said it had reaffirmed the need to use condoms and clearly conveyed the different messages. It had made gay men think about the type of sex they had. And, importantly, it had been produced with the correct degree of interest, respect and relevance to all gay and bisexual men.

That's the bottom line.
Appendix 2 - Thinking ahead

National campaign

Terrence Higgins Trust needed to increase the awareness of the possibility, extent, duration and outcome of undiagnosed HIV infection within the UK gay community. Currently, one in three HIV positive gay men aren’t aware that they are positive. And the average time between infection and diagnosis is four years. This clearly has implications.

A three part integrated campaign was planned to encourage gay men to take an HIV test and so reduce the time between infection with HIV and diagnosis. Our objective was to develop a distinctive campaign with legs. A concept that we could use to deliver the facts whether via ads, outreach gimmicks, condom packs, banners, t-shirts etc. We wanted to develop a campaign ident that could be used for this campaign and have the longevity to work on future HIV health promotion to the wider population. Our solution has done just that.
“Of all our recent interventions, the one that gained the most universal interest and approval from the end users was the THINK HIV campaign.”

Richard Scholey, National Social Marketing Manager
Appendix 3 - Like it is

Sex and drugs resource

Some gay men use drugs to enhance sex. On the gay scene, it’s called ‘chemsex’. It’s been going on for years. Terrence Higgins Trust knew this. It also knew that gay men had died or contracted HIV as a result of chemsex. And it understood that many HIV positive gay men weren’t aware of the dangers of mixing their medication with street drugs. So it asked us to develop a campaign to raise awareness.

We knew it had to be real. We knew it had to get noticed. So, we called it ‘drugf**ked’. Twelve leaflets on twelve different street drugs, from cocaine and ecstasy to poppers and steroids. For each drug, we developed a unique character. For each leaflet, we used copy that told the truth – both the highs and the lows – about street drugs. Then we distributed them around gay clubs and bars, while the message was simultaneously promoted online.

We knew the campaign had to tell it like it is. As a result, it was criticised in some parts of the press. To us, though, that was a result. It helped to further raise awareness of the dangers of chemsex and mixing drugs among gay men. Sometimes you have to tell it straight.
Appendix 4 - Get an icon
Condon reinforcement campaign

“Being sex positive it aligns beautifully with Terrence Higgins Trust’s ethos.”

Marc Thompson, Deputy Head of Health Promotion, Terrence Higgins Trust

In amongst the clutter of sexual health campaigning, the matter in hand – sex – sometimes gets forgotten. Terrence Higgins Trust wanted to change this. It has a simple core message. Sex is universal. Sex is good. Sex should be safe. So they asked us to develop an iconic, sex positive campaign to break through the background noise.

Our response was straightforward: a message that stated, simply, get it on. A clever slogan and eye-catching ident, however, wasn’t enough. We had to ensure that the message would be seen - initially within the gay community.

So we developed a range of materials featuring the logo, including t-shirts, condom dispensers and magazine ads. In addition, we also produced light boxes displays featuring the logo, which have been installed in gay bars and clubs across the UK.

The campaign had extremely positive pre-test results among gay men. Now we’re hoping to take it further, rolling it out in straight bars and clubs, and reaching the tipping point when the logo becomes a universal cultural icon. So when people get it on, they remember to get it on.
In the gay community, PEP had the reputation as the morning after pill. The myth was that if you’d had unprotected sex with someone who was HIV positive, you simply took PEP and you wouldn’t get HIV. Terrence Higgins Trust knew it wasn’t that easy. It asked us to create a campaign to refute this misinformation.

We knew we had to keep the messaging simple: after all, PEP isn’t a single pill. It’s a month-long course of combination therapy with unpleasant side-effects and you must start the treatment within 72 hours. So it’s only for emergencies. Our creative solution was equally straightforward: an image that evoked an emergency, with accompanying copy succinctly explaining the reality of PEP.

The results were staggering. Awareness levels in the gay community doubled as a result. Simultaneously, the number of clinics offering PEP also doubled. And, to top it all, the campaign was awarded a BME Patient Information award.

That’s a fact.
Appendix 6 - Pull your finger out
Rapid HIV Test campaign

Our latest campaign promotes the new HIV Rapid Test in London. The simple finger prick test gives accurate results within 20 minutes rather than up to two weeks as in the past. The online and offline campaign is the latest of a series which attempts to chip away at the perceived barriers in testing.

The route was unanimously well received in the pre-testing focus groups. Men found the approach humorous, engaging and most importantly, informative. The beauty of the idea and its delivery lay in its simplicity. The message of convenience and speed cuts through gay men’s apathy towards testing.

We pulled our finger out again to create another powerful campaign.
Herpes. Syphilis. Chlamydia. Gonorrhoea. Non-specific urethritis. All are members of the STI family. All infect the members of the gay community. Many gay men, however, were not getting tested and so the problem was getting worse. Much worse. So Terrence Higgins Trust asked us to devise a campaign that would turn their heads and change their attitudes towards testing.

Our first step was positioning: we decided to appeal to their vanity rather than adopt the usual scare tactics. Then we developed a creative approach that would grab their attention and used the tagline, “So get it checked. Get back out there”. We used five male models, each designed to turn heads, wearing nothing but a pair of pants. Unlike the Calvin Klein ads, each pair of pants had the name of an STI on it and each model displayed an extra element of realism, depending on the nature of the infection. The government's “Essential wear” condom campaign have since used the same idea.

The response was overwhelming. STI testing increased. We were commissioned to do another series of ads for both straight men, and straight women. And the creative approach is a pioneer in sexual health messaging.

It’s all in the pants.
Appendix 8 - Challenging behaviour
Anti-homophobia campaign

“We’re proud that this was the first ever anti-homophobia campaign in Europe.”

Faggot. Poof. Batty boy. The words alone are offensive. But Terrence Higgins Trust was more concerned about the attitudes surrounding homophobia. They knew that increases in homophobic abuse led to increased sexual risk taking by those being abused. Which in turn led to increased HIV infection. So they asked us to design a series of campaigns targeted at the non-gay community.

Over ten years, we have run three distinct campaigns. The first was aimed at the general public, and included press ads in Loaded and the News of the World, as well as a cinema commercial. Featuring the slogan, It’s prejudice that’s queer.

The second was aimed at the black community, where homosexuality is still a taboo subject, and featured bus shelter posters in areas with high BME population densities. Our aim was to get the issue discussed. The third was targeted at mothers, and used advertorials in Take a Break and similar magazines to get the message over.

All have succeeded in raising awareness. The first was reproduced by the police force and the Halifax in their in-house magazines. The second resulted in phone-in discussions on black radio stations and equally frank exchanges on BBC online. The third had one of the highest levels of positive pre-testing we’ve ever experienced.

And, while the words are still used, the attitudes have been challenged. But it’s a slow process.
Appendix 9 - Back to the future
Syphilis awareness campaign

The last time syphilis reared its ugly head was back in the 1970s. Thirty years later, it was back with a vengeance, spreading quickly among a certain group on the gay scene. The Department of Health asked Terrence Higgins Trust to run a campaign to help stamp out the disease. So Terrence Higgins Trust turned to us.

The campaign had to overcome three challenges. First, to raise awareness of an infection among a generation of young men raised solely on HIV education. Secondly, to cut through the myriad of marketing messages aimed at the target audience. And, finally, to not cause panic within the community.

So we went back to the future. Retro images. Retro typography. Retro styling. The idea was engagingly sexy, and suitably creative. Ads were placed in the gay press. Banner ads on Gaydar. Posters and promotional gimmicks distributed to gay bars and clubs around the country.

The campaign ran for three months and was a great success. The number of gay men attending sexual health clinics doubled. Visitors to gaydar voted it their favourite campaign, ahead of Virgin and Ford. And the NHS asked Terrence Higgins Trust to repeat the campaign in Scotland.

Most importantly, the infection was stopped in its tracks.

Explicit image not published. The full version of this evidence is available in the Parliamentary Archives (http://www.parliament.uk/business/publications/parliamentary-archives/).
“The Department of Health was so pleased with our campaign, it funded Terrence Higgins Trust to rerun the campaign in the gay press.”

Richard Scholey, National Social Marketing Manager

June 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.

**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
Memorandum by Sarah Stephenson, Programme Manager for Sexual Health & HIV, Greater Manchester Sexual Health Network (HAUK 82)

- 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 NHS.

13. What can be learnt from the experience of the London SCG in using HPA indicators to monitor HIV treatment and care more widely?

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22 “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
Supplementary Memorandum by Sarah Stephenson, Programme Manager, Sexual Health & HIV, Greater Manchester Sexual Health Network and Sarah Doran, Public Health Manager, NHS Manchester (HAUK 103)

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.
Supplementary Memorandum by Sarah Stephenson, Programme Manager, Sexual Health & HIV, Greater Manchester Sexual Health Network and Sarah Doran, Public Health Manager, NHS Manchester (HAUK 103)

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:
Memorandum by the Haemophilia Society (HAUK 42)

‘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
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.23 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.\(^\text{24}\) £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.\(^\text{25}\).

**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

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 HPA26 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 27.

d.3. In addition, the joint British HIV Association, British Association of Sexual Health and HIV; and British Infection Society guidelines for HIV testing 28 recommend offering HIV tests to the following groups, who may be regarded as being ‘at risk’ of HIV infection:

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• 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.29 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.30

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.31

a.9. Thanks to combination ART, the life expectancy of someone living with HIV has increased markedly over the last 15 years. Recent research32 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.33

c.2. In addition, needle and syringe sharing has declined in recent years, but around one-quarter of injecting drug users continue to share.34

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.35

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.36

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.37 The vast majority of HIV-infected injecting drug users in contact with specialist HIV treatment services are receiving ART.38

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.\(^{39}\)

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.\(^{40}\)

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

\(^{39}\) Publication in preparation

\(^{40}\) Prescription for change, Barton S, The House Magazine, 25 May 2009
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. 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

Memorandum by the “Halve It” Coalition (HAUK 50)

recommendation of the 2008 British HIV Association, the British Association for Sexual Health and HIV and the British Infection Society National Testing Guidelines. 47,48

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 clinics49.

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 150), which demonstrates the key role testing can play in HIV prevention.


Memorandum by the “Halve It” Coalition (HAUK 50)

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{51} WHO issued guidance on provider-initiated HIV testing and counselling in health facilities\textsuperscript{52}. 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{53} 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.

**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{54} 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{55} 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.

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Memorandum by the “Halve It” Coalition (HAUK 50)

a.2. In 2010, a study to demonstrate the cost effectiveness of screening in the French population was published.56 This evidence led to national recognition and support of a nationwide testing programme which was published by the HAS in late 2010. A subsequent publication57 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$^3$)

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.

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\(^5\) 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

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
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 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).
Diagnosed HIV-infected persons living in Scotland | 3803
---|---
Number of HIV-infected persons attending for specialist care and treatment | 3254
Average number of new diagnoses per annum over last six years | 400

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 that 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&Page&HPAwebAutoListName/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

c) To inform the targeting of health promotion, the evaluation of preventative measures, and the planning of medical and social services for those affected by HIV.

3. 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 immunosuppression 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 from 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>
</tr>
</thead>
<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.
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**

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 received 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)

![Bar chart showing proportions of MSM and heterosexual routes of HIV acquisition 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 outside the UK)

![Bar chart showing number of heterosexually acquired HIV infections and non-UK nationals infected outside the UK from 2005 to 2009.]

Year              | Number of infections | Non-UK nationals infected outside the UK
---                |----------------------|------------------------------------------
2005              | 200                  | 170                                      
2006              | 180                  | 150                                      
2007              | 200                  | 175                                      
2008              | 180                  | 150                                      
2009              | 200                  | 170                                      
Depending upon the group being targetted, 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 targetted 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 targetted 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/ 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 ) 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.
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.

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?

There can be no doubt that HIV treatment must be delivered within specialist HIV treatment centres. Outcomes are improved for patients in relation to a number of factors, including level of throughput of clinics.

[http://www.namlife.org/cms1254921.aspx](http://www.namlife.org/cms1254921.aspx) and

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 [http://www.hivscotland.com/documents/HIV_Report.pdf](http://www.hivscotland.com/documents/HIV_Report.pdf) 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 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/ 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.

Healthy Working Lives has an excellent network, support and information for employers, and should promote more proactively sexual and HIV-related health http://www.healthyworkinglives.com/advice/workplace-health-promotion/sexual-health.aspx

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/
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 the International Centre for Prison Studies (ICPS)\textsuperscript{59} (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.’\textsuperscript{60} 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:

\textsuperscript{59} 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.

\textsuperscript{60} National AIDS Trust (2011) \textit{Injecting drug users and HIV}. London: NAT. p2.
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.\(^{61}\)

In 1997 UNAIDS stated

\[T\]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.\(^{62}\)

A substantial number of documents have been produced based on these principles setting out in more detail what is required from national prison systems.\(^{63}\)

**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.\(^{64}\) 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.\(^{65}\)

A study in Northern Ireland’s prisons published in 2005 gave figures of five prisoners with hepatitis B, seven with hepatitis C and none with HIV.\(^{66}\)

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.\(^{67}\) 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.

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\(^{63}\) See, for example, United Nations Office on Drugs and Crime (2006) HIV/AIDS Prevention, Care, Treatment and Support in Prison Settings. New York: UNODC.


\(^{67}\) HL Deb 10 Mar 2010: Column 351W.
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.’\(^{68}\) 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.\(^{69}\)

**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).\(^{70}\) 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.”\(^{71}\)

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.\(^{72}\)

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.’\(^{73}\) 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:

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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 disproxil 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
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 £236 million in 2009/2010 of which £155 million is spent on antiretroviral treatment, £15 million on non antiretroviral medication and on high costs diagnostics, £59 million was spent on infrastructure and £6 million on inpatient care. The estimated budget for 2010/11 is £241 million.

2. The LSCG budgeted estimated was £246 million (2009/2010) for London and a £9 million 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 £236 million / 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](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](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

 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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<tr>
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<th>Costs</th>
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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>2009/2010</th>
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<td>% Deviation</td>
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**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

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<th>Female Caseload (Thousands)</th>
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## Supplementary memorandum by Kevin Kelleher (HAUK 39)

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<th>Female (Thousands)</th>
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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".

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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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Gender of claimant

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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:** DWI 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

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Supplementary memorandum by Kevin Kelleher (HAUK 39)

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Supplementary memorandum by Kevin Kelleher (HAUK 39)

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Denote information obtain from NHS statistic database

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**Total spend:**
- £59,200
- £928,811
- £1,200,00
- £2,465,00
- £1,832,37
- £1,311,13
- £2,650,92
- £1,522,00
- £1,622,00
- £1,585,00
- £1,666,00
- £42,000
- £1,232,50
- £1,11,142
- £1,037,45
- £1,106,71
- £7,561
- £1,070,70

**Total payments:**
- £1,138,74
- £1,695,13
- £1,135,74
- £991,447
- £1,832,37
- £1,311,13
- £2,650,92
- £1,522,00
- £1,622,00
- £1,585,00
- £1,666,00
- £42,000
- £1,232,50
- £1,11,142
- £1,037,45
- £1,106,71
- £7,561
- £1,070,70

**Note:** The table above shows the distribution of spending across different categories such as carers, DWP, DOH, and others, with specific amounts and percentages allocated to various boroughs and regions.
### Supplementary memorandum by Kevin Kelleher (HAUK 39)

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### Abbreviations.

- **No. - Number**: Denotes additional income from Primary Care Trust
- **Bold**: Denotes FOI response relates to how the income is spent for that financial year
- **DWP - Dept. Work Pensions**: Denote additional through the allocation of Dept. for Schools and Families (Aim High)
Supplementary memorandum by Kevin Kelleher (HAUK 39)

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![Graph showing distribution of No. of Authorities asked and Total No.](chart.png)
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:
  o Diagnosed – people living with HIV have the skills and confidence to work together to live well and prevent onward transmission.
  o Affected – culturally and age appropriate support, advice and information is available to carers, partners and family members who support an HIV positive person.
  o Undiagnosed – targeting the ‘at risk’ populations to increase access to testing and decrease the time between infection and diagnosis.
  o 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-stigmatise 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 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 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 lose 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
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

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Memorandum by the Medical Research Council (HAUK 58)

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 HIV\textsuperscript{77}, 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 trial\textsuperscript{78} \textsuperscript{79} 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)\textsuperscript{80} 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.

\textsuperscript{78} Routine versus clinically driven laboratory monitoring of HIV antiretroviral therapy in Africa (DART): a randomised non-inferiority trial, DART Trial Team\textsuperscript{;}
The Lancet, Volume 375, Issue 9709, Pages 123 - 131, 9 January 2010
http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(09)62067-5

\textsuperscript{80} 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-1 RNA by the viral Gag protein
- Role of ESCRT-I and ESCRT-II in HIV-1 budding
- Role of the secretory pathway in HIV-1 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
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 naïve 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 neurocognitive 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
Supplementary Memorandum by Mildmay UK (HAUK 108)

Following our submission to this committee in February and the recent discussion about our work in the House of Lords (Evidence Session No.9, Tuesday, 8 March, 2011) we thought it right to present the following late submission to inform the committee of the increasingly grave situation currently facing Mildmay’s UK unit.

In 1988, Mildmay Mission Hospital UK was opened as the first hospice in Europe for patients with HIV and AIDS in response to the growing epidemic of HIV infection in the United Kingdom. Whilst palliative care is still provided to a small minority of patients, the advent of antiretroviral therapy has changed both the course of the disease and the nature of our work in the UK.

HIV remains a significant and growing problem in the UK with an estimated 86,500 people living with HIV, a figure which has been predicted to grow to 100,000 by 2012 in a recent Health Protection Agency report. The nature of the care required for patients with HIV infection has changed. However, a significant number of patients continue to be diagnosed in the late stages of disease. It is also becoming clear that HIV infection increases physical ill-health due to it increasing the risk of serious events other than AIDS, including heart disease, cancer, neurocognitive impairment and other diseases associated with ageing. This appears to be happening to patients at an earlier age than their peers without HIV infection. The disability caused by these problems is often compounded by mental health problems, stigma, and difficult psychosocial circumstances.

Mildmay Mission Hospital UK remains a unique and specialised setting that continues to serve the needs for the most vulnerable affected by HIV infection. It has responded to the changing needs and presentation of people living with HIV over time, evolving to be the sole hospital in Europe providing a comprehensive rehabilitation program for people with neurocognitive impairment and associated physical and mental health impairments caused by HIV. It has become an internationally renowned centre of excellence in rehabilitation of HIV-related neurocognitive impairment. Such a specialised service with intensive physiotherapy, occupational and speech and language therapy, medical and nutritional intervention, neuropsychological input and social care is not possible within a normal NHS setting.

The need for the specialist rehabilitation service provided by Mildmay Mission Hospital UK is increasingly vital, particularly as those living with HIV age. However, in the context of recent rapid change and the requirement for cost savings within the health service, issues with securing funding for placements from the Primary Care Trusts have resulted in a fall in patient numbers and subsequent closure of one ward in the hospital. This could threaten the financial viability of the hospital and force it to close permanently.

An admission to Mildmay Mission Hospital involves a period of assessment which allows therapy to be tailored to a patient’s individual needs. Some patients may require a brief period of physical and psychological respite before going home, where as others will require intense therapy for a number of months in order to be able to adequately and safely carry out activities of daily living and function at a level conducive to a safe discharge.

Neurocognitive impairment remains very challenging to treat. An essential aspect of treatment for HIV-related neurocognitive impairment is strict and timely adherence to antiretroviral medication. Mildmay Mission Hospital UK provides a step-wise programme...
with increasing impetus on the patient to ensure effective drug adherence. Poor self management of HIV-related neurocognitive impairment can lead to poor adherence which affects viral load and infectivity, in a group of individuals which has increased rates of risk taking behaviours due to their cognitive state. This could lead to increased transmission rates of HIV, and increased costs as more expensive drugs may have to be used if viral resistance occurs.

There remains a substantial minority of patients who due to difficult psychosocial circumstances, neurocognitive impairment, or stigma and trust issues that do not engage well with traditional services. Many of these patients have been kept alive and able to function independently due to the unique care that Mildmay provides.

Mildmay Mission Hospital UK also runs a programme of day services which provide a vital facility for patients that have been discharged home (via Mildmay or directly from hospital). Their timetable of activities includes a gardening group, music therapy, art therapy and external trips. This service also provides a safe environment for social interaction for a frequently isolated and vulnerable subset of people living with HIV, and helps them further develop necessary social skills within a rehabilitative environment.

The closing of the only UK service dedicated to the rehabilitation of patients with this condition at this time does not make clinical or economic sense. For instance, our programme of rehabilitation prevents many patients requiring lifelong care in a nursing home, as many of our patients return to independent living in the community. Closure has the potential of making the quality of life for these patients considerably poorer, and would lead to worse health outcomes including increased rates of death and disability in this group of patients living with HIV.

July 2011
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-retro viral 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
Memorandum by the National African HIV Prevention (NAHIP) Programme (HAUK 59)

Evidence being submitted from the National African HIV Prevention (NAHIP) programme answers the committee’s questions in relation to HIV and AIDS amongst Africans living in England. The NAHIP programme 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 current systems for HIV surveillance produce robust and respected monitoring data on many different aspects of the HIV epidemic in the UK. The data is used locally and nationally to assess need and understand the changing epidemic, but the data is mainly quantitative and based on clinical records. NAHIP and its agencies are reliant on the information provided by the HPA to design, commission and plan prevention work, but are aware of gaps which exist within the data regarding those who have not sought clinical intervention.

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

The Department of Health White Paper81 proposes the creation of a new public health body, Public Health England, into which the Health Protection Agency will be incorporated. This aims to “strengthen public health surveillance” and “develop and enhance the public evidence base” (para 4.78) by integrating all 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 impacts:

- According to the proposals, Public Health England will take on the current functions and powers of the HPA. There will be substantial negative impacts if the functions are not transferred in full and some functions of the current HIV monitoring systems are lost. It is imperative that the reforms do not result in 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 possibly transparency in HIV monitoring. Even after incorporation into Public Health England, HIV surveillance and analysis must remain free from a politicised agenda.
- The proposed funding and commissioning structure, where prevention is likely to be commissioned by Public Health England and treatment commissioned under the NHS, risks fragmentation of monitoring treatment and diagnosis.

Some impacts of the proposed reforms are not yet clear as, although the Department of Health has promised to safeguard the income generating activities of the HPA82, it is not yet clear how much will be spent on public health monitoring.

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81 Department of Health, “Healthy lives, healthy people: our strategy for public health in England”, 30th November 2010
c. Could anything be done to improve monitoring?

The national HIV prevention programmes, NAHIP and CHAPS, have supplemented HPA’s monitoring of the key populations at higher risk with independent research. The programmes have proved ideally placed to investigate and provide detailed insight into particular trends identified by national HIV prevalence data. The research has been used to improve prevention initiative design and commissioning both inside and outside the programmes.

However, as NAHIP’s research funding is limited, the HPA could support the programme with more regular community profiling and provision of qualitative data. Publishing special reports annually, such as the 2008 report on “Sexually transmitted infections in black African and black Caribbean communities in the UK”, would significantly improve monitoring and understanding. This could be achieved by increasing opportunities for joint working between the HPA and other programmes investing in research into specific aspects of the UK’s HIV epidemic.

NAHIP would also welcome cross-departmental collaboration between the Home Office and HPA to produce monitoring data on the number of people living with HIV who are in detention centres and who are deported, as this is not currently available.

d. What groups in particular are 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. 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). In 2009, 54% of all new diagnoses in the UK were acquired through heterosexual sex, of which 63% were in black Africans.

NAHIP 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. 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:
  In the UK, African men who have sex with men are twice as likely to have HIV as those who do not have sex with men. A 2004 study showed that African men who have sex with men are twice as likely to be living with HIV as white men who have sex with men.

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83 E.g. Bass Line 2007-08, 2008-09 and the Gay Men’s Sex Survey
86 Health Protection Agency: HIV/STI Department (2010) “United Kingdom: New HIV Diagnoses to end of June 2010”: Table 10 and Table 11
87 Mayisha II Collaborative Group (2005) “Assessing the feasibility and acceptability of community based prevalence surveys of HIV among black Africans in England”
Memorandum by the National African HIV Prevention (NAHIP) Programme (HAUK 59)

- People in sexual relationships with people living with HIV\(^89\).
- People with multiple sexual partners and people in relationships with people who have multiple sexual partners.
- Those with low levels of education\(^90\)

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

**Prevention**

**a. Is Government policy sufficiently focused on HIV prevention?**

The proposed Government policy focuses on sexual health with little reference to HIV or HIV prevention and treatment. This indicates that HIV is insufficiently prioritised, which may result in HIV prevention not being adequately funded and addressed at local and national level.

Currently, national investment into HIV prevention is limited to the national prevention programmes; whilst local HIV prevention is commissioned by PCTs, where the lack of ring-fenced funding means that prevention initiatives vary immensely across the country.

The following recommendations could be considered in order to ensure that Government policy sufficiently focuses on HIV prevention:

- 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.
- Better cohesion in national and local prevention policy: This includes ring-fenced funding for local prevention, so that prevention initiatives are consistent nationwide. Local prevention initiatives need to amplify the national prevention programmes, rather than the current reliance on CHAPS and NAHIP to fill some local gaps in prevention funding.
- Prevention policy also needs to recognise that transmission and acquisition does not happen in isolation to the key populations seen as of greater risk. This means international cohesion in prevention policy and internationally consistent testing and prevention messages. Prevention messages need to recognise that the key populations are not isolated.
- There needs to be greater understanding of how testing policy interacts with prevention policy: focusing on early diagnosis and starting treatment at the right time have prevention benefits, thus reducing the long term burden on the NHS.

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

Recent prevention campaigns have been delivered through the national prevention programmes, which are targeted at key populations at higher risk of acquiring HIV in the UK; Africans and men who have sex with men. Therefore, the right groups have been targeted in recent campaigns.

NAHIP 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 tailor information in a culturally appropriate way. However, the NHS’ general sexual health campaigns, which are

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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?

NAHIP’s focus is the prevention of sexual acquisition and transmission of HIV rather than via IDU. The number of Africans diagnosed as acquiring HIV through IDU in the UK is very low (98 diagnoses between 1995 and mid 201091). 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% have been as a result of IDU92). Incidence has remained stable since 1995 (between 110-215 new diagnoses per annum93) and prevalence is estimated at about 1.5%92. This represents a huge decline 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 England93. 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?

NAHIP currently spends 15% of its budget on external, independent evaluation, research and development with the aim to improve delivery of the prevention initiatives. “The Knowledge, the Will and the Power”94 plan of action for prevention demonstrated that one-to-one interventions are more costly and time consuming, but have better outcomes and outcomes which are easier to demonstrate than widespread prevention initiatives. Stronger delivery and evaluation could be delivered by investing more in intensive interventions. However, to better deliver and evaluate prevention initiatives the following challenges must be overcome:

- There is little funding available for evaluation within most programmes which 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 not conducive to innovation. This can limit the usefulness of an evaluation once it has been completed and 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.

Testing

a. Are current testing policies adequate across the country?

Although there have been some successes (e.g. high uptake of testing in antenatal clinics and increased uptake in STI clinics95), recent statistics on late diagnosis and undiagnosed infection show that current testing policies are inadequate, and that in some cases, they fail African communities disproportionately.

The HPA estimates that 26% of people living with HIV are unaware of their status – this is 22,200 people in the UK, of whom approximately 6500 are Africansv. African men are significantly more likely to have undiagnosed infection (36% of those living with HIV are undiagnosediv). Although it is crucial that testing policy aims to reduce the total amount of undiagnosed infection, it is particularly important that there is an increase in acceptable opportunities for African men to test.

52% of adults were diagnosed with HIV at a late stage of infection in 2009v (CD4 counts less than 350 per mm3, the stage at which treatment is recommended to begin, within three months of diagnosis). Late diagnosis is more common amongst heterosexual men (66%) and women (59%) than men who have sex with men. The most recent statistics show that 42% of African diagnoses were lateiv.

Late diagnosis and undiagnosed infection have negative knock-on effects on prevention and treatment and care costs. Inadequate testing policy may be compromising prevention efforts.

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

Reasons for Africans in the UK not testing and testing late are complex, but are often related to fear and stigma96. This means that there needs to be a review of the ways that HIV testing is offered and delivered. Guidelines which have aimed to increase take-up rates (for example, the 2008 BHIVA guidelines97) have not been made mandatory, and the extent to which they were implemented is unclear98. Recommendations made in the guidelines, such as testing new patients at GP surgeries in high prevalence areas, would normalise testing and should increase take-up. In order to do this, health care workers need to be made aware of the guidelines and feel comfortable offering a test.

Testing policy also needs to address and respond to the specific needs of those who are currently reluctant to test. For Africans in the UK, these issues include:

• Underestimation of prevalence and risk: Of Bass Line respondents who had never tested, 52.7% answered “I’ve no reason to think I have HIV”. A further 14% did not think it was important to know their HIV statusxvi. Apathy and underestimation both stem from a lack of knowledge, which needs to be addressed to increase uptake of testing.

• Not recognising the benefits of testing: 16% of Bass Line respondents did not know about HIV treatment at all, and 38% did not know that treatment works better when taken before a person becomes ill99. Lack of accurate knowledge about treatment could

95 Health Protection Agency (December 2010) “Time to test for HIV: Expanded healthcare and community HIV testing in England”
98 Health Protection Agency (December 2010) “Time to test for HIV: Expanded healthcare and community HIV testing in England”
contribute to an individual’s fear of testing or reinforce apathy; it is imperative that testing messages are accompanied with information about treatment availability and options.

- Fear and stigmatisation: 27% of Bass Line respondents had never tested for reasons related to fear and stigma (for example, 19.4% of those who were unsure of their status answered “I am too afraid I might have HIV”\textsuperscript{xvi}). Some fear may stem from not recognising the benefits of testing (see previous point), but this is also key to understanding why stigma can be a barrier to addressing HIV as a public health issue (see final section on stigma).

- Lack of access to treatment: Those with irregular immigration status who cannot access HIV treatment free of charge from the NHS may see no reason to test. Fast, reliable referral pathways to free treatment and care for everyone make the benefits of testing clearer.

- Lack of trust in ‘official’ services: 7% of Bass Line respondents who had never tested had not done so either because they didn’t trust the places where they could test or because they did not want to use ‘official’ services\textsuperscript{xvi}. For those with irregular immigration status, reluctance to engage with any government service may be affecting testing take up. Lack of trust was also found to be more acute amongst behaviourally gay and bisexual African men and women, perhaps because of fear of multiple discrimination.

Testing policy must continue to increase opportunities for testing in non-official and non-NHS settings. NAHIP has been aware of shortfalls in PCT funding for community based testing and has tried to plug the gap in some areas. This needs to be addressed in the commissioning proposals.

**Treatment**

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

- The NHS should deliver free HIV treatment to everyone, regardless of 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 commissioned by the NHS while Public Health England would be responsible for commissioning prevention. By funding HIV treatment 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’ and a lack of co-ordination in the response to HIV.

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?**

Although the current model of clinical delivery works well for most patients, there is a need to investigate alternative settings for treatment delivery to minimise the number of patients who drop out of care. This is particularly important for migrants who can find the NHS difficult to navigate; those with irregular immigration status and others who are reluctant to engage with ‘official’ services and those that fear they will be stigmatised if they access treatment. 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 in HIV:

   i. In prevention policy; and
   ii. Treatment policy?

The lack of ring-fenced funding for targeted HIV prevention causes disparities in addressing public health imperatives in HIV across England. HIV prevention competes with other sexual health targets and funding decisions rest with local commissioners. This results in an imbalance between unmet HIV prevention need and the eventual increased cost in treatment that this causes.

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\textsuperscript{100}. 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\textsuperscript{101}. 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\textsuperscript{xx} 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.

b. Is research funding currently prioritised?

Both quantitative and qualitative research needs to be prioritised and sufficiently funded in order to achieve better delivery of prevention interventions at greater value for money.

Stigma

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

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\textsuperscript{102,103,104}. People with diagnosed HIV infection can internalise stigma, which can cause low self-esteem. This may


\textsuperscript{102} Doyal & Anderson (2005) "'My fear is to fall in love again...’ How HIV-positive African women survive in London”


\textsuperscript{104} Doyal et al (2005) “’I want to survive, I want to win, I want tomorrow’ An exploratory study of African men living with HIV in London”
affect an individual’s motivation to seek support, disclose\textsuperscript{105} 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\textsuperscript{106} all of which make HIV harder to address in public health. Misinformation and HIV-related stigma tend to reinforce one another. There is also evidence that fear of stigma and discrimination prevents some African people from testing\textsuperscript{107} (26\% of Bass Line respondents who had never tested cited reasons related to fear and stigma\textsuperscript{108}) or accessing services\textsuperscript{109}, both of which have public health consequences.

b. Where are problems of stigmatisation most acute?

HIV related stigma has many layers and every individual has different experience. However, stigma is most acute in already marginalised groups, as it can act to reinforce existing stigma and discrimination against a marginalised community. This then reinforces the stigma connected to the virus. 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). 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\textsuperscript{110}.

c. What measures are currently taken to tackle HIV stigmatisation? 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. NAHIP has attempted to tackle stigma through two settings where it is particularly acute in the African community by producing toolkits for the media and for faith leaders.

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.

18 February 2011
Supplementary Memorandum by the National African HIV Prevention (NAHIP) Programme (HAUK 102)

Efficacy of recent campaigns

1. How effective have recent national HIV prevention campaigns been?

NAHIP’s national HIV prevention campaigns have been increasingly successful in the last few years. NAHIP’s campaigns have a variety of streams, which comprise of mass media elements traditionally associated with campaign work and direct contact intervention work, which is increasingly being associated with more effective behaviour change campaigns\(^{111,112}\) (see Q2 and 10). NAHIP’s external evaluators (see Q8) have shown that in 2009-10 NAHIP delivered 744 HIV prevention interventions to 11,162 African people. There has been significant improvement this year, which shows the programme’s ongoing commitment to improving the effectiveness of its campaigns. In the last six months of 2010-11, NAHIP delivered 1,151 interventions to over 9,900 people, making it the best performing year in NAHIP’s history.

By delivering a mixture of mass media and direct contact interventions, as is considered best practice for the most effective behaviour change campaigns, NAHIP is currently delivering a wide diversity and high volume of prevention interventions at very high cost-effectiveness.

a. How does this compare to levels of success seen in other health promotion campaigns? What lessons can be learnt from successes elsewhere?

NAHIP’s own campaigns have been increasingly successful because they follow the good practice principles of successful behaviour change campaigns\(^2\). The principles are considered to have improved the successes of HIV prevention campaigns internationally. Their application in NAHIP campaigns is covered in detail in Q7, which includes a reliance on direct contact interventions in addition to mass media, and use of carefully designed, behaviour change focused campaign messaging. By incorporating these principles into NAHIP’s campaign designs, NAHIP demonstrates that it is learning from successes elsewhere and would compare favourably to other successful international campaigns.

It is not realistic to compare the success of NAHIP’s campaigns with other health promotion campaigns on other public health topics in the UK, because NAHIP only receives a fraction of the investment (see Q3 for a full comparison).

\(^{111}\) Dodds C, NAHIP partners et al (2008) The Knowledge, the Will and the Power: a plan of action to meet the HIV prevention needs of Africans living in England

Funding of campaigns

2. Evidence submitted to the Committee suggests that the Department of Health currently spends £2.9 million annually on national HIV prevention programmes. Do you feel that this amount is sufficient to undertake the health promotion work needed to reduce unsafe sexual behaviour?

The amount currently spent by the Department of Health on HIV prevention is not sufficient. Of the £2.9 million allocated annually to the two national HIV prevention programmes (CHAPS and NAHIP), NAHIP receives £1 million for HIV prevention work targeted to Africans in England. Population estimates vary, but this equates to £1-£2 for an individual African resident in England each year. Effective behaviour change interventions are expensive. Given that new infections are highest amongst the African population; this is insufficient and disproportionate to need.

Comparison of the UK’s spend on prevention with prevention budgets in other countries with similarly focused HIV epidemics indicates that the total investment in prevention is also inadequate. In addition, UNAIDS estimates that the average national spend on prevention is 21% of their spend on HIV treatment and care. The £1 million that the DH currently spends on prevention for Africans is 0.25% of the £399,960,000 annual cost of treatment and care for that population. Greater spend on prevention is an investment to lowering the HIV treatment and care costs to the NHS in the future. Reducing this future burden is one reason why UNAIDS recommends that spending on prevention should be close to 45% of the total spend on treatment and care.

NAHIP’s work is split into a number of different streams. Of the £1 million investment into the programme, £150,000 is ring-fenced by the DH to fund and promote the national helpline. Of the remaining £850,000, 17% is spent on independent evaluation and development and more than 65% funds NAHIP’s campaign activities, most of which funds direct contact interventions delivered by regional agencies.

Health promotion work delivered through NAHIP’s local agencies is always HIV prevention focused, but prevention is more complex than simply reducing unsafe sexual behaviour. NAHIP must also promote PEP, HIV testing, etc., which make significant contributions to reducing incidence but do not reduce unsafe sexual behaviour.

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116 Compare to funding of equivalent programmes in France, US and Canada
117 In 2009, there were 22,220 black Africans seen for HIV treatment and care (http://www.hpa.org.uk/web/HPAwebFile/HPAweb_C/1221482345789). The lowest estimate for the average cost of treatment and care for one person living with HIV per year in the UK is £18000 (http://www.aidsmap.com/Annual-UK-HIV-treatment-and-care-costs-could-reach-750-million-by-2013/page/16181377/). This means that HIV treatment and care for black Africans is currently costing the NHS a minimum of £399,960,000 per year.
119 2010-11 budget figures
Campaigns and health promotion work on these other issues come from the same £1 million budget.

3. How much money would be needed for an effective national campaign to increase HIV awareness? To what extent is efficacy linked directly to the amount of money spent on the campaign?

Although it is not possible to estimate how much an effective national campaign would cost without considering in detail the objectives, outcomes, desired exposure, target audience, evaluation methodology and expected duration; it is clear that the current funding is not enough to fund a fully effective campaign, neither is it in line with UNAIDS guidelines (see Q2), nor comparable to DH spending on other public health campaigns.

The £1 million that the DH currently spends on HIV prevention campaigns for Africans is a fraction of the DH investment into other health promotion campaigns: the 5 month “Sex: Worth Talking About” campaign had a budget of £7.67 million (sexual health and teenage pregnancy campaigns have cost £16.49 million between 2006-10); the “F.A.S.T” stroke campaign cost £12 million and smoking cessation campaigns have seen an investment of over £82.74 million between 2005-10. Investments into similar targeted HIV prevention campaigns in the US and Canada are also far greater.

The costs reveal the scale of expenditure needed in order to generate significant outcomes from campaigning: the “F.A.S.T.” stroke campaign reported a big increase in awareness, which was measured by the number of emergency calls for stroke. This is a simple awareness raising or ‘knowledge change’ outcome, yet it still needed considerable investment. HIV prevention campaigns typically aim for long-term sexual behaviour change, which is far more complex both to provoke and to measure, yet it receives considerably less investment.

It is notable that NAHIP has proved that it is possible to have some success in campaigning despite budgetary constraints. The African Health Policy Network has brought considerable added-value by exploiting the organisation’s media contacts and its membership relationship to many organisations in the African sexual health sector. For example, the summer 2010 ‘mini-testing campaign’ had a total advertising expenditure of £967.50; about 7% of the full value of advertising the campaign received, which totalled £13,201.12. This included online, print and radio advertising in national African media and had a projected exposure to over 200,000 Africans. (See evidence Qs 936 - 937). While AHPN represents excellent value for the DH’s investment into campaigning, this will not be sustainable in the future without further investment into campaigns, particularly in the current economic climate.

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121 http://www.guardian.co.uk/healthcare-network/2011/jan/13/department-health-doubled-advertising-spending-60m; Accessed 6th June 2011: In 2005-08 the DH had an annual media spend of £30 million, this doubled to £60.28 million in 2009-10. In 2009-10 the DH spent £154.5 million through the COI.
General versus targeted campaigns

4. Do you believe that HIV prevention campaigns should continue to target particular high prevalence groups, or should they be focused upon the population at large?

HIV prevention campaigns should continue to target particular high prevalence groups. Both policy\textsuperscript{126} and academia\textsuperscript{127} advocate targeting “key affected groups and populations”\textsuperscript{128} in prevention campaigns.

For example, recent UNAIDS guidelines on prevention work, which explicitly include mass media campaigns, state that successful prevention work will be “differentiated and locally-adapted” and “address [...] cultural norms and beliefs”. A systematic review\textsuperscript{129} of 34 national HIV campaigns, found that successful campaigns “targeted defined audiences developed through audience segmentation procedures” to “maximise the chances of success”.

A move to general HIV prevention campaigns in the UK would contradict moves by other countries with similarly focused epidemics that are progressing to increasingly targeted HIV prevention campaigns. For example, the US is investing with even tighter focus: in 2011 the Centres for Disease Control and Prevention (CDC) has invested US$2.5 million for 2 years of campaigning targeting black African American men who have sex with men (MSM)\textsuperscript{130}.

In the UK, the two most affected populations: black Africans and MSM\textsuperscript{131} (and sub-populations within them), have separate, specific HIV prevention needs, which is why they emerged as disproportionately affected groups. These individual complex needs can only be met through corresponding, targeted HIV prevention campaigns and by engaging specialist agencies in delivery. NAHIP’s targeted HIV prevention work concurs with the international emphasis on targeted and tailored HIV prevention campaigns.

a. Bearing in mind the limited resources allocated to prevention and awareness initiatives, what balance between targeted and general work would be most appropriate?

Given the limited resources available for HIV prevention work, it is more cost-effective to focus on targeted work. This would echo the decisions made by other countries with similarly focused epidemics\(^\text{132}\) and recommendations in international policy\(^\text{133}\) (see Q4).

However, the UK could achieve a better balance between targeted and general work by taking advantage of existing opportunities to communicate HIV prevention messages to the UK’s population. This could increase the cost-effectiveness and efficacy of targeted work; reduce stigma (see Q5); contribute to HIV prevention in the wider population and would not increase the cost of general work significantly. NAHIP recommends that:

- There are increased opportunities for HIV testing and discussion about HIV in clinical and non-clinical settings\(^\text{134}\), in line with the BHIVA\(^\text{135}\) and NICE\(^\text{136}\) guidelines. Ongoing professional development opportunities need to be available for practitioners to keep up-to-date with HIV testing, treatment and care guidelines to implement this, for example training or briefings.
- All young people receive adequate education about HIV and AIDS through compulsory sex and relationships education in the national curriculum\(^\text{137}\).
- Messages which support HIV prevention objectives are integrated into general health and sexual health campaigns and information, even if a campaign’s main message does not explicitly mention HIV (for example, encouraging increased condom use or regular sexual health check-ups: see Q5).
- HIV is included in national sexual health guidelines and strategies.

Content of sexual health awareness campaigns

5. Do you believe that HIV prevention should be integrated more closely into general sexual health awareness campaigns, or does HIV require a dedicated campaign of its own? Is it possible that inclusion of HIV in general sexual health campaigns could ‘confuse’ the messages being promoted?

Dedicated HIV prevention campaigns are needed to achieve specific behaviour changes which correspond to the HIV prevention needs of the UK’s most disproportionately affected populations: black Africans and MSM (see Q4). The content needed to do this is specific, complex and would not be appropriate for a general sexual health campaign (e.g. NAHIP provides information on HIV testing and treatment entitlements according to immigration status). A general sexual health campaign could

\(^\text{132}\) See France, Canada and US


\(^\text{136}\) National Institute for Health and Clinical Excellence (March 2011) \text{Increasing the Uptake of HIV Testing to Reduce Undiagnosed Infection and Prevent Transmission among Black African Communities Living in England (NICE public health guidance 33)}

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Not be expected to tackle specific behaviours delivered through culturally sensitive messages in settings that are appropriate to small pockets of the population, whilst remaining relevant to the wider UK population.

However, **NAHIP would welcome greater inclusion of simpler HIV prevention messages into general sexual health campaigns** to ensure that anyone who needs HIV information has access to it, whether or not they are considered part of a specific target audience. NAHIP recognises that general sexual health campaigns do make a contribution to HIV prevention, regardless of whether they explicitly acknowledge HIV; for example, by advocating for regular sexual health check-ups and condom use. Because these messages are consistent across HIV prevention and SRH, previous general sexual health campaigns (for example, “Sex: Worth Talking About”) could have included some HIV information without confusing the message. Inclusion could also help reduce HIV associated stigma by increasing the visibility of HIV, increasing the availability of accurate information and raising awareness in the public domain. Despite the possibility of including these simpler messages, many HIV prevention messages are too complex to be merged into general sexual health campaigns.

6. Some evidence received by the Committee suggests that, in seeking to reduce the stigma around HIV, recent prevention campaigns have been too moderate in tone. Would more ‘hard-hitting’ campaigns, such as the 1980s ‘Don’t Die of Ignorance’ campaign, be more likely to influence behaviour change?

NAHIP’s recent campaigns have been moderate in tone because evaluations of previous campaigns found that the target audience responded better to more moderately toned messages. Producing a campaign which is acceptable to the target audience is more likely to influence behaviour change. NAHIP ensures acceptability by pre-testing new campaign messages and material and incorporating previous lessons learnt.

NAHIP’s decision is also based on evidence that ‘hard-hitting’ campaigns are less likely to influence behaviour change. In an evaluative study, the 1987 Australian ‘Grim Reaper’ campaign was found to have “fail[ed] to arouse personal and social concern in a productive manner” and caused “little change in knowledge and high anxiety”. In their drive to be ‘hard-hitting’ such campaigns often lack the balance needed to present the prevention messages in a thoughtful enough way to effect behaviour change.

‘Hard-hitting’ campaigns have also been found to “scare much of the population unnecessarily”; again emphasising the need for targeted, sensitive prevention campaigns (see Q4). **Campaigns must be delivered by agencies, like African Health Policy Network (AHPN), that have knowledge and understanding of the target audience, to produce behaviour change without increasing stigma** (see Q6a).

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a. Is there a risk that stronger campaign messages could increase or encourage stigma around HIV? If so, how can the appropriate balance be struck between reducing stigma and providing a deterrent against HIV transmission?

The same study of the Australian ‘Grim Reaper’ campaign found that 'hard-hitting' messages could “have...stigmatizing and neurosis-producing results”: it “produced social discord” and “hysterical and exaggerated perceptions of AIDS and potentially social divisive attitudes” and “incited strong negativity among the public”.

In 2009, attempts at a strong campaign message in Germany based on the same premise as the ‘Grim Reaper’ campaign (“aids ist ein massenmörder”), provoked an international outcry as tasteless, inappropriate and “incredibly stigmatising”. This shows that there is a very significant risk that such ‘hard-hitting’ campaigns can vilify people living with HIV and incite stigma and discrimination against them and against people who are from countries with high HIV prevalence or from other affected groups, such as MSM. This example from 2009 also shows that these 'stronger campaign messages' are still considered stigmatising in the current HIV prevention context.

The appropriate balance between reducing stigma and providing a deterrent against HIV transmission can be achieved by presenting comprehensive, accurate facts (e.g. HIV is not a ‘death sentence’ but it is lifelong, incurable and there are limited treatment options); and by greater and meaningful involvement of people living with HIV in campaign design. NAHIP’s new Do It Right campaign has done both of these things to strike the right balance.

**Behaviour Change**

7. The Committee has received evidence that suggests that current prevention campaigns are failing to change the behaviour of those at risk of HIV infection. What is required for health promotion campaigns to change unsafe behaviours? Are these elements lacking in existing HIV prevention campaigns?

Health promotion campaigns need to be targeted to a specific, segmented audience, based on formative research, focused on behavioural change (not increased knowledge), designed using behavioural change theories and achieve a high message exposure. The following table demonstrates that the elements needed to effect behaviour change are not lacking in NAHIP's existing HIV prevention campaigns:

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140 http://www.time.com/time/health/article/0,8599,1921012,00.html: accessed 26th May 2011
141 “AIDS is a mass murderer”
144 www.idoitright.co.uk
146 Healthy Foundations, DH
## Elements needed to change unsafe behaviours

<table>
<thead>
<tr>
<th>Targeted audience</th>
<th>All NAHIP campaigns are targeted to Africans living in England aged 16-49, as specified by the DH. The 2008 Do It Right campaign and the earlier It’s Better to Know campaign both provided resources specifically for men and women. With greater investment, NAHIP would segment the population further as we know from research that campaigns are needed for Africans with low levels of education, for young people, for behaviourally LGBT Africans and others.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Based on formative research</td>
<td>NAHIP uses research extensively in the development of campaigns. This includes, but is not limited to, NAHIP’s Bass Line surveys[^147] which were designed to assess the sexual HIV prevention needs of African people in England. One example of this in the new Do It Right campaign is the inclusion of detailed information about PEP (which 36.8% of Bass Line respondents wanted to know more about).</td>
</tr>
<tr>
<td>Campaign themes focus on behavioural change (not knowledge)</td>
<td>NAHIP’s campaigns tend to have high information content because Bass Line has shown that this is necessary. However, direct contact interventions are focused on behaviour change and are designed to deliver this, alongside the campaign aims, in the most effective way possible[^148].</td>
</tr>
</tbody>
</table>
| Designed using behavioural theories | NAHIP’s direct contact interventions include 1-to-1 and group therapeutic change. These are focused on behavioural change and skill building outcomes (recent examples include sessions on condom negotiation or declining unwanted sex) and the sessions are designed by trained counsellors or clinical psychologists using behavioural theories.  

1-to-1 therapeutic change interventions take place over a series of weeks and start with an assessment to determine how to help the individual change their behaviour. Such assessments are grounded in behavioural theory. These interventions report high outcomes, such as increased self esteem or deciding to start HIV treatment. |
| Achieve high message exposure | Greater message exposure typically requires greater investment. NAHIP achieves high message exposure at lower cost by using targeted media and utilising online opportunities to reach the target audience. The 2010 summer mini-testing campaign had 201,222 projected impressions to Africans in the UK. Depending on the population estimate used, this is up to 40% of Africans. |

[^147]: Department of Health Healthy Foundations Life-stage Segmentation Model (Version 1: April-June 2010) and accompanying electronic resources.  
Despite adhering to best practice principles for effective behaviour change campaigns, to achieve sustained sexual behaviour change and demonstrate that the campaigns are delivering this, NAHIP requires an investment that is proportionate to the task (see Q3). Behaviour change is dependent on a wide range of factors; including environmental, structural, beliefs, attitudes, intentions and person’s ability to enact behaviour change, and with the current investment of £1-£2 per African person it is simply impossible to have, or expect, a concerted impact on long-term behaviour.

With greater investment NAHIP could expand its evidence base, achieve greater message exposure, provide more media interventions and provide more intense interventions that facilitate the necessary levels of knowledge, will and power to choose precaution over risk. Greater investment would also see more robust evaluation so that NAHIP could better demonstrate the impact on behaviour change that its campaigns have.

Evaluating campaigns

8. How can the success of health promotion and advertising campaigns be properly measured and evaluated?

The NAHIP health promotion and advertising campaigns are externally monitored and evaluated.

NAHIP currently spends £150,000 per year on the programme’s evaluation and development. This is contracted to Sigma Research which is an organisation independent to AHPN based at the London School of Hygiene and Tropical Medicine. Contrary to the evidence given in Evidence Session No 18, on Tuesday 17th May to Q931-934, independent evaluation is highly valued in the NAHIP programme. As such, the programme commissions independent researchers for evaluation in exactly the way that the committee recommends. The commissioning for independent researchers is based on a tendering process. To improve the accuracy of the monitoring and evaluation of NAHIP’s work, the monitoring tools have been developed in consultation with the agencies that use them.

a. What improvements could be made to the evaluation of HIV prevention campaigns?

NAHIP recommends that local HIV prevention campaigns follow NAHIP’s model of independent measurement and evaluation. NAHIP’s KWP website provides examples of the tools used by the NAHIP agencies to help non-partnership agencies improve their own evaluation. Other improvements could include:

- Stronger research designs for evaluation outcomes.

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150 www.kwp.org.uk

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- Include measures of behaviour in outcome assessments
- Greater involvement of agencies who are expected to use the tools in development
- Methodology – expensive for blanket campaigns, hard for targeted campaigns

Improvements to evaluation require adequate investment, which is something often overlooked by funders when there are such tight budgetary constraints on delivering the campaigns themselves. It is important for funders to recognise the value of evaluation and set aside funds for that purpose. **With a larger budget it would be feasible to invest more in the kinds of in-depth, face-to-face interventions that change sexual behaviour, and in the research designs that demonstrate the impact of such interventions over time.**

**Tackling Stigma**

9. The Committee has heard evidence that suggests stigma remains a problem for people living with HIV. How effective would a campaign aimed at influencing stigmatising attitudes be likely to be? In light of competing priorities around HIV awareness, would you consider such a campaign to be a productive use of limited resources?

Given the limited resources directed towards HIV prevention and the significant work being done to reduce stigma outside of campaigns\(^{152}\), **HIV prevention should remain the priority**. This is particularly as there have been attempts at stigma reducing campaigns from very early on in the epidemic\(^{153}\), yet stigma remains a huge\(^{154}\) and growing\(^{155}\) problem in the UK. This suggests that it is difficult to create an effective campaign aimed at influencing stigmatising attitudes, so it is unlikely to be the most productive use of limited resources.

HIV prevention work should represent a more productive use of limited resources because prevention work has a knock-on effect in reducing stigma: earlier diagnosis, less undiagnosed infection, greater understanding of transmission paths etc. reinforce that HIV is a manageable, long-term condition which cannot be transmitted through normal social contact. Prevention campaigns also increase public exposure to prevention messages; increase the visibility of HIV; increase the availability of accurate information and provide a stimulus for discussion, all of which will contribute to reducing stigma. However, this is unlikely to be achieved by ‘hard-hitting’ campaigns, which usually produce the opposite effect (see Q6a).

A forthcoming Stigma Index Study has shown that stigma and discrimination in the UK “impede on the ways in which migrants exercise their rights to HIV-related care and support”\(^{156}\). Stigma can be a barrier to successful prevention work, particularly when people feel they cannot access services such as HIV testing. Therefore, **NAHIP would support a campaign aimed at influencing stigmatising attitudes funded**

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\(^{152}\) E.g. NAT’s Press Gang; The Stigma Index Studies; International Labour Office (2010) *Recommendation concerning HIV and AIDS and the World of Work* (Number 200) and the Disability and the Equality Act 2010

\(^{153}\) for example, “I have AIDS please hug me – I can’t make you sick” campaign in the US in 1987


separately from existing HIV prevention work. For this to be a productive use of resources, it would need to be delivered in a supportive policy environment; developed with great and meaningful involvement from people living with HIV; recognise the wider social determinants of health and target the general population\textsuperscript{157}.

**Delivery and new technologies**

10. Evidence received by the Committee has suggested that current HIV prevention campaigns suffer from an over-reliance on written materials. What, in your experience, is the most effective medium for delivering health promotion campaigns?

The structure of NAHIP follows a model suggested to be the most effective for delivering health promotion campaigns to effect behaviour change. This is known as a ‘multicomponent’ campaign. It recognises that *mass media alone cannot change behaviour and that a campaign must be delivered in multiple-settings, through multiple mediums, at the local and individual level*\textsuperscript{158}.

For NAHIP, this means that campaigns are delivered through prevention interventions in a variety of settings using varied mediums. In the past this has seen mass media aspects of a campaign (such as TV and radio advertising) supported by small media (e.g. small cards and knick-knacks) which have been disseminated interactively to individuals through direct contact interventions delivered by NAHIP’s local agencies. In 2010, resources associated with the *Do It Right* campaign were distributed at 665 NAHIP interventions. In addition, campaign material is provided to be used in group work (e.g. *Do It Right*’s film series *Kobana’s Stories*) or interactively by individuals online (the *Do It Right* website hosted an interactive quiz). By relying on differing distribution techniques and mediums, NAHIP has avoided over reliance on written resources.

NAHIP bases decisions on which medium to use depending on the target audience, the campaign message and behaviour change objectives. Recently, NAHIP has had some success in driving calls to the helpline using radio advertising which has been more effective than the use of written materials in this instance.

Delivering a ‘multicomponent’ campaign increases the cost and complexity of organising and executing the campaign. However, they are thought to have a greater effect on behaviour change as the consistent campaign messages are delivered to the audience in the public domain and individually.

The following diagram from www.kwp.org.uk shows the relationships between the cost, efficacy and reach of the direct contact interventions that NAHIP delivers. NAHIP attempts to achieve a balanced, effective multicomponent campaign by delivering a range of the interventions to provide optimum coverage through a mixture of intensive 1-to-1 interventions (at the top of the pyramid) and wide reaching mass media interventions (at the bottom):

\textsuperscript{157} Forthcoming report: Chinouya, M., Hildreth, A., Goodall, D., and Inegbenebor, D., *Migrants and HIV stigma: findings from the stigma index study (UK)* Due for publication July 2011.

11. We have heard that previous campaigns have not lasted long enough to ensure that messages reach their targets. How sustained must campaigns be to be effective?

Campaign duration needs to strike a balance between adequate exposure and audience saturation. NAHIP is attempting to achieve the right balance with the revamped Do It Right campaign. The campaign has kept the title Do It Right to keep a clear identity and brand and build on existing target audience recognition. This will act as a sustained, umbrella title underneath which NAHIP intends to deliver shorter, more targeted campaigns. This aims to give the Do It Right campaign longevity whilst keeping the target audience interested with changing messages. It enables the campaign to respond to external circumstances to ensure it is always relevant, up-to-date and appropriate. However, increasing the duration of a campaign also increases the cost.

12. How could new technologies, including the internet and mobile phone applications, be better utilised in prevention campaigns?

NAHIP has introduced new technologies as part of the revamp of the Do It Right campaign, both to provide information and to support direct contact interventions (e.g. by providing online alternatives to a telephone helpline). The decision on whether and how to use internet and mobile phone applications was based on findings that show this is appropriate for NAHIP’s target audience, including Ofcom reports¹⁵⁹, Bass Line findings¹⁶⁰ and focus group discussions. It is thought that the “interactivity of such

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program may help to build skills and foster behavioural changes”\cite{161}, showing that this is an area likely to expand in prevention campaigns.

a. How can the use of internet applications be properly managed and coordinated, to ensure consistency and quality of provision?

NAHIP has collaborated with NAM to ensure that the provision of online information for NAHIP campaigns is up-to-date, accurate and consistent with NAM’s award-winning HIV treatment and prevention information. NAM is a certified member of the Information Standard. This process is managed by the NAHIP programme and falls under NAM’s contract as a NAHIP agency.

Like any organisation, NAHIP can only manage its own internet content to ensure consistency and quality. The use of external internet applications, like social media (i.e. Facebook, Twitter or forums), to campaign is time-intensive and difficult, or sometimes impossible, to manage. Where NAHIP has decided to campaign using external internet applications, careful provisions have been made to use the helpline staff to monitor online activity, as well as regular overview from within AHPN.

**Oversight and coordination of campaigns**

13. Should HIV prevention campaigns be locally or nationally led and delivered?

For campaigns targeted to the UK’s African population, **HIV prevention campaigns need to be nationally led and locally delivered.**

National leadership is necessary to ensure:

- Consistency in HIV prevention messages and the creation of a clear national campaign identity to provide continuity for a very mobile population. This includes providing a clear strategic direction for all local delivery agencies to follow.
- Greater accountability: A national leader is able to be fully accountable for funding, despite the complexities of delivering a multicomponent campaign. This may be increasingly complicated at a local level and increase the monitoring burden that small community based organisations face.
- Greater value for money through the development of resources and interventions at a national level, which can then be adapted locally. NAHIP ensures that local adaptation is possible within national cohesion by engaging its agencies throughout the development process, from planning to delivery.
- That Africans who do not live in areas with high African population density still have access to the best information about HIV and how to access services regardless of whether there are local community based organisations in their area

A specialist agency, like the AHPN, which understands the African population needs to lead the process of campaign development to ensure that the messages are appropriate, acceptable and targeted to the right behaviour change nationwide.


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Local tailoring is imperative in delivering HIV prevention campaigns to the ‘African population’ as Africans in the UK represent a huge variety of nationalities, cultures, religions and languages and cannot be considered one homogeneous group. Local tailoring is achieved through a network of local delivery agencies. NAHIP’s response to local need has ranged from agencies delivering workshops in African languages to engaging with a particular community for a culturally specific celebration (e.g. an Independence Day parade).

This ‘nationally led, locally delivered’ strategy fits perfectly with NAHIP’s multicomponent campaigning (see Q10) as it encourages delivery of campaigns at the individual as well as mass media level. Engaging organisations who understand this is fundamental to the success of delivering targeted prevention work.

a. How could a joint approach across both the national and local levels be managed and coordinated?

NAHIP currently coordinates HIV prevention campaigns in exactly the way described. There is a need to have a national agency, such as the AHPN, which understands the target audience through its detailed, experienced understanding of the complex needs of Africans living in England, and has the ability to coordinate and understand local delivery. To deliver locally, NAHIP commissions smaller, mostly African-led, community based organisations which deliver campaigns and other prevention interventions in their locality to individuals and groups.

There also needs to be coordination between programmes, such as NAHIP and CHAPS, and clinicians, commissioners and NHS managers, to ensure that consistent messages are being promoted everywhere. Local delivery needs to be supported by local services providing consistent clinical services (i.e. there is little value in having a national campaign promoting PEP if its availability is inconsistent across various regions in England).

The current coordination has allowed NAHIP to set strategic priorities that reflect that neither sexual HIV risk nor unmet HIV prevention need is evenly distributed. These priorities are clearly described in “The Knowledge, The Will and The Power”; NAHIP’s strategic plan of action to meet the HIV prevention needs of Africans living in England162, which drives the programme towards achieving its shared goal of minimising the number of sexual HIV acquisitions and transmissions involving African people living in England. This has enabled a clear, joint approach between national leadership and local tailored delivery to manage a programme that best serves the HIV prevention needs of Africans in England. This joint approach is the most efficient and effective use of limited resources, targeting HIV prevention interventions to those most likely to benefit.

Evidence submitted on behalf of the National African HIV Prevention (NAHIP) Programme by:

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Joanna Moss, Programme Development Officer, African Health Policy Network

162 See www.kwp.org.uk
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Thank you to Francis Kaikumba (CEO, African Health Policy Network), Eunice Sinyemu (Deputy CEO and Head of Policy, African Health Policy Network), Diana Inegbenebor (Policy and Research Assistant, African Health Policy Network) and Peter Weatherburn (Director, Sigma Research).

Special thanks to the NAHIP agencies who contributed to this submission via consultation.

7 June 2011
Memorandum by National Study of HIV in Pregnancy and Childhood (NSHPC) (HAUK 30)

Prepared by Dr Pat Tookey (Principal Investigator NSHPC)
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I. Summary
The National Study of HIV in Pregnancy and Childhood (NSHPC) is the confidential active reporting system for

- pregnancies in HIV-infected women
- babies born to HIV-infected women
- other children with HIV infection and AIDS

The Committee has identified six key issues. The NSHPC contributes directly to four of them:

- monitoring of HIV in children and in pregnant women,
- prevention of mother-to-child transmission of HIV,
- development and monitoring of antenatal HIV testing,
- and the evaluation of treatment for pregnant women, HIV-infected children, and uninfected children exposed to antiretroviral drugs in fetal life

The NSHPC cost was £179,136 (Health Protection Agency (HPA) funding) for the year 2010/11. Our current contract runs out on 31 March 2011. We are seeking an extension of this contract (at a reduced level) through the HPA, but this has not yet been approved.

We don’t directly tackle stigma, but we provide comprehensive, reliable and valuable data about HIV in pregnant women and children to those who do, including people living with HIV, the voluntary sector, the research community, commissioners and health professionals. Over 14,000 pregnancies (including more than 5,000 occurring between 2007 and 2010) and 2,340 infected children have been reported to the NSHPC to date. We make a substantial contribution to the national HIV surveillance programme, and also provide an invaluable platform for audit, research and collaboration at regional, national and international levels.

2. Brief outline of NSHPC methods
The study was established in 1986 at the Institute of Child Health (ICH) to study AIDS in children, and extended in 1989 to cover pregnant women with HIV, and their infants. This is non-selective, anonymised, comprehensive, observational, active surveillance, and we have virtually complete coverage of HIV diagnoses in pregnant women and children since the beginning of the epidemic in the UK. HIV-positive pregnant women accessing antenatal care, their infants, and HIV-infected children living in the UK are reported to the NSHPC through two parallel reporting schemes run with the support and collaboration of the Royal College of Obstetricians and Gynaecologists, the Royal College of Paediatrics and Child Health, and the Children’s HIV Association (CHIVA). We collect standardised information about the diagnosis and management of these pregnant women, the outcome of their pregnancies, and the management and infection status of their children. We are able to respond to newly

163 Current NSHCP data, methods and associated material available at www.nshpc.ucl.ac.uk
emerging contemporary clinical and research questions as they arise, by revising our processes and data collection forms as necessary.

3. **How our data are used**

We are able to make extensive use of our data for multiple surveillance, research and audit purposes (‘collect once, use many times’).

3.1 **Through the NSHPC surveillance programme we**

- provide national paediatric and obstetric surveillance data to the HPA and Health Protection Scotland which is then combined with other national surveillance data on HIV in adults to produce a comprehensive picture of the epidemic
- monitor the prevalence of diagnosed HIV infection in pregnant women and children at a local, regional and national level
- track changes in the management of HIV in pregnancy and transmission of infection from mother to child\textsuperscript{165} and contribute to the development and evaluation of the national antenatal HIV screening programme\textsuperscript{166} (see 4.1)
- collect data on the second generation – infants born to perinatally infected women (see 4.2)
- record information on maternal and infant exposure to antiretroviral drugs, monitor the health of uninfected children born to HIV-positive mothers and exposed to both HIV and antiretroviral drugs in fetal life (for example by monitoring congenital abnormalities, prematurity, child health, and death and cancer registrations), and contribute to pharmacovigilance studies (see 4.3)
- provide baseline prenatal, infant and child data for the Collaborative HIV Paediatric Study (CHIPS) which follows up infected children, and contribute to longer term studies of survivors of paediatric HIV infection\textsuperscript{167} (see 4.4 and 4.5)
- contribute to national CHIVA and British HIV Association (BHIVA) guidelines,\textsuperscript{168} and international guidelines on the management of HIV in pregnancy and paediatric HIV
- contribute anonymised population-based data to regional, national, European and other international research and surveillance collaborations

4. **Some examples of contemporary issues addressed by the NSHPC**

4.1 **How can we reduce the number of perinatal infections even further?**

About 500 children have been diagnosed with HIV in the UK in the last five years, two-thirds of whom were born abroad. Despite high uptake of antenatal HIV screening, and effective interventions to prevent mother-to-child transmission, some UK-born children still acquire infection from their mothers: about 1% (10-15) of the 1200-1300 infants born each year to diagnosed HIV-positive women are infected.\textsuperscript{169} Another 20-30 newly diagnosed children are also reported each year whose mothers were not previously known to be HIV-positive. These women were either not tested in pregnancy, or acquired HIV after their antenatal test


\textsuperscript{167} Judd \textit{et al}. Morbidity, mortality, and response to treatment by children in the UK and Ireland with perinatally acquired HIV infection during 1996-2006: planning for teenage and adult care. CID 2007 Oct 1;45(7):918-24


\textsuperscript{169} Townsend \textit{et al}. Low rates of mother-to-child transmission of HIV following effective pregnancy interventions in the UK and Ireland, 2000-06. AIDS 2008; 22:973-981
later in pregnancy or after their baby was born and while they were still breastfeeding. We are now attempting to explore these remaining mother–to-child transmissions in more detail, in order to identify ways to reduce the infection rate even further. This builds on our 2007 audit of perinatal transmissions\(^{170}\) which resulted in a number of recommendations now embedded in BHIVA and antenatal screening guidelines. We are also planning to extend the information we collect about infant feeding by HIV-positive mothers, in the light of the recently revised WHO and BHIVA Guidelines on infant feeding.\(^{171}\) Only through routine and standardised data collection will we be able to assess the impact on mother-to-child transmission of any changes in infant feeding practices.

4.2 Second generation pregnancies, and women having repeat pregnancies
We are now receiving the first reports of births to women who were themselves perinatally infected (second generation pregnancies).\(^{172}\) We are also recording increasing numbers of women having two or more pregnancies after their HIV diagnosis (under investigation by PhD student). These scenarios present new challenges for treatment and care, and we can provide reliable and comprehensive information for recognising new issues and developing appropriate management guidelines.

4.3 Drugs in fetal life – exploring the long term consequences
Since 2000 about 10,000 infants have been born in the UK to women who have taken antiretroviral drugs in pregnancy, and treatment is now so successful that 99% of these infants escape infection. Nevertheless there are concerns about potential long-term side effects of exposure to HIV drugs in fetal life, particularly since an increasing proportion of women are taking antiretroviral drugs for their own health at the time of conception. We have already established a system to monitor cancer diagnoses (anonymously) in this steadily increasing population of children.\(^{173}\) In the long term we should be able to identify any increased risk of cancer, and establish whether it is related to specific drugs. We believe we are the only country in the world where this can be done on a comprehensive basis. Exploring other long term outcomes of fetal exposure to these drugs is an aspiration, but currently beyond our scope.\(^{174}\)

4.4 CHIPS – children growing up with HIV
One of our key collaborators is the MRC Clinical Trials Unit, which hosts the Collaborative HIV Paediatric Study (CHIPS).\(^{175}\) CHIPS is a joint venture of the NSHPC, the MRC CTU, and the clinics caring for children with HIV; since 2000 this multi-centre cohort study has collected annual clinical, laboratory and treatment information, and data on hospital admissions and use of paediatric services, on virtually all HIV-infected children living in the UK. CHIPS is funded by the NHS (London Specialised Commissioning Group) on an annual

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\(^{171}\) Taylor et al. BHIVA / CHIVA position statement on infant feeding in the UK 2011. *In press* HIV Medicine 2011

\(^{172}\) Thorne et al. Pregnancies in young women with vertically-acquired HIV infection in Europe. AIDS 2007, 21:2552-56


\(^{174}\) Hankin et al. In utero exposure to antiretroviral therapy: feasibility of long-term follow-up. AIDS Care 2009; 21(7): 809-816

\(^{175}\) CHIPS data and full list of publications available at [www.chipscohort.ac.uk](http://www.chipscohort.ac.uk)
renewable basis (£87k in 2010/11). Currently there are 1,245 children in CHIPS follow-up, most of whom were infected perinatally. About 30-40 young people move from paediatric to adult care annually (~250 total to date) and thus leave CHIPS.

4.5 Transition to adult care
Through the NSHPC and CHIPS we have comprehensive data collected from conception, birth or diagnosis and throughout childhood on HIV-infected children in the UK. We need to build on this valuable prior investment and track these young people into adult life in order to understand the long-term impact of perinatally acquired HIV infection. Many clinical research questions are yet to be addressed which are of international relevance, with the first cohort of survivors of perinatal HIV infection only now reaching adult life. A new cohort study (Adolescents and Adults Living with Perinatal HIV (AALPHI)) has recently secured charitable funding. AALPHI will recruit 400 young people transferring from CHIPS to adult care, along with a control group, and follow them for 5 years to examine longer-term outcomes of lifelong exposure to HIV and long-term exposure to HIV treatment. There is also an urgent need to continue comprehensive anonymised surveillance linked to the NSHPC/CHIPS data, since those who consent to detailed follow up may well be different from those who prefer not to be involved. Transition to adult services in other chronic disease areas is associated with very poor health outcomes.

5. Dissemination
Our data are incorporated into the HPA’s regularly updated surveillance tables and reports, and WHO and European HIV surveillance reports. We make substantial and regular reports to our clinical respondents, and regularly contribute to local, regional and national professional and community study days and conferences. We provide specific local and regional data to, for example, commissioners, clinicians, and screening co-ordinators, and we contribute to the development, monitoring and evaluation of the antenatal HIV screening programme. We also publish our findings as original research papers, and contribute to regional, national and international collaborations. Our data are an invaluable resource for the regularly revised BHIVA and CHIVA guidelines on management of HIV in pregnancy and children.

Up to date data and resources are on our website www.nshpc.ucl.ac.uk, including our quarterly newsletter, slide sets, and details of all publications, conference abstracts and presentations.

6. Funding and Staff
The NSHPC was originally funded by AVERT (AIDS Education and Research Trust), and subsequently from the early 1990s by the Department of Health which transferred funding responsibility to the Health Protection Agency (HPA) in 2006. Our current 3-year contract with the HPA ends 31 March 2011. The current funding (£514k 2008-2011) supports three full-time staff: Study Coordinator/Data Manager, Scientist/Analyst, Clerical Assistant. We are currently seeking an extension of this contract, and are currently proposing to provide some additional data to the HPA, and cut back the sum requested for the next 3 years (2011-2014) to £379k to support two staff members only. We are trying to identify other sources

176 Foster et al. Young people in the UK and Ireland with perinatally acquired HIV: the paediatric legacy for adult services. AIDS Patient Care and STDs 2009; 23(3):159-166
of funding in order to retain the Study Scientist/Analyst, and maintain data quality, high response rates and excellent coverage. Other crucial support for the NSHPC is provided without study-specific funding. The Principal Investigator, who manages ethics and research governance, funding, collaborations, and dissemination, is currently HEFCE funded. Statistical support is provided by the Co-Investigator who is also currently HEFCE funded. IT and other technical support is provided through the MRC Centre of Epidemiology for Child Health, and the ICH. Studentships and Fellowships also provide vital support, and we seek additional support from a variety of sources for specific add-on research and audit studies.

7. Ethics and Governance
The NSHPC has MREC and NIGB approval. The NSHPC steering group provides specialist support and advice, ensures the effective collection, use and dissemination of data, and assists in developing the research potential of the study. Membership of the steering group includes colleagues from the HPA and Health Protection Scotland, health professionals working in the HIV field, and lay members (current membership on website).

8. Conclusion
The NSHPC provides invaluable data about HIV in pregnant women and children in the UK which is used by clinicians, commissioners, researchers, public health specialists, policy makers and people living with HIV. It has virtually complete data on HIV in pregnant women and children from the beginning of the HIV epidemic in the UK to the present day. About 80 peer reviewed papers have been published, along with numerous reports, abstracts and presentations. The NSHPC is responsive to contemporary clinical and policy research questions, and contributes to the development and audit of testing and management policies, standards and protocols. All this is done with a small number of dedicated and highly experienced staff, collaborating with many partners, at a very low cost.

17 February 2011
Memorandum by Naz Project London (HAUK 3)

Monitoring

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

- The system is working. However it could be improved by putting robust surveillance systems on targeted groups.
- The biggest problem and gap in the current monitoring system is the weak follow up of diagnosed cases. These loose diagnosed cases are “time bombs” and are potentially the ones who will multiply new cases. No study of these new diagnosed cases of HIV has been conducted to propose solutions or means of keeping them under the radar.
- There is no incentive for marginalised, immigrant HIV positive cases. As a result, they may decide to hide and not to come for treatment and care. These potentially represent a significant number.

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

- Yes, and most likely in negative ways. This is mainly because the disintegration and abolishing of PCTs will have repercussions for those who already have difficulties in accessing the existing statutory health care. Reasons for this include:
  - Immigration status, unemployment, stigma, religion, culture, sexuality, homophobia (mainly in the BME communities) have already made accessing existing services difficult. The reformed public health system will make surveillance more difficult because they add new layers of complexity and depend primarily on access to local GPs where, for example, confidentially can be harder to ensure.
  - HIV services have to be delivered and managed by health professionals. In the current reform, it is vague how local authorities with less knowledge in health care delivery will achieve the expected impact for the community at large. With the spending cuts, service delivery and contact tracing in areas of health like HIV will be undermined and in return monitoring will be not as efficient as it should be.

c. Could anything be done to improve monitoring?

Monitoring could be improved by incorporating it with major strategies of HIV prevention and health promotion that reach marginalised communities and services at the grass root level.

- Incorporate HIV testing as a routine part of care in traditional medical settings and extend the service post diagnosis to new cases.
- Implement new models for diagnosing HIV infections outside medical settings (e.g., rapid testing) by emphasizing community based organizations (POCT). Follow-up of new cases has to be part and parcel
of the monitoring since newly diagnosed cases need further care and support
- Prioritise work with people diagnosed with HIV and their partners
- Include counselling for people with HIV within the monitoring framework to catch as many people as possible.
- Although sub-populations (BME, MSM, IDU and CSW) at high risk may continue to contribute disproportionately to the spread of HIV, sexual networking in the general population is sufficient to sustain an epidemic independent of sub-populations at higher risk of infection. Hence, monitoring also has to focus on this wider population.

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

- BME
- MSM who have unprotected sex
- IDU (Intravenous Drug Users)
- CSW (Commercial sex workers)
- Individuals with multiple sexual partners
- Sero-discordant partners
- Individuals infected with co-infections, e.g., TB, Hep C

Prevention

a. Is Government policy sufficiently focused on HIV prevention?

- The policy is ok. The problem is implementation

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

- Yes, the right groups are targeted but the pathway is not exhaustive. The prevention campaign should not stop at diagnosis. Like that of TB, treatment and especially follow up has to consistently occur if the epidemic is to be stopped.

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

- Naz Project London is not familiar with this area: No comment.

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

Better delivered:

- Ensure linkages between programme level (Local authority, GP consortia, Hospitals, GUM clinics, community based prevention activities) and country level disease trends and impact;
- Collaborate with partners to access strategic information related to other key priorities, including sustainability; provision of services to the
poor and vulnerable groups; health system-wide effects; and contributions to poverty reduction.

Most relevant for Evaluation is:

- **Process** – the activities, systems, actions and other outputs that need to be completed in the near term to achieve improvements or increases in coverage or delivery of HIV services to target groups;

- **Coverage** – the changes in key variables in the medium term that demonstrate that larger numbers of individuals in identified target groups are being reached by and benefit from improved services or interventions;

- **Impact** – the changes over a longer period in sickness and death, reducing the burden of disease in the target population that indicate that the fundamental objectives of the interventions have been achieved.

**Testing**

a. Are current testing policies adequate across the country?

Naz Project London is not sure. There is probably room for improvement.

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

- Health Promotion activities for testing should focus on:-
- Importance and benefits of early HIV diagnosis
- Implications of the test outcome
- Information on referral services
- How and where to access services
- Focus has to be on targeted communities

**Mechanisms:**

- Integrated activity by NHS, Local authorities, GP consortia and community based organizations
- Community-based activities to reach the marginalized “Hard to reach Communities”
- Papers at conferences and in journals
- Mass media such as television and radio
- Small media such as brochures and pamphlets
- Interpersonal communication and peer education

**Treatment**

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

The main success which the GP consortia will bring is in relation to treatment. So, HIV treatment should/must be through the consortia. However, if public
health and prevention is under Local authorities, it is unclear what mechanisms will link diagnosis, prevention, treatment and care.

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

As long as treatment is governed by clinicians and not decentralised, e.g., to over the counter Boots and other pharmacies, the treatment protocol is fine. The new reforms should not make much of a difference to treatment.

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

Unlike testing, treatment is preferable in a clinical setting.

Cost

Naz Project London is not familiar enough with this area to comment.

Stigma

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

Certain groups, e.g., men who have sex with men, sex workers and injecting drug users, often bear the heaviest burden of HIV-related stigma.

- Isolating people who are HIV-infected
- Restricting participation in local events, e.g., not including partners and children of in activities or gatherings
- Using violence against a partner or family member who has tested HIV-positive
- Limiting support for grieving family members, including orphans
- Non-disclosure due to fear of response from others, and as a result reduced access to support from family, friends, community
- Avoidance of health and social services due to fear of unfair treatment/fear that action would be admission of HIV-status, potentially leading to; this will lead to increased risk of transmission to partners or children and limited choice in health care
- May deter people from getting tested
- May make people less likely to recognize their risk of infection
- May discourage those who are HIV-infected from discussing their HIV status with partners
- May prevent adoption of risk-reduction practices that may lead to being labelled as HIV-infected
- May obstruct prevention, treatment, and care programs

b. Where are problems of stigmatisation most acute?

- BME communities
- LGBT communities
• Newly arrived immigrants
• In religious groups
• In sex workers

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

• Address human rights of people living with HIV
• Prioritise HIV-related prevention, treatment, care support services

High-ranking politicians, other well-known individuals:
• May serve as leaders and role models
• Advocate for legislation
• May engage the media to increase publicity
• Promote implementation and enforcement of legislation

Educate and engage the national media
• Increase knowledge about HIV
• Raise awareness of issues faced by people with HIV
• Increase awareness of domestic violence faced by newly-diagnosed women and MSM
• Communicate that such violence against is inappropriate, immoral, illegal
• Encourage leaders to make workplaces “HIV-friendly”

Community level interventions:
• Build partnerships with religious, educational, social, civic organizations
• Facilitate exchange of information, ideas among healthcare professionals and other caregivers of
• Provide input into curricula for students in healthcare professions (for example, nurses, midwives, physicians)

Health care setting:
• Health Care Workers and managers take the lead in challenging long-held community beliefs and practices, including stigma and discrimination
• Support HIV-infected workers to continue to work
• Implement policies guaranteeing clients equal treatment
• Give clients a confidential means of reporting discrimination

8 February 2011
Letter from the North East London HIV and Sexual Health Clinical Network (NELNET) (HAUK 6)

1.1 We are very pleased to be given the opportunity to submit evidence to the Select Committee on HIV and AIDS in the United Kingdom.

1.2 This response comes on behalf of the North East London HIV and Sexual Health Clinical Network (NELNET). The Network has high level clinical, commissioning, third sector and service user involvement across the NE London Health Service Economy. The membership is drawn from 5 acute NHS Trusts (Barts and the London, Homerton, Newham, Barking and Whipps Cross), clinicians from multiple disciplines involved in HIV/sexually transmitted infections (STI) care, commissioners and public health professionals from 7 PCTs (Tower Hamlets, City & Hackney, Newham, Waltham Forest, and Barking, Dagenham and Redbridge), together with Reproductive and Sexual Health (RSH) services, voluntary sector services, and service users from across the locality.

2.0 Monitoring

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

2.1 The HIV surveillance and monitoring system, run by the Health Protection Agency (HPA) is one of the best in the world, providing borough-level data with a lag time of only one year. The HPA data informs multiple work streams and provides a robust basis for service planning. It will be an important part of the way in which HIV clinical care is funded via payment by results (PbR). Much of the current success depends on the close liaison between the HPA and clinical services.

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

2.2 Any reduction or compromise to the current function of the HPA once it is incorporated into Public Health England threatens this system. For example, devolution of data collection to local authorities carries a risk of delay and error in data reporting and information on rates of undiagnosed HIV would be lost if the anonymous seroprevalence survey was stopped.

c. Could anything be done to improve monitoring?

2.3 Common HIV-related data fields are collected across the UK from clinical services, but the information technology (IT) equipment, software and systems differ in type and quality between clinics, even within the same network. Investment in HIV-specific IT software that could be standardized across HIV clinical services would improve the quality of data and the efficiency of the data collection process.

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

2.4 There are two groups at risk of the effects of HIV.

2.5 The first are those who are already infected but as yet undiagnosed. The profile of this
group is changing under several influences, including that of migration patterns. In northeast London these are currently Sub Saharan Africans, people from the Caribbean, Men who have Sex with Men (MSM) and people from Eastern Europe, especially people with a history of intravenous drug use (IDU). Women and heterosexual men are over represented amongst those diagnosed late, with advanced disease. People who do not fit into recognizable high-risk groups are at high risk of late diagnosis – for example the over 60s and non-African women. Late diagnosis is the leading cause of HIV-related mortality and morbidity in the UK.

2.6 The second are those who are at risk of becoming infected in the UK. This group includes the first group, but because of sexual mixing, the second group includes all sexually active people in the UK, with young people at particular risk for the same reasons they are at risk of Chlamydia infection. Epidemiological evidence suggests that most new infections acquired in the UK are transmitted through sex between men.

3.0 Prevention

a. Is Government policy sufficiently focused on HIV prevention?

3.1 It is encouraging that the Public Health white paper explicitly mentions sexual health and HIV, including an intention to ringfence money for local authorities to commission non-discretionary open access sexual health services. However, there is no mention of HIV prevention as a specific priority in the white paper. Nor is there acknowledgement of the fact that appropriate treatment and prevention of onward transmission is critically and inextricably linked to prevention.

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

3.2 Recent national prevention campaigns have been too generic or focused on the wrong groups eg young white British people. Most prevention campaigns in northeast London have been targeted at black African people and MSM. Health professionals recognize that more prevention work could be done with people living with HIV to reduce their risk of transmitting HIV to others, but barriers to this are often related to the inability to disclose status because of stigma.

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

3.3 The harm reduction strategies for IDUs across the UK have been very successful, but there seems to be a growing group of IDUs from Eastern Europe who have more difficulty accessing services.

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

3.4 The ultimate in prevention would be for people to know how to reduce their own risk of infection, have the capacity to reduce the risk and to choose to do so. The Government’s focus on creating cultural norms of healthy choices is welcome, but needs to take into account the many different cultures existing in small geographical areas throughout the UK.

3.5 More work is needed to reduce onward transmission in the MSM community, and in the Sub Saharan African communities. A broader approach might be more effective:
looking at drug and alcohol misuse and mental health in the MSM community, and education around transmission and access to treatment in the African communities.

3.6 Evaluation should still focus on the proportion of undiagnosed people and the number of new infections occurring in the UK, with local figures reported back to local authorities.

4.0 Testing

a. Are current testing policies adequate across the country?

4.1 No. The proportion of people who are infected but not yet diagnosed is falling too slowly, and the rates of late diagnosis are not consistently falling in most of north east London.

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

4.2 Two things are necessary. More people need to offer the test, and more people need to accept it.

4.3 People are most likely to accept the test if it is seen as normal, especially if the default option is to test – as evidenced by antenatal testing rates of >95% in north east London. Other successful approaches in NE London include testing at new registration visits in GP surgeries, embedding HIV testing in a men’s health checkup, delivering rapid tests in non clinical settings and introducing opt out testing for all people admitted to secondary care.

4.4 HIV testing and prevention needs a national focus, with an incentive system to encourage the offer of testing. Ideally HIV testing and prevention will become part of the public health outcomes framework, with public health incentive payments to local authorities for early diagnoses. Testing in acute care could be improved by making increasing numbers of HIV diagnoses a national clinical target, as with decreasing numbers of MRSA or C. difficile infections. Testing in acute care could also be increased via the financial incentive of CQUIN targets.

5.0 Treatment

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

5.1 Commissioning HIV treatment carries a considerable financial risk because of expensive, though highly cost-effective, drugs. The geographical area commissioned needs to be large enough to achieve a manageable financial risk, and small enough to allow meaningful management of providers, given the different clinic profiles which exist. This includes the ability to set and monitor standards through clinical governance bodies. The pan London approach works well, partly because the size of the pan London HIV Consortium gives it bargaining power with pharmaceutical companies and therefore best value for the NHS, and partly because the number of clinicians engaged is large enough to reach a meaningful consensus on clinical issues including standards.

5.2 Good practice must be rewarded and guided by the use of CQUINs and the QIPP agenda.
b. What impact might the proposed new commissioning reforms have on HIV treatment?

5.3 Commissioning directly by the National Commissioning Board should mean equality of access to HIV drugs for patients, but the commissioners will not be able to focus on local details, and so there are the risks for providers of inadequate accountability to commissioners and inadequate or inappropriate reward for good practice. These could be mitigated by regional clinical networks, which could focus on clinical governance including performance, and act as a communication hub. However, this would require additional investment into regional networks, and networks the size of NELNET are too small to cope with the financial risk of HIV drugs and too small to have significant bargaining power. The same issues would face local GP consortia. Patients would face a postcode lottery of access to drug treatment.

5.4 The Government’s decision to allow a maximum tariff for care, and for competition between providers on the basis of price to be expected, opens the way for non-NHS providers to offer cheap care for the large subset of stable patients on lower cost drugs, leaving NHS providers to treat the patients who need the greatest resources of time and money.

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

5.5 HIV is a long-term condition that is often complicated by physical and mental health co-morbidities, the effects of stigma, drug resistance, social deprivation and intercurrent pregnancy. Patients need coordinated care with specialist care provided by the relevant specialist, including general practitioners. It is not feasible to co-locate all necessary services. To ensure compliance with the key British HIV Association national standard that all those living with HIV have access to all the services they require it is essential to have clear lines of communication, clear patient pathways and clear lines of internal and external accountability. Clinical networks such as ours provide the structure for this model to work in practice.

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 Whilst prevention policy focusing on regular testing in at-risk groups is to be applauded the follow-on costs of lifelong HIV treatment must be recognized. Condoms are highly cost-effective in reducing risk of transmission but their effectiveness is limited by (male) user-dependence and failure rates. It is likely that other prevention technologies will soon be recommended e.g. vaginal microbicides and pre-exposure prophylaxis (PrEP). Initial evidence suggests that these approaches reduce risk of HIV infection in high risk individuals by around 40% overall but efficacy is significantly greater, particularly for PrEP in those with the highest adherence to treatment. This is likely to involve short to medium term increased cost but a longer term reduction in the epidemic. Treatment as prevention with increased HIV diagnosis through testing has been shown to be an effective strategy in reducing transmission as durable viral suppression is associated with a significant reduction in the risk of transmission to uninfected partners. However this will also
cause short term cost pressures. Mathematical models predict a long term cost reduction if these strategies are successful.

b. Is research funding correctly prioritised?

6.2 HIV is a multifaceted condition with biomedical, political and social causes and consequences. Health inequalities are particularly pertinent in this context and the intersection between the global and local HIV epidemics has particular resonance in the UK with the longstanding historical links to high endemicity regions of the world. This means that research questions frequently cross academic disciplines and intellectual boundaries. NE London is ideally placed to take forward some of these important questions by virtue of the diversity of the patient population living and seeking care in the area. However research funding structures in the UK are poorly equipped to deal with this intellectual complexity and important research questions remain unaddressed and unfunded as their natural home is disputed by funding bodies. As NHS clinical services become ever more constrained and funding is tighter it is likely to become more difficult to embed research in overstretched clinical settings. Much of the finance for HIV research comes from the pharmaceutical industry and may drive the research agenda in a particular direction. Increasing research funding in areas of disciplinary overlap with collaboration between research councils would help. Only certain funding streams are eligible for study adoption into the NHS research portfolio with any funding coming from outside the UK being excluded. This excludes various HIV related funding bodies such as the Gates Foundation. We would ask the Committee to look at this issue during its deliberations.

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?

7.1 Professionals working with people living with HIV often see their patients lose their spousal relationships, family relationships, friends, income, accommodation, physical safety and mental health as a direct consequence of their HIV diagnosis. We regularly see patients who have refused to follow medical advice to test for HIV until they develop an AIDS-defining condition, patients who are unable to believe their positive HIV test result, and others who disappear from services once they have been diagnosed. Fear of losing intimate relationships and social capital influence people’s ability to disclose their HIV infection to their partners and family members. Services that provide HIV specific care are not used by many who need them for fear of recognition by others form their communities or anxiety about confidentiality. These factors increase social isolation, inhibit health promotion and restrict the lives of people with HIV.

7.2 People with HIV still experience stigma when trying to access health and social care services, and this reduces their willingness and ability to access care.

b. Where are problems of stigmatisation most acute?

7.3 Groups most affected by stigma in north east London are Black Africans, especially those from western Africa, and Caribbeans. MSM and women who have sex with women from these groups face stigma because of their HIV and stigma because of their sexuality. People who belong to some religious groups face stigma because of their HIV or their
sexuality.

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

7.4 Current legislation banning discrimination is very useful, as is Personal, Social, Health and Economic work in schools. An agreement by the national press to report responsibly on HIV-related issues would be useful.

7.5 To reduce stigma requires a change in people’s worldview. Because of the many cultures within the UK, there are many different group worldviews, and it is unlikely to be cost-effective to try to change many of them. A detailed discussion of strategies to reduce stigma is outside the capability of the authors of this response, but many members of our network have ideas, which could be collated into a separate document if requested.

14 February 2011
Memorandum by Ruth Hutt, Consultant in Public Health, NHS Lewisham (HAUK 31)

1. Context

1.1 Lewisham PCT has a high prevalence of HIV infection of 7 per 1,000 (2009). Most newly diagnosed HIV infection in Lewisham is heterosexually acquired, and late diagnosis is more common in this group.

1.2 Lewisham PCT received Department of Health funding to pilot opt out HIV testing for new patients registering with GP practices in line with the 2008 BHIVA testing guidance. After 9 months of implementation between January and September 2010 over 4,342 patients were offered an HIV test as part of the new patient check, of which 2,713 accepted. Nineteen patients were HIV positive. The pilot is continuing with the support of Gilead funding across Lambeth, Southwark and Lewisham.

2. Monitoring

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

2.1 The UK has good systems in place for providing up to date information on people with HIV infection across the UK. A number of different sources contribute to this information and the Health Protection Agency (HPA) provides regular reports which help support commissioning and service developments in relation to HIV care.

2.2 Estimates of undiagnosed HIV infection are largely based on anonymised testing in GUM settings. These estimates do not allow for the fact that many (particularly heterosexual men) may not use these services and therefore may underestimate prevalence where the epidemic is largely Black African heterosexually transmitted. SOPHID does not account for people that choose not to engage with specialist services.

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

2.3 Changes to the HPA may put at risk some of the work currently done to compile a complete and comprehensive overview of HIV epidemiology. This work should be safeguarded in new organisational structures.

2.4 There is a clear need for some GP engagement around HIV in light of an ageing cohort of patients whose needs have changed dramatically over the last two decades. Service configurations do not reflect these changes at present. If more care is provided by primary care in the future, this would potentially impact on the ability to collect data on HIV positive patients accessing care as current systems in primary care would not allow for this level of data collection.
c. Could anything be done to improve monitoring?

2.5 Linkage to laboratory testing data may give an overview of testing activity. A minimum data set for labs for HIV related testing could be established which would enable the epidemiological information to be collated. A similar system is being proposed for Chlamydia screening data. In Lewisham our local experience of HIV testing in primary care has been that a quarter of patients may not engage with specialist services. These patients would not appear on SOPHID and therefore are not counted in official prevalence estimates.

2.6 There should be an imperative on specialist service to routinely communicate with GPs about HIV care their patients receive. As commissioners GPs need to understand their local population needs and the current lack of communication between HIV services and primary care means that GPs are not necessarily aware of the extent of HIV infection in their own registered populations. This makes their commissioning role very difficult. With better disclosure of HIV infection in primary care, in the future estimates of HIV prevalence could be made using primary care data as is currently the case for other long term conditions.

2.7 The current (Read) codes used in primary care are inadequate for recording HIV testing in this setting, particularly in relation to point of care testing. New Read codes should be developed for HIV infection and point of care testing which enable primary care to get reliable data for their local populations on the number of tests performed and local disease prevalence.

2.8 Some HIV services still do not hold electronic patient records (EPR). Electronic patient records should be a minimum standard for all HIV services, so patient records can be searched for the purposes of audit or patient recall (for example following a change in treatment guidelines or following clinical incidents) without a manual search of paper notes. Anonymised data from EPR could be used to complement existing data sources.

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

2.9 Men who have sex with men and Black Africans are currently at highest risk of HIV infection. However, there are other groups which are emerging as higher risk groups in including Eastern Europeans and Black Caribbeans. Currently there is very little HIV prevention activity focused on these groups.

3. Prevention
a. Is Government policy sufficiently focussed on HIV prevention?

3.1 HIV testing should be seen as a key component of HIV prevention. Diagnosing HIV infection and linking patients into treatment can dramatically reduce transmission of infection. Diagnosis of HIV itself has a big impact on risk behaviour.

3.2. The link between testing as part of HIV prevention is not currently strong enough.

3.3 Local experience of extending HIV testing into community sexual health (family planning) settings has also highlighted that the intervention of the HIV test itself to be a good opportunity to reinforce safe sex messages following a negative result.
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?

4. Testing

a. Are current testing policies adequate across the country?

4.1 There is considerable variation in the implementation of the 2008 BHIVA testing guidance across the country. Lewisham is an area of high HIV prevalence however testing activity in relation to the BHIVA guidance remains low. In Lewisham we have had Department of Health funding to successfully implement HIV testing to newly registering patients in primary care. However with conflicting financial priorities locally it will be challenging to secure the funding that will enable us to continue testing and roll it out to the remaining 30 practices. During the first 9 months of implementation 19 new infections were diagnosed. None of these patients presented symptomatically and these infections are unlikely to have been detected without the screening offered at the new patient check.

4.2 Healthcare workers are currently tested for Hepatitis B but not HIV in many healthcare organisations. HIV testing of healthcare workers should be standard practice given the vast amount of public money spent on patient recall exercises for patients exposed to HIV positive healthcare workers (despite the low risk of transmission). Many clinicians are still under the impression they are required to ‘counsel’ a patient prior to an HIV test. If more health professionals had an HIV test they would be better informed about HIV infection.

4.3 Healthcare workers (outside of specialist HIV services) themselves are a considerable barrier to HIV testing. The way in which a test is offered (normalised versus exceptionalised), the way in which patients are required to consent to testing (by being asked to ‘sign’ something, book a special clinic appointment or have a pre-test discussion) all continue to contribute to the stigma of having an HIV test and of HIV infection.

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

4.4 Universal ‘opt out’ testing for antenatal screening has been hugely successful in increasing HIV testing in pregnant women. A similar approach should be adopted in other care settings in line with the BHIVA guidance.

4.5 Experience from the primary care testing pilots funded by the DH has demonstrated that HIV testing is acceptable to patients and that staff are often the biggest barrier to testing.

4.6 The use of point of care testing can increase uptake of an HIV test by ensuring results are available immediately and patients aren’t put off by requiring a blood test. It also makes results management easier as patients do not have to return for a second appointment or telephone in for results.

4.7 Some patients wrongly assume they have been tested for HIV when they have
had blood tests for other reasons, potentially giving them the mistaken belief that they do not have HIV.

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

   5.1 HIV treatment needs to be commissioned over large population areas, centred in specialist services but with satellite services or networked services locally. There needs to be far more engagement with GPs to meet the ‘non’ HIV needs of patients.

   5.2 While GUM services have been the home of HIV services since their inception there is perhaps an opportunity to consider them outside of sexual health context in an attempt to de-stigmatise HIV infection. As GUM services have never communicated with primary care about patient care it is not considered standard practice as it would be in any other area of clinical care. This is a barrier to safe patient care. The GMC guidance on sharing information states:

   - **Sharing information with other healthcare professionals is important for safe and effective patient care.**
   - **When you refer a patient, you should provide all relevant information about the patient, including their medical history and current condition.**
   - **If you provide treatment or advice for a patient, but are not the patient’s general practitioner, you should tell the general practitioner the results of the investigations, the treatment provided and any other information necessary for the continuing care of the patient, unless the patient objects.**
   - **If a patient has not been referred to you by a general practitioner, you should ask for the patient’s consent to inform their general practitioner before starting treatment, except in emergencies or when it is impractical to do so. If you do not inform the patient’s general practitioner, you will be responsible for providing or arranging all necessary after-care.**

   5.3 This guidance should be implemented in HIV care in the same manner as it is for all other specialties. This is particularly important given the increasing numbers of HIV positive patients being diagnosed in primary care.

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

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

   5.4 HIV services should be looking to develop community treatment models and shared care arrangements with primary care to manage the cohort of ageing HIV positive patients. A stepped approach to care should be encouraged that will require HIV specialists to work in better partnership with primary care. The current lack of coordination of care by a GP puts patients at risk.

6. 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?
7. Stigma

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

7.1 Stigma regarding HIV infection has an impact on how prepared people are to disclose their HIV status, both to other healthcare professionals, family and work. Stigma is also a barrier to HIV testing and perpetuated by healthcare professionals making judgements about an individual’s risk.

7.2 While confidentiality is clearly very important within health services, the idea that HIV services are MORE confidential than other healthcare services is not helpful in de-stigmatising HIV infection. The more people feel able to disclose their HIV status and talk about it openly without adverse reactions from healthcare workers the greater the impact will be on de-stigmatising HIV infection.

7.3 Within the wider population and even amongst some healthcare professionals there is still no clear message that HIV is now a treatable condition and that with treatment the risk of transmission of infection can be reduced to almost zero.

7.4 For children and adolescents growing up with HIV the stigma of HIV infection presents huge hurdles as they become sexually active and try to manage their condition in a responsible way.

b. **Where are problems of stigmatisation most acute?**

7.5 Many health care professionals lack up to date knowledge of HIV infection. Part of the stigma of HIV is perpetuated by health care professionals and the collusion between HIV specialists and patients that other parts of the NHS will not respect their right to confidentiality. Because patients have been told they don’t need to inform their GP or other healthcare workers of their HIV status there is an underlying assumption that if they divulged this information it would in some way change their treatment.

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

7.6 Given that the highest burden of HIV is felt by those who may already be stigmatised by the ethnicity and sexuality, consideration should be given to moving HIV treatment services out of GUM/sexual health clinic settings and into mainstream general medicine. This would begin to bring HIV treatment and care in line with other conditions such other immune disorders, hepatitis which do not experience the same levels of stigma.

7.7 Normalisation of HIV testing so that HIV is discussed openly in the context of wider health issues rather than just the context of sexual health will help de-stigmatise HIV. Local experience from the HIV testing pilot has shown that when offered an HIV test patients are willing to disclose their HIV (positive) status.

17 February 2011
Memorandum by the Rehabilitation and HIV Association (HAUK 40)

This evidence is submitted on behalf of the Rehabilitation and HIV Association, an association of Occupational Therapists, Physiotherapists and Speech and Language Therapists who specialise in working with people living with HIV in a range of settings.

1.0 Treatment

1.1 Recommendation 1: That rehabilitation should be included alongside prevention, testing, treatment and support as a cornerstone of HIV care. That HIV clinical services should have a dedicated multi-disciplinary rehabilitation team. That rehabilitation services outside of HIV clinical services are accessible and responsive to the needs of individuals living with HIV.

1.2 As well documented, the number of people living with HIV in the United Kingdom has increased year on year since it was identified in 1981[^178]. Whilst advances in the medical management of HIV have lead to greatly increased life expectancy[^179], living longer term with HIV has lead to increased rates of both HIV related opportunistic illnesses[^180] and other related co-morbidities[^181]. Several studies have shown that this translates in to a significant proportion of people living with HIV living with impairments, activity limitations and participation restrictions[^182][^183].

1.3 Our members, many of whom work within the larger HIV clinics in both inpatient and outpatient settings, have continued to see increasing numbers of people presenting with impairments and disabilities related to living with HIV. These include physical, sensory, cognitive, social and psychological impairments and disabilities. In our own clinical practice, and through our work educating and supporting rehabilitation professionals working in a range of settings, we are aware of many individuals living with HIV accessing rehabilitation services throughout their HIV journey including within acute inpatients settings, community rehabilitation services, social services and work rehabilitation services.

1.4 Rehabilitation professionals aim to ameliorate impairments and disabilities through a range of interventions ranging from direct hands-on treatments, exercise based interventions, functional practice, giving of advice and information, environmental adaptations and recommendations for support services. The effect of these

interventions is more far reaching than improving the quality of life of the individual living with HIV; successful rehabilitation also aims to reduce hospital admission rates, reduce length of stay in acute care, reduce reliance on medical and social services, and supports people to enter and maintain paid employment. Many rehabilitation interventions also have a public health benefits, for example advising on life style changes in diet, activity and stress management to reduce the risk of cardiovascular disease. All of these interventions have the potential for reducing the financial burden on the state.

1.5 Given the change in profile of people living with HIV in the UK, we would recommend that future guidelines and commissioning strategies provide for rehabilitation for people living with HIV. This is also in line with international recommendations from the World Health Organisation, which states that governments should “provide comprehensive HIV testing, treatment, care and support services which...include early intervention and referral to rehabilitation and support services for people experiencing activity limitations or participation restrictions as a result of their HIV infection.”

1.6 We would recommend that specialist HIV clinics continue to have access to rehabilitation professionals with specialist HIV knowledge. Clinics without access to rehabilitation professionals with specialist HIV knowledge should be supported to develop these services.

1.7 Evidence from other long term condition management strongly supports that multidisciplinary team management (MDT) is highly effective. Our members report that MDT working is also highly effective within HIV services. We recommend that HIV clinical services include MDT members such as specialist physiotherapy, occupational therapy and speech and language therapy.

1.8 We also recommend that provisions are made for training and support of rehabilitation professionals working in non HIV specialist settings (see below).

2.0 Stigma

2.1 Recommendation 2: That rehabilitation services across the UK are provided with education and support to provide services that are sensitive to the experience of stigma that many people living with HIV report.

2.2 The experience of our members suggests that generic services such as community rehabilitation teams and social services teams have over time become more appropriate in their response to referrals of people living with HIV. Our members have in the past encountered services who had incorrectly assumed an individual living with HIV did not require rehabilitation because they had a deteriorating, life limiting illness. Conversely, members have also experienced services who had incorrectly assumed that people receiving effective antiretroviral treatment did not require services even though they presented with impairments or disabilities, often ignoring

the episodic nature of HIV. Our members’ experiences suggest that there is a
variance in the quality of managing stigma related issues by rehabilitation services; in
areas with high prevalence of HIV such as inner city areas, services tend to have more
sensitivity to the stigma and discrimination experienced by people living with HIV than
those living in areas with lower prevalence. Our members are concerned that as the
trend towards people living with HIV living primarily in inner cities that instances
stigma may increase and this supports the need that education needs to be wide
reaching.

2.3 Our members report more recent instances where generic rehabilitation teams have
been reluctant to accept referrals or where there were concerns over occupational
transmission of HIV that were based on outdated, incorrect information, as well as
instances where individuals living with HIV have reported they felt they were treated
inadequately or in a discriminatory manor by non-specialist services because of their
HIV diagnosis.

2.4 We recommend that rehabilitation professionals working in all areas are given the
opportunity to access HIV training, and that HIV education is included in the
undergraduate training of rehabilitation professionals. This is also recommended by the
World Health Organisation.

3.0 Research

3.1 Recommendation 3: That support and resources be available to undertake
quality research into the benefits of rehabilitation for those living with HIV.

3.2 As a relatively new and now long term condition the evidence for the effectiveness of
rehabilitative therapy and input is often borrowed from other fields with over lapping
issues, such as neurological rehabilitation. Research into the benefits of exercise and
HIV, summarised in two Cochrane Library reviews, show an encouraging example of
research which as informed therapeutic intervention specifically targeted for HIV
positive individuals.

3.3 However research into physical and cognitive sequelae of HIV and rehabilitation in the
context of HIV are often lacking, with the bulk of research funding and resources going
to prevention and drug therapies. Coupled with the very small number of rehabilitation
professionals working directly in HIV, and the career structures for rehabilitation
professional less geared towards research than their medical counterparts, creating a
strong robust evidence base is extremely challenging. This could propose a particular
difficulty with the upcoming changes to commissioning for NHS services, as little
understood about the vital services for people living with HIV.

186 O’Brien, K, Davis, AM, Strike C, Young N, Bayoumim AM. Putting episodic disability into context: factors
that influence disability experienced by adults living with HIV. Journal of the International AIDS Society. November
2009, 12:30.
Living with HIV/AIDS: Systematic Review and Meta-Analysis of Randomized Trials. AIDS Care, 2008 20(6): 631-
653.
3.4 There is a growing body of evidence suggesting that amongst older people living with HIV, that there is a growing need for rehabilitation and therapy support as well as complex issues relating to barriers to accessing appropriate care targeted at this group.\(^{190, 191}\)

3.5 To fully understand and investigate the positive outcomes seen in individuals receiving rehabilitation interventions from our members, we recommend that support and resources be given to boost research activities in the areas of prevalence of HIV related disabilities and impairments, the experiences of those with HIV accessing care and support, and specific therapeutic interventions which may benefit those living with HIV.

February 2011


Introduction

With a membership of over 410,000 registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in the NHS and the independent sector. The RCN promotes patient and nursing interests on a wide range of issues by working closely with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

The RCN welcomes this opportunity to submit evidence to the House of Lords Select Committee inquiry into HIV and AIDS in the UK.

Executive Summary

- The RCN maintains that there should be sustained and structured nursing involvement during the design, development and delivery of any reforms to healthcare services and healthcare commissioning. This must include designated nursing posts on the NHS Commissioning Board, GP Consortia and Local Health Boards, as nursing leaders play a pivotal role in helping to close the gaps between hospital and community and health and social care. This ensures the delivery of integrated and seamless care to patients.

- Reforms should be designed to address health inequalities, which will need monitoring and addressing to ensure that all health needs are met. This is particularly important in relation to socio-economic disadvantage and hard to reach groups, including people who have not tested for HIV before and African communities where the impact of stigma is higher. The commissioning process needs to have an overall view of the population, which will require joint working to take place across agencies.

- The RCN believes that it is important that national political accountability is not lost in the new system.

- The RCN is concerned that there may be the possibility of fragmentation of access to sexual health and HIV services following the reforms. The renewed 2011 strategy for sexual health and HIV for England is likely to be commissioned by the National Commissioning Board rather than from Public Health England. However prevention, behaviour change in all aspects of sexual health, and open access sexual health services will become a Local Authority responsibility. The RCN recommends that all services relevant to sexual health should be commissioned by the same organisation. This would include prevention initiatives, sexual health services, HIV treatment, family planning, termination of pregnancy and screening services.

- The RCN calls for the commissioning proposals outlined in the Public Health White Paper to be amended to reflect this coherent approach. It is important that joint working arrangements will be in place to work across different commissioning streams and delivery routes to avoid gaps in the system.

• The proposed renewed 2011 strategy for sexual health and HIV for England must look to “invest to save” models of evidence based preventative care and it is important that progress made in recent years is sustained and improved upon.

• Self-care models should be developed and supported by well resourced nurse-led clinics in community settings. This must be delivered by staff with appropriate competencies which are maintained with regular Continuing Professional Development (CPD) opportunities, working with multi-disciplinary care plans with clear escalation pathways to acute settings where necessary.

• The proposed renewed 2011 strategy for sexual health and HIV for England should focus on the development and normalisation of HIV self-care and public campaigns to increase knowledge and reduce stigma around HIV and AIDS.

Inquiry questions

1. Monitoring

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

1.1 The robustness of the current system is subject to the adherence of specialist HIV centres to British HIV Association (BHIVA) and The Children's HIV Association of the UK and Ireland (CHIVA) standards and guidelines with appropriate reporting to the Health Protection Agency (HPA) or its replacement. Centres in high grouping areas (London, Brighton, Manchester) have high throughput, which maintains the skills and experience of staff. However smaller centres or centres in areas of low prevalence tend to have a lower throughput so links including those with centres of excellence need to be developed and maintained. Vital to the network of treatment centres are nurse-led clinics with nurse consultants and clinical nurse specialists.

Will the proposed public health reforms impact on this system?

1.2 The RCN is concerned that the proposed reforms could lead to the possibility of fragmentation of access to sexual health and HIV services. The planned 2011 strategy for sexual health and HIV for England is likely to be commissioned by the National Commissioning Board rather than from the new Public Health England. However, prevention, behaviour change in all aspects of sexual health, and open access sexual health services will become a Local Authority responsibility. The RCN recommends that all services relevant to sexual health should be commissioned by the same organisation. This would include prevention initiatives, sexual health services, HIV treatment, family planning, termination of pregnancy and screening services.

1.3 The commissioning proposals outlined in the Public Health White Paper should therefore be amended to reflect this coherent approach. Joint working arrangements should be in place to work across different commissioning streams and delivery routes to avoid gaps in the system.
Could anything be done to improve monitoring?

1.4 The RCN endorses adherence to BHIVA and CHIVA guidelines in all settings.

What groups in particular are at risk from HIV?

1.5 At risk groups include: gay men; men who have sex with men (MSM) (including men who are also in heterosexual relationships); African communities; and adults who have multiple sex partners (including sex tourists).

1.6 In relation to risk, approximately 25 per cent of people living with HIV are undiagnosed193 and are not aware that they are carrying the virus. This increases the risk to their sexual partners and also to themselves as late diagnosis and treatment leads to poorer health outcomes.

2. Prevention

Is Government policy sufficiently focused on HIV prevention?

2.1 The 2011 strategy for sexual health and HIV for England must look to “invest to save” models of evidence based preventative care. It is also important that progress made in recent years is sustained and improved upon. HIV is an area that would directly benefit from the Wanless principle to “invest in reducing demand by enhancing the promotion of good health and disease prevention”194. This also reflects the Public Health White Paper focus on health prevention.

2.2 The 2011 strategy for sexual health and HIV for England must also focus on earlier detection targeted at high risk groups to complement prevention initiatives.

Have the right groups been targeted in recent prevention campaigns?

2.3 The RCN notes that some past campaigns have been poorly targeted and recommends more targeted prevention campaigns focussing on at risk groups (gay men/MSM, African communities). Additional campaigns aimed at the general public should focus on increasing knowledge and reducing stigma. For example, lessons could be learnt from the success of antenatal screening programmes.

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

2.4 Needle exchange projects, including testing, are working well and this group is a well defined and understood population. The RCN recommends that needle exchange programmes should be extended into criminal justice and prison settings.195

194 Securing Our Future Health: Taking a Long-Term View, Derek Wanless, 2002
How could prevention initiatives be better delivered and evaluated?

2.5  Under a local commissioning structure, it is essential that nurses working in sexual health, HIV and health promotion areas have the knowledge, skills and competence to agreed standards. This will help to ensure the delivery of effective behavioural changing interventions.

2.6  The cost benefit in the development of nurse-led community models of care which reduce hospital admissions can be complemented by qualitative evidence showing the benefit to patients of increasing responsibility for self-care and managing their conditions.

2.7  Prevention initiatives must be evidence based and the evaluation of initiatives should then be used to increase this evidence base. Prevention initiatives could be better evaluated if robust outcomes are set before initiatives are launched so that the initiatives could then be evaluated against delivery of these outcomes.

3.  Testing

Are current testing policies adequate across the country?

3.1  As referred to previously, approximately 25% of people living with HIV are undiagnosed and are not aware that they are carrying the virus. For this reason, more could be done to increase testing take-up rates.

What can be done to increase take-up rates?

3.2  There is a need to increase the rates of early diagnosis by early testing of at risk groups. This could be done by improving the availability of testing in community settings and venues, which would increase take-up rates. The RCN notes the importance of identifying hard to reach groups and people who have not tested before and engaging with these groups and people to encourage them to test. The involvement of the voluntary sector and faith groups could be used to help with identifying, engaging with and encouraging people who have not tested before.

3.3  The RCN supports the legalisation and regulation of home testing to enable people who wish to test at home to do so in safety and with access to appropriate services if required.

3.4  The RCN notes the importance of the normalisation of routine testing and suggests targeted testing at point of entry to any healthcare system. Investing in and supporting nursing staff to deliver this programme of testing is important. Nursing staff includes: practice nurses; occupational health nurses; midwives; health visitors; A&E nurses (including routine testing for all those exhibiting symptom related A&E admissions); nurses in criminal justice services; and respiratory nurses. These practitioners need to have the knowledge, skills and competence to promote testing and to perform the test.

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4. **Treatment**

How can the NHS best commission and deliver HIV treatment?

4.1 As referred to previously in the submission, the RCN has concerns regarding the impact of the proposed public health reforms on the commissioning on sexual health and HIV services. The RCN therefore recommends that joint working arrangements should be put in place to work across different commissioning streams and delivery routes to avoid gaps in the system.

4.2 NHS commissioning should include cost benefit modelling, including data to show the added value of the service commissioned. This should include opportunities for qualitative data to be collected which will demonstrate the benefit of supportive and sustained nurse/patient relationships.

4.3 The RCN notes that HIV treatment can learn from other long term conditions with promotion of self-care models. These self-care models should be supported by the commissioning of nurse-led community clinics for people living with HIV. These “invest to save” models confer the cost benefit of reduced hospital admissions.

4.4 Nurse led community clinics mean that if patients are well and stable they can be seen by a specialist nurse who can prescribe, undertake physical assessment and monitoring and see the patient in a setting that normalises HIV. These nurse specialists will have extensive knowledge of conditions and concurrent conditions. It will be important that these nurse specialists are resourced and have access to CPD so that care givers maintain their specialist knowledge of treatment and care plans. Care pathways to a medical consultant must be in place to escalate across if the patient requires a medical review.

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

4.5 Please see previous answers, where the RCN has outlined its concerns regarding the new reforms.

In what setting can treatment most effectively be delivered?

4.6 The RCN notes that national BHIVA and CHIVA guidelines must be followed in any treatment setting. In addition, the normalisation of HIV care is increased if care is delivered in community settings such as nurse-led community clinics. There is also a role for the development of new technology, including websites such as myhiv.org.uk, which empower patients to access services, manage their condition and access peer support.

5. **Cost**

Have cost considerations been satisfactorily balanced with public health imperatives in HIV: (i) prevention policy; and (ii) treatment policy?

5.1 Prevention policy should be evidence based and evaluated. It should consider the cost implications of changes to public health budgets in the future.
5.2 There is a need for a stronger focus on the lifetime costs of diagnosis, treatment and care of a patient living with HIV. This data can then be compared to the costs of prevention campaigns so an accurate cost benefit model for prevention and behaviour change initiatives can be produced.

Is research funding correctly prioritised?

5.3 The RCN recommends that qualitative research on patient experiences should be undertaken, which will demonstrate the benefit of supportive and sustained nurse/patient relationships. The RCN would also welcome further research into treatment options.

6. Stigma

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

6.1 The RCN is concerned that a number of people living with HIV do not disclose their status to their GP. Stigma can affect the mental health of people living with HIV in relation to disclosure issues – who to tell, who not to tell and the ramifications of disclosure.

6.2 The RCN notes the role of healthcare professionals in normalising care of patients living with HIV by designing services in the same way as those for any long term condition, such as diabetes or chronic obstructive pulmonary disease.

Where are problems of stigmatisation most acute?

6.3 The principle of “need to know” transmission of disclosure in education and employment settings is important. The RCN notes that disclosure to employers is covered by Disability and Discrimination Act (DDA) legislation but believes that employers may be unsure as to their responsibilities following disclosure.

6.4 There is an important intermediary role for occupational health nurses and school nurses, who can advise employment or education staff that a long term condition exists whilst restricting confidentiality as to the type of condition on a need to know basis. There is also a role for third sector organisations in undertaking the signposting role that occupational health nurse would play if patient is employed by a Small to Medium Employer (SME), which does not have occupational health facilities.

6.5 The RCN is concerned about the stigmatisation of healthcare workers who are themselves living with HIV and notes the importance of the availability of occupational health services to support staff. It is vital that confidentiality is maintained in workplace settings and recommends that employers consider HIV awareness programmes in the workplace.

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

6.6 General public awareness campaigns need to focus on reducing stigma and levels of fear and increase education and awareness across all age ranges.
6.7 There is an important role for nurses and Health Care Assistants (HCA) in having the knowledge to challenge beliefs or discriminatory behaviour. The RCN recommends that training for public services staff includes the issues around HIV instead of focussing on the risks to staff. The education of healthcare staff in HIV issues, in pre and post registration education and training, and in the induction of HCAs is extremely important. The RCN notes the relatively short induction period for HCAs and the importance of getting anti-stigmatisation education into this induction package.

February 2011

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197 RCN Think Positive campaign (2007)
http://www.rcn.org.uk/newsevents/campaigns/think_positive/news_stories/rcn_launches_campaign_to_raise_hiv_awareness
Letter from Dr Paul Lister, Consultant HIV Physician, St George’s Healthcare Trust (HAUK 32)

I am submitting this response on behalf of senior HIV clinicians and managers at St George’s Healthcare Trust. The Trust provides medical care to over 1300 HIV patients and is involved in extensive HIV testing initiatives.

Monitoring

a. How robust is the current system for monitoring the number of people with HIV in the United Kingdom?
St Georges Healthcare NHS Trust adheres to HPA notification protocols on HIV diagnoses and deaths. The data is invaluable in mapping the changes in the epidemic enabling services to respond to national and local trends. St Georges Healthcare NHS Trust uses trends in local HIV prevalence based on HPA data to target education initiatives to primary care professionals on HIV testing to reduce delayed diagnosis of HIV.

b. Will the proposed public health reforms impact on this system?
There is a risk to good quality data on HIV epidemiology. The HPA’s central chelating and reporting of data will need to be re-housed in the new National Public Health body.

c. Could anything be done to improve monitoring?
The HPA have easy to use online monitoring system for new diagnoses and deaths. The burden of undiagnosed HIV needs continuous monitoring through unlike seroprevalence monitoring systems.

d. What groups in particular are at risk from HIV?
MSM were the biggest group of people diagnosed with HIV last year at St Georges Healthcare NHS Trust, which is a change from previous years where individuals from high prevalence areas being the biggest group. UK born individuals from marginalised and deprived communities pose an emergent new risk group in South London.

Testing

a. Are current testing policies adequate across the country?
There is considerable room for improvement. There are many HIV testing pilot initiatives. An initiative in Wandsworth with primary care and secondary care physicians resulted in a 45% increase in new diagnoses to St Georges Healthcare NHS Trust between 2009 and 2010. St Georges Healthcare NHS Trust is currently involved with a number of additional initiatives on HIV testing at Accident and Emergency, primary care, termination of pregnancy and the colposcopy clinics. The GUM service at St Georges Healthcare NHS Trust has a partnership working relationship with the British Pregnancy Advisory service supporting HIV testing and STI screening initiatives in women seeking termination of pregnancy. Formal evaluation and publication of the effectiveness of primary care and hospital initiatives on HIV testing is required to inform this further.

b. What can be done to increase take-up rates?
Further work needs to be done to normalise HIV testing across primary and secondary care. GUM services have a major role in education of other local providers to enable implementation of more widespread HIV testing. The evidence base from initiatives need
clear and widespread dissemination to relevant specialties. An area for priority is to encourage testing of male partners of pregnant women. Women who seroconvert in pregnancy after a negative test probably represent the greatest risk for vertical transmission now that we are so successful in preventing transmission with ART.

**Treatment**

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

The London Specialised Commissioning Group is an example of good practice where joint purchasing of antiretrovirals on behalf of 23 London providers has achieved an almost 25% saving on the antiretroviral budget. In addition the commissioners working with clinicians have provided guidance on how high cost drugs should be prescribed preventing spiralling costs for London. The specialist commissioners and clinicians at St Georges Healthcare NHS Trust link through a sexual health and HIV network (SWAGNET) to ensure even and equitable dissemination of information from commissioners and feedback from clinicians across a large sector. A collaborative commissioning arrangement linking through funded provider networks is a model of good practice. However tariffs should be the same for each trust.

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

The cost of a years worth of antiretroviral treatment is in the order of £7000 in London. Any disruption to collaborative commissioning arrangements is likely to result in a spiralling of costs. If specialised commissioning of HIV continues through a National body, sexual health and HIV networks would be key in ensuring success of communication and implementation of best practice models.

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

Through collaborative commissioning arrangements which link to sexual health networks. Currently St Georges Healthcare NHS Trust offers clinics based both at a hospital site and community setting (Roehampton clinic. Primary care engagement of non-HIV related long term complications such as heart disease need to developed further.). Routine HIV patient follow up intervals are increasing (up to 6 monthly for stable well people) with options for emails/telephone appointments. A proportion of patients may be suitable for monitoring in the community but there may be a risk to quality of care and increasing costs from fragmentation of the service and these need to be carefully considered.

**Cost**

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

Antiretroviral treatment is highly cost effective in terms of QUALYs – let alone the public health benefit of rendering infected individuals much less likely to transmit infection to others. There is increasing concern about the long term toxicity of many of the older drugs which will come off patent soon. It is imperative that we are not forced to use more toxic drugs to reduce short term costs – for instance long term dialysis and osteoporosis are expensive and rates will increase if we do not have flexibility to choose optimum regimes for our patients.

*(i) prevention policy;*

The drive to develop new tariffs for sexual health potentially put at risk complex work undertaken GUM services around HIV partner notification and testing of contacts including
children. Testing and treatment of HIV positive contacts is a good model for the prevention of onward transmission.

b. Is research funding correctly prioritised?
There is concern about premature ageing in this cohort of patients impacting on cardiovascular, renal and CNS disease particularly. These long term complications should be priorities for research. Additional research into increasing identification of the undiagnosed in a cost-effective manner is needed

Stigma

a. What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?
Stigma can stop people being tested, accessing services (in case someone sees them), taking medicines and telling family, friends and partners/potential partners. All lead to more spread and late diagnosis.

b. Where are problems of stigmatisation most acute?
Probably in communities in which homosexuality is heavily stigmatised African and Caribbean particularly.

18 February 2011
Memorandum by the Scottish Government (HAUK 62)

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

1. Scotland has robust surveillance systems for monitoring HIV in Scotland, developed and maintained by Health Protection Scotland (HPS). (http://www.hps.scot.nhs.uk/bbvsti/surveillancesystems.aspx)

2. Health Protection Scotland runs a database of all known HIV infected persons in the country. Information held includes risk category, demographics and clinical data.

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

3. The Public Health reforms are not applicable in Scotland.

c. Could anything be done to improve monitoring?

4. As part of ongoing policy developments, Scottish Government is working with HPS and other key stakeholders to identify areas where HIV monitoring could be augmented and developed.

5. As part of the HIV Action Plan (http://www.scotland.gov.uk/Publications/2009/11/24105426/0) this has included;
   - A data review by NHS Health Scotland and Health Protection Scotland under ‘Action 6’. This will improve the quality of data on people living with HIV (PLWHIV) attending clinical services and data linkage with NHS Information Services Division (ISD) and the Health Protection Agency (HPA). In addition, a new card based one year non-attendee recall system for last known contact in clinical services will be piloted.
   - A key action to improve monitoring of HIV incidence and risk behaviours.

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

6. In Scotland, those most at risk of new transmissions of HIV are men who have sex with men (MSM).

7. Those also at risk include those originating from areas of high prevalence, particularly African countries. There is anecdotal evidence of late presentation/diagnoses of HIV in the white Scottish population.

8. Current policy planning will support work to reduce late diagnoses in all populations and to increase awareness of HIV in all professionals (not only specialists) as well as the general public.

Prevention
a. Is Government policy sufficiently focused on HIV prevention?

9. HIV prevention is a key part of Scottish Government HIV policy.
10. In November 2009, the Scottish Government published the HIV Action Plan. The plan contains 14 actions, of which 10 include a prevention element.

11. This includes:
- The development of NHS Quality Improvement Scotland (QIS) HIV Services Standards which contain standards devoted to HIV Prevention. These standards will be a key tool in continuing to make progress on HIV prevention activity in Scotland.
- The development by NHS Health Scotland of guidance on HIV prevention targeting MSM and people originating from areas of high HIV prevalence, particularly African countries. Health Scotland are also linking into UK draft NICE Guidance on increasing testing in MSM and Black Africans as a contribution to the prevention approach in Scotland.

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

12. In Scotland MSM are most at risk of new HIV infection. Thus, as part of the HIV Action Plan, NHS Health Scotland have developed the ‘HIV Wake Up’ Campaign (http://www.hiv-wakeup.org.uk/)

13. The campaign targets MSM with a primary message on regular HIV testing. It also has a secondary approach of safer sex through condom and lube messages. The campaign was informed by research with the key audience and materials were developed in partnership with third sector organisations as well as clinical and health improvement colleagues.

14. The HIV Wake Up campaign recently won the ‘Best Website’ award and received a ‘Highly Commended for Partnership Working’ at the Association for Healthcare Communications and Marketing (AHCM) Annual Conference.

15. The campaign has shown good recognition by local professionals and some early signs of acceptability of online communication to those MSM who do not traditionally access gay venues and organisations. As part of this process there have also been two pilots of enhanced, local support for implementation in NHS Boards to ensure that prevention messages are strengthened and local professional practice developed.

16. Scottish Government has also developed the ‘SexualHealthScotland’ website (http://www.sexualhealthscotland.co.uk/) which supports improvements in sex, sexual relationships and sexual health in Scotland. This website is targeted at those aged 20-40 and includes advice on HIV, as well as more general communication and safer sex advice.

17. Outwith Scottish Government campaigns, NHS Boards in the central belt of Scotland have also delivered local MSM focused campaigns which have been evaluated as a useful contribution to HIV prevention.

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

18. HIV prevention initiatives targeted at IDUs have been successful in Scotland in preventing new infection amongst this group. A major decline in the transmission of HIV among IDUs in Scotland occurred contemporaneously with the implementation of harm reduction measures, namely needle exchange and methadone maintenance therapy, in the late 1980s and early 1990s.
d. How could prevention initiatives be better delivered and evaluated?

19. Key developments within the HIV Action Plan are informing prevention approaches in Scotland with the development of clinical standards, guidance and recommendations for action with a focus on those considered to be most at risk.

20. There is a great deal of expertise in HIV prevention within Scotland, particularly within the Greater Glasgow and Clyde and Lothian NHS Boards where the great majority of those at high risk of, or living with, HIV reside. Work is ongoing to disseminate this expertise throughout Scotland but also to tailor prevention techniques to the needs of the NHS Boards’ populations.

21. The NHS QIS Standards on HIV prevention will support an increased evidence based approach to HIV prevention, particularly within the NHS.

Testing

a. Are current testing policies adequate across the country?

22. As a result of action set out in Respect and Responsibility, Scotland’s Sexual Health Strategy, Sexual Health (GUM) clinics in Scotland now offer ‘opt out’ HIV testing, i.e. it is offered as a routine recommended test. This has seen HIV testing rise considerably in Scotland and has enabled progress in addressing undiagnosed infection, particularly amongst men who have sex with men.

23. As part of the HIV Action Plan, it is expected that there will be an increase in testing uptake, particularly amongst MSM and persons originating from areas of high prevalence, with a lowering in the numbers who remain undiagnosed.

24. The HIV Action Plan also encourages NHS Boards to develop testing policies that take into account British HIV Association (BHIVA) HIV standards and guidelines, including routine testing for patients with early sentinel conditions in order to identify infection and prevent late diagnosis.

25. There are, however, some challenges in recognition and diagnosis of HIV in some acute and primary care settings, despite the BHIVA Guidelines and the CMO letter on ‘Improving the Detection and Diagnosis of HIV in non-HIV Specialties Including Primary Care’ (http://www.sehd.scot.nhs.uk/mels/CEL2007_15.pdf).

26. In acknowledgment of this, work is ongoing nationally on professional education and training which will include support for non-specialists to identify and test for HIV. This is important in addressing issues around late diagnosis, particularly in those populations where late presentation is of particular concern.

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

27. Opt out testing in sexual health (GUM) clinics has been key to increasing HIV testing take up rates in Scotland.
28. In addition, key components of the HIV Action Plan encourage increased uptake in testing.
   • The NHS QIS HIV Standards will support improvements in the recognition and diagnosis of HIV.
   • National work currently being undertaken by NHS Education for Scotland (NHS NES) will support professional education and training, including recognition and diagnosis of HIV, particularly in non specialist health professionals.
   • The national ‘HIV Wake Up’ campaign promotes HIV testing amongst MSM.

29. Community testing by voluntary sector organisations is also important in reaching those who may be challenging to engage with, such as those using public sex environments or migrant populations.

Treatment

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

30. NHS services in Scotland are not commissioned.

31. HIV treatment in Scotland is currently delivered highly effectively; recent Health Protection Scotland data indicate that continuing high levels of care and treatment are being provided for the increasing number of people living with HIV in Scotland (PLWHIV).

32. A formal HIV Treatment and Care Needs Assessment by the Scottish Public Health Network (ScotPHN) (2008) has informed both the HIV Action Plan and local service delivery.

33. The HIV Action Plan actions on HIV treatment include:
   • The national procurement of HIV anti-retroviral therapy to support NHS Scotland cost savings.
   • NHS QIS clinical standards for HIV treatment and care services.
   • NHS Health Scotland work to support PLWHIV, particularly more vulnerable groups, to attend and remain in clinical care.

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

34. New commissioning reforms are not applicable in Scotland.

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

35. In Scotland, HIV treatment is delivered effectively in both GUM and Infectious Disease (ID) settings.

36. Treatment is also available to some PLWHIV through ‘HIV Homecare’ where treatment is delivered directly to PLWHIV.

37. The clinical expertise required for effective HIV treatment delivery currently remains a specialist role within HIV services.
38. However, in managing HIV, particularly as a long term condition, there are areas of ongoing monitoring and anticipatory care which primary care services could potentially deliver in partnership with specialist providers.

39. Self-management of life with HIV can also potentially be supported by voluntary and community led initiatives and peer support. A cohesive and collaborative approach across these sectors would provide choice for people living with HIV with accountability to ensure follow up and outreach.

Cost

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

(i) prevention policy; and

40. Scottish Government provides prevention funding through a BBV Prevention annual funding allocation to NHS Boards. This funding will be sustained in 2011/12.

41. NHS Boards work with partners in local authorities and voluntary sector organisations to deliver prevention initiatives with support from this key allocation. A one off review of BBV Prevention funding was carried out in 2010 to ensure that local deployment of projects and interventions was delivered appropriately.

42. As treatment costs increase, the cost efficiency benefits of preventing HIV infection are increasingly key, particularly as the cohort of PLWHIV begins to age adding increasing complexity, and cost, to their clinical care as well as an increase in care and support needs.

(ii) treatment policy?

43. As part of the HIV Action Plan, national procurement of HIV therapies has, and continues to, secure cost savings for NHS Scotland.

44. Ongoing treatment is acknowledged in the HIV Action Plan as contributing to prevention of HIV transmission and thus associated with cost benefits in prevention of HIV infection as well as the morbidity and mortality associated with non treatment of HIV.

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

45. Informing strategy and local delivery with evidence is key to Scottish Government approaches. Specific funding grants remain accessible through the Chief Scientist Office, for example.

46. Due to their key risk status, research on MSM is a particular area of focus and yields useful indications of behavioural surveillance and local prevalence but there are considerable challenges in assuring that robust evidence, beyond epidemiological data, is available. Due to the lower numbers of people from areas of high prevalence, evidence is more challenging to source for research studies, although some local qualitative studies have been funded by NHS Boards.
Stigma
a. What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?

47. It is unclear whether wide scale stigma towards people living with HIV is prevalent in Scotland, but associated stigma which vulnerable populations experience, notably racism and homophobia, appear to amplify any which does arise.

48. HIV-related stigma, whether perceived or real is, however, still a key area to be tackled in terms of ensuring the normalisation of HIV testing and ensuring PLWHIV feel equal and valued members of our society.

49. Within Scotland, normalising HIV testing is key not only to reducing undiagnosed HIV amongst those most at risk but also those not traditionally ‘at risk’ and who perceive HIV testing as an implication of negative behaviours.

b. Where are problems of stigmatisation most acute?

50. Within at risk communities, there are indicators that stigma can isolate individuals, interfere with positive health outcomes and stifle prevention initiatives but these have yet to be robustly researched.

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

51. Addressing HIV-related stigma is a theme that runs throughout the HIV Action Plan.

52. Education on and increased awareness of HIV in all populations is key and is part of the Scottish Government’s on going policy on HIV. The Health and Wellbeing theme within the Curriculum for Excellence in Scotland’s schools also seeks to remove stigma around health conditions, such as HIV.

This evidence is submitted by the Minister for Public Health and Sport on behalf of the Scottish Government.

23 February 2011
Memorandum by Shield South Yorkshire HIV Support Group (HAUK 26)

1. Prevention

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

1.1 There seems to be a differentiation between the national and local campaigns resulting in varying results. Shield receives many prevention leaflets and other literature from the national agencies both statutory and voluntary sector and Shield’s staff have noticed a continued dominance of BME and MSM individuals on this information, we struggle to find a photo of a white British middle aged women on any of the prevention materials. This for us does not represent our socio-demographics of our clients. We cover both Rotherham, a small Metropolitan Borough Council, and Sheffield a large Metropolitan City and the White British heterosexual demographic is 25% of our base and increasing annually.

1.2 At the local level in Rotherham the NHS has been extremely responsive to the local groups that are being diagnosed and therefore supportive of our localised Education and Welfare Programme. Part of the reason the programme was set up was due to demand as national campaigns through videos etc were ineffective. National prevention campaigns do not target for example a young male in a small mining village and although this may group may only represent a small percentage of those being diagnosed Rotherham has high rates of STI’s in general and increasing rates of HIV in the borough. Prevention is about looking forward ten years to those who will be sexual active.

1.3 Our Education and Awareness Programme focuses on working with 13 to 18 years old young people within schools integrating HIV into PHSE curriculum. Between September 2010 and February 2011 we have delivered the session to more than a 1000 young people across Sheffield and Rotherham. By taking local people including a woman who lost her 24 year old daughter, a male rape victim and a Black African woman who is well integrated into the local community able to link her own cultural observations to those found with these target groups Shield makes HIV real. A key target group should be these young people as there is high sexual activity within small local towns and city neighbourhoods, not necessarily promiscuous sex rather having a relationship with a person they went to school with for a few years and then someone from their local pub. Very soon there will be webs of sexual activity and with HIV taking years to present but the potential risk is there.

1.4 The other seemingly forgotten group is the White British women aged 40 to 70 years of age. In the last 2 years Shield has seen rising registration numbers from this demographic then previously in its 25 years. Divorce is creating a new sexually active group who are naive to HIV, having spoken to this target group they agree with the ideas put forward for reasons for increased risk. In the 1970’s this group were concerned only with contraceptive as they were in their late teens, during the 1980’s HIV was projected as an issue for only gay men and they were married, in the 1990’s Africa was the main place for HIV and they were not worried. After 2000 there was no effective general public campaign and any there were evident were for the BME and MSM group. At this time their children had grown up and divorces increased. A new lease of life meant becoming sexual active again and as they were no concerns of pregnancy and HIV and other STI’s did not feature they put themselves at risk. There has been increased press about pregnancies within this group showing ultimately a risk of HIV transmission. At Rotherham Show in September 2009 a middle aged White
British women who was with her young teenage daughter told Shield she was safe as long as she had the contraceptive implant.

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

1.5 As mentioned above target groups should include the local heterosexual young population and in a form that understands the sexual activity trends and cultural dynamics of the area.

1.6 Evidence of this approach being successful can be found from the evaluations of these sessions at a local Rotherham college as part of our World Aids Day programme. After speaker sessions and GUM talks attendances at the sexual health services at the college increased 26% with a large proportion requesting HIV testing. This group of 16 – 18 years old may not be highly active sexually but it shows an understanding of the risk and hopefully a continued trend of accessing services in the future.

1.7 Quantitative data is not enough to reflect on something that requires a change in behaviour and beliefs. It is important to gain qualitative opinions, evidence for Shield’s Education and Awareness Programme includes:

School Year 2010/2011

- Cnt blive ery1 cn gt hiv n nt jst battys.

School Year 2009/2010

- “This was excellent, real life situations, real experiences, informative and it just makes you think.”
- ‘I am more aware about the dangers of HIV and also from XXXX’s story about date raping and being more careful on a night out’

Staff feedback –

- Rotherham College of Arts and Technology - From my view I thought it was very good, not only the fact from learning something about HIV and Aids, I mean the information they gave, but also because it was from their actual real life experiences which obviously makes it more realistic and it hits home with the students.
- Rawmarsh Comprehensive, Rotherham - Shield will have spoken with approx 200 students. The sessions provided by Shield have been invaluable in teaching students about the 'human aspect' of how HIV affects people and how the virus can be transmitted to a variety of people in different circumstances. Providing the opportunity for students to meet with people who have the virus is really important in overcoming and challenging stigma and stereotypes often passed down from parents.

1.8 There are two points to be taken from the above evaluations. Firstly the ability of spelling and language found within the 2010/2011 comment. There is a presumption in a lot of the prevention initiatives that are leaflet and website based that the general public have a certain level of literacy skills. Literature can be found in other languages but prevention campaigns are missing a key group of the population who cannot read or write very well, this not only includes young people but adults. They may not constitute a large percentage of
the population but handing them a leaflet will be of no value. It requires either a TV and radio campaign at the national level and small locally based face to face grass roots level work. Following an audit of the preferred information source for young people at a rural youth centre at Barnsley in 2006 they rated Youth Workers as the key source of information.

1.9 Secondly HIV and AIDS is not on the radar of the general public, it’s something that will never affect their daily lives, however risky behaviour in the form of speeding, binge drinking, substance misuse and the more frequently found STI’s are, this is something any prevention initiative must acknowledge. Young people and adults are likely to do one of the above at some point in their lives. There has been a national campaign regarding the date rape drug which young people have seen and thus the comment shows the speaker above struck a chord. Over the last few months in Yorkshire there has been press around crashes involving young people, 1 in 10 young people have Chlamydia, adults do go out on a weekend and drink too much, many young people will be offered drugs at some point in their lives.

1.10 By making HIV relevant and acknowledging the following issues methods can be created to ensure the future target groups will be addressed:

- BME and MSM are of course the groups of concern and require prevention work however there is a risk of over publicising such groups making prevention initiatives too focused and stigmatising the whole issue.
- Campaigns at the national level must acknowledge firstly how young people prefer their information but also the mediums they are able to access and understand.
- HIV must be linked to general risky behaviour.
- The preoccupation with testing must be delivered hand in hand with life skills and sexual and relationship advice, at some point a couple may wish to have a baby, condoms are no longer relevant, they must be able to negotiate taking responsibility of their sex lives.
- Prevention initiatives must take into account cultural trends, and importantly know their local geographies.
- Finally and most importantly finding the right balance between the message of prevention and the consequences alongside an attempt to put forward the idea that people living with HIV can due to treatment have a longer life expectancy, plan a future and have children. This is an incredibly difficult balance to promote, hence it must be acknowledged with initiatives that thoroughly understand the required messages. Evidence has proven that grass roots work that offers such balance can give a more holistic representation, speakers at Shield are purposely chosen to recognise the required balance therefore we have the mother of the daughter who died but also a HIV+ male who made bad life choices but works full time and has been positive for 20 years. Initiatives must ultimately focus on prevention must take into account the messages of HIV becoming a long term condition. At this point stigma work with all sectors of society must be delivered as discussed below.

2 STIGMA

2.1 Shield produces Individual Support Plans for all clients registering based on the governments 5 key categories for supporting vulnerable people, namely ‘Be Healthy’, ‘Be
Safe’, ‘Enjoy and Achieve’, ‘Make a Positive Contribution’ and ‘Achieve Economic Wellbeing’. Due to treatment and increasing life expectancy the physical side of ‘Be Healthy’ no longer dominates. Mental health issues through isolation, depression and fear of disclosure are the key needs on the support plans of either the newly diagnosed or established clients who may be facing new difficulties and move into the intensive support category. Therefore many plans focus on ‘Be Safe’ and ‘Enjoy and Achieve’ through attending social groups with the aim of moving towards ‘Making a positive contribution’ and ‘Achieving Economic Wellbeing’, getting back into employment, accessing cultural activities and re-establishing connections with family and friends. All these care needs are associated with stigma whether that which exists or a perception of clients who fear or presume it will happen. Trying to support clients to understand that stigma is not always the cause of their daily issues is a large part of support time, particularly those who have mental health problems. In encouraging clients back into society anti-stigma work must be effective.

2.2 In terms of addressing HIV as a public health problem it is difficult for voluntary sector agencies that work purely within the UK supporting people living with HIV and education programmes. Small local charities cannot rely on public fundraising events to gain funds as stigma still prevails. It takes the form of a view that people who become positive have done so because of their lifestyle or as has been emphasised above people do not see HIV as relevant to their own life choices and thus a public health problem. People see themselves at being at risk of catching Swine Flu, people they know have had it, they do not see themselves at being of risk of HIV and have never known anyone with the virus.

2.3 Stigmatisation is difficult to generalise as at Shield we have had clients from a similar socio-demographic group receive very different responses from peers and the community. There is not one client from the various groups who has not felt they have been stigmatized.

2.4 Despite years of successful work within the MSM community there is some evidence of ignorance and discrimination against people living with HIV. Local examples in Sheffield include a young gay man who told a Shield Worker that they did not have to worry about HIV as long as they did not have any sexual contact with older gay men. It is not MSM work this person necessarily needed but general awareness work through the education system making it clear it can affect anyone who has sexual activity.

2.5 The other group where Shield has case studies showing examples of HIV stigma is within the small local BME communities with towns and neighbourhoods. For Africans dispersed through the asylum system the fear of being found out by the few BME individuals they may know who also live in the area is profound. Shield recently moved out of its Rotherham Office as its clients were too scared to come to it in case they were seen and would prefer to come to Sheffield.

2.6 Again the above groups feature highly in HIV prevention work and can be perceived as the only groups effected resulting in extreme stigma as there is no campaigns addressing the other socio-demographic groups. If there were it may decrease stigma, Shield case studies high light the danger of such stigma. In 2009 a BME client was hounded out of her house with dead animals put on her doorstep by neighbours who found out about her status.

2.7 Addressing stigma needs to be taking place within the HIV community and externally. Although there is again national attempts to reduce stigma through media campaigns there lacks a focused approach that looks into a more specific areas. In July 2009 Shield received funding from Rotherham Metropolitan Borough Council as part of its Voluntary Sector
Training fund to deliver HIV awareness training to social care workers. The aim of these sessions is not only to address stigma found within the public but the professions that due to increased life expectancy and increased diversity of people being diagnosed with HIV are likely to have to care for someone living with HIV. The aims are as follows:

• Increase general facts about HIV, transmission and risk – as there had been previous cases where workers refused to enter premises, bathe clients or have any physical contact.
• Address their own personal stereotypes they may hold and allow them to discuss these in a safe environment.
• Hear a life story from someone living with HIV
• Analyse the policies and procedures of their work place, do they accommodate the confidentiality needs of people living with HIV.
• Increasing their confidence.

2.9 Evaluations of the sessions include:

Why did you choose to come on this session?

• “In 24 years of working in mental health have never had any HIV/Aids training – should be mandatory”
• “Because I found it interesting and with me not knowing much I thought it would be good, especially if we get residents with it”

When asked whether participants felt their learning needs had been addressed the mean score was 9.1 out of 10.

Professional Development:

• “I found the whole training very informative and thought provoking”
• “How to handle situations”

Verbal comment made at the 25th January 2011
‘I was scared of HIV this morning and now I am not’

2.8 In December 2010 Shield coordinated and delivered Social Care and Residential Settings awareness sessions at a regional conference (Positive Yorkshire 3).

2.9 Professionals who come into contact with people living with HIV will be seen by these people as role models or people who are off professional standing and they expect to be respectful and thus it is important in a attempt to reduce cases of stigma within the field and the often devastating effect this can have on people living with HIV. All statutory and voluntary sectors who are likely to come into contact with HIV+ people require this awareness work as many have either not had any training or it was in the 1980’s. The focus areas should be disabilities, asylum (in new dispersal areas), school staff and youth workers (to accommodate the children of positive parents), social workers (as the AIDS Support Grant in no longer ring fenced) and GP surgeries (as the consortiums take a greater part in care). It would only require a short awareness programme of in this case a three hour sessions to address this need for education to reduce stigma and discrimination.

Shield feels that the fact that on many of the national campaigns there is a lack of ethnic, gender, ages and sexuality diversity not only constricts any prevention work but establishes clear reasons for stigmatisation.
Memorandum by Shield South Yorkshire HIV Support Group (HAUK 26)

Evidence by Zoe Davies, Strategic Director on behalf of Shield South Yorkshire HIV Support Group

16 February 2011
Memorandum by Shika Tamaa Support Services (STaSS), Milton Keynes (HAUK 4)

1. Monitoring/commissioning

Could anything be done to improve monitoring?

1.1. STaSS experiences at first hand the difficulties in accessing monitoring data to allow us to plan, both operationally and strategically, to meet the needs of our client group.

1.2. Others will comment on the robustness of data, but we find that accessing timely and comprehensive data is at best problematic. Sensitivities about confidentiality are understood, but a more open approach to allowing access to local data would be helpful. We have built good relationships locally with our colleagues, but the difficulty of accessing data that is ‘fit for purpose’ confounds our attempts to take prompt actions together.

1.3. When data is provided, difficulties can be encountered when the data relates to ‘a hospital’ rather than the whole resident population. Trying to ‘join the dots’ between the numbers of people who have opted to access medical services away from the population in which they live, does not allow a comprehensive view of the impact that HIV is having on any given population.

1.4. Those who have families and conduct their everyday lives away from their treatment networks need support in their home location, and potential demand on local services needs to be planned for to allow the development of cost effective and integrated services. This local need does not just ‘go away’ if clients seek medical support away from home in more established providers and we need better information to plan local delivery in the community. Even if remote access to medical services is the chosen option for some as a result of fears of ‘stigmatisation’, we still find clients will more readily seek our community based services locally as a result of our discretion, confidentiality and relative anonymity.

1.5. With regard to perceived ‘gaps’ in information provision, we would note that we have so far been unable to identify sources of information to assess if infants are becoming HIV positive due to mothers being tempted to breastfeed due to, for example, economic circumstances. Many will not ‘disclose’ their status to their GP and thus prescription of infant feeds cannot be obtained, if indeed mothers are eligible for this. Investment in complex regimens to ensure that babies are born HIV negative is wasted if breastfeeding reverses the ‘success’ initially reported. In addition, ‘lifetime’ costs of infection are high and are in this case are an eminently avoidable commitment.

1.6. Furthermore, the numbers of children and indeed other close members of the family affected (not infected) by HIV are increasing. There is no robust way that we have found locally of monitoring this comprehensively and yet there are material consequences arising from the pressures of caring for infected parents, siblings, or partners which represent a cost to society.
1.7. Whilst the majority of our client group is drawn from the black African community, we are seeing increasing numbers of clients from the white heterosexual community who are diagnosed with HIV - many extremely angry and bitter that they 'did not know about HIV'.

1.8. A 'one stop shop' for data and more comprehensive population based data, produced on a more timely basis, with better local expertise in analysing the data, would help local commissioning and provision of prevention, treatment and community based care and support.

2. Prevention

Is Government Policy sufficiently focussed on HIV Prevention?

2.1. Given the enormous lifetime cost - both financial and human - of being infected with HIV (and given that infections acquired in the UK are not seeing the same rate of decrease as those acquired outside the UK) the need for effective prevention is clear. Prevention is fundamental to reducing levels of HIV infection, and there is of course a strong link with sexual health campaigns in general. However the fact that messages have been subsumed under the general sexual health agenda has been - in our opinion - potentially catastrophic. Also the message that HIV is simply 'another chronic condition' has been misleading.

2.2. The lack of an up to date strategy for HIV (we believe that 2001 is the most recent substantive document) may be a significant indicator of perceived current priorities in respect of HIV services in general, and prevention activities in particular. It is also difficult to call to mind 'recent prevention campaigns' which may say something about their effectiveness and also the degree of focus on this issue.

2.3. However, any number of words contained in documents telling agencies what they should do about HIV prevention, and furthermore any number of words presented as proof that prevention activities are underway in response is no substitute for evidence that they are being successful.

Have the right groups been targeted in recent prevention campaigns?

2.4. Targeting, though on the one hand naturally and necessarily focussing on highest proven prevalence, can be 'overdone' and can reinforce stigmatisation - which itself can feed back into self-stigma, mental health problems, risk taking behaviours and infection.

This is a pan population issue, and the diverse society in which we live, where relationships cross boundaries of ethnicity, religion and sexual orientation needs to be taken into account.

How could prevention initiatives be better delivered and evaluated?

2.5. Carefully crafted campaigns at a nationwide level focussed on the 'whole population', with greater emphasis on the third sector's involvement, particularly at local level given their 'grass roots appeal and knowledge, would be constructive. Approaching this issue through statutory health agencies alone, (some of whom may
have lost touch with the detail of issues relating to HIV due to the plethora of targets and competing priorities that they have struggled with) will not work.

Better evaluation would be facilitated by better and more timely and comprehensive data (see above) produced on a geographical basis and evaluated in partnership across the sectors providing services to a given population with emphasis on trends and better understanding of what data really ‘means’.

2.6. We would, however, wish to point out that concentration on ‘Prevention’ activities alone runs the risk of disregarding the needs of those currently infected and affected by this insidious condition. HIV infection and its social and medical consequences will not go away during the lifetime of those infected even if prevention activities are shown to be completely effective.

3. Treatment

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

3.1. Our experience of GP’s knowledge and sensitivity to clients with HIV (and to be fair that of some other health professionals) suggests, in some instances, that these are attributes which are often ‘lacking’. This has been evidenced by ‘literature returns’ based on the premise that ‘We do not have any HIV +ve patients’ (we know quite categorically that the contrary is the case) and the clients who visit us in tears due to outrageously stigmatising behaviour on the part of some health professionals.

3.2. We feel that this context will not make for a constructive basis for commissioning via GP consortia. We observe that the understanding of the issues surrounding HIV is poor at local level and any move to provide alternative contracted treatment services out with the hospital setting to save costs would be risky.

3.3. However, whatever the commissioning structure is agreed to be, it must not be too remote from the local situation, given the complex variables that exist at that level.

4. Stigma

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

4.1. Stigmatisation of HIV is an irrational response to the condition that fosters feelings of rejection and fear in the recipient and debases those who stigmatise. It is based on fear, ignorance, feelings of superiority and phobic attitudes. It stops people from presenting for testing, seeking help, creates enduring mental health problems, creates pent up anger leading to intentional infection of others- and worse.

4.2. Stigmatisation by the wider society rapidly ‘turns inwards’ as clients self-stigmatise and this leads to denial. Denial impacts on family life as disclosure is felt to be impossible and so the greatest support mechanism can become the greatest barrier.
4.3. Even now, many of our clients are so fearful of being identified that they will only keep in contact with us by phone—albeit in the early hours of the morning on occasion when people feel particularly vulnerable. This limits the amount of support that we can give.

4.4. HIV as an ‘issue’ appears somehow to have ‘gone underground’ and this exacerbates the ‘mythical’ nature of the condition. Immigrant communities, from countries previously ravaged by the condition have particularly strong responses when a community member ‘discloses’. Some religious groups persist with their judgement that the condition is a ‘punishment’ and some even recommend not taking drug therapies, with prayer and ‘miracles’ being the preferred course of redemption. We have recently lost clients under these conditions and we actively try to reach out and to educate to prevent this.

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

4.5. Greater openness and understanding about HIV—effectively a greater ‘normalisation’ of a very abnormal situation—could start to lay the foundations of a societal response that is less ‘judgemental’ and more sympathetic. This could lead to a greater willingness to disclose and seek help—indeed to admit that a person is at risk in the first place.

4.6. In order to ‘prevent’ transmission naturally there has to be a greater understanding that HIV, though treatable, is a lifelong condition and one that no-one would choose to embrace. The long term impact of the toxic cocktail of drugs available to treat people is unknown, but unpleasant side effects are common. However demonising those who have the condition is not the answer.

4.7. Whilst continued stigmatisation of the condition by the general public is worrying, the approach of some clinicians can be alarming, and we have found that face to face client: clinician debates have—with our support—helped to drive home, in a constructive way, the impact that stigma has on an individual.

4.8. Ridding the country of HIV stigma will be a slow process: education is key—both in educational establishments, workplaces, religious and ethnic groupings, but also in the ‘caring institutions’ such as hospitals, GP surgeries, and other statutory organisations. We believe that the third sector has a crucial role in delivering these services and should be supported in the work that they are doing in this field.

4.9. Sadly, the principles of the ‘BIG SOCIETY’ do not work as well for this care group when the general public find the idea of HIV abhorrent; when they consider infection with HIV to be a ‘Lifestyle choice’ and akin to a modern day leprosy. Breaking down barriers at a community level, with groups working on the frontline connecting directly with all people—not just those infected or affected directly—must form an important plank of future strategy and action.

February 2011
Memorandum by South West London HIV and Sexual Health Network (SWAGNET) (HAUK 60)

Monitoring

a. How robust is the current system for monitoring the number of people with HIV in the United Kingdom?
The HPA does an excellent job at collating both national and local trends for HIV. The detail is excellent and it would be a pity for this to be reduced because of reduced staffing numbers. Local data on wards have been used to target education and to increase HIV testing.

The 2009 figures have just been published at the beginning of 2011 and interim figures for 2010 would be very welcome especially in view of local targets to increase testing.

There have been issues of patients attending more than one clinic and it is difficult to know the scale of the problem.

b. Will the proposed public health reforms impact on this system?
With change there is always concern that excellent services are dismantled. It will be important to maintain the service within the new NHS England/ Public Health.

c. Could anything be done to improve monitoring?
It is important to continue zero prevalence testing in a variety of settings to ensure that the increased testing is meeting the target to reduce late diagnosis.

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

Prevention

a. Is Government policy sufficiently focused on HIV prevention?
The general public have switched off, increasing there is a perception of not being at risk and consequently those undiagnosed are increasing putting others at risk.
Young people born in the UK do not perceive themselves at risk.
There is concern that with the cuts SRE programmes will not be addressing areas of sexual health including HIV.

b. Have the right groups been targeted in recent prevention campaigns?
People are sexually active across different age ranges and are involved in sexual experimentation. Insufficient work has been done with young people.
We would like to see more opportunistic testing with opting out rather than opting in.

c. To what extent have prevention initiatives targeted at injecting drug users been successful?
Those not working directly with injecting drug users the local data appears to show that prevention initiatives have been working.

d. How could prevention initiatives be better delivered and evaluated?
Whilst it is difficult to evaluate prevention work, it is important to try and measure. This is possible through local research and we in SWL have found for example: that advertising for Chlamydia Testing on buses has been effective.
Testing
There is concern that in this present economic climate increased testing will not be reflected in the funding available for ongoing treatment and care. Whilst all professionals are working hard to reduce late diagnosis, funding must follow.

a. Are current testing policies adequate across the country?
Through our HIV Testing taskforce it is quite clear that testing policies need to be delivered locally. Even at sector level there is difference of client group and prevalence that prevents an all encompassing approach.

On the whole SWAGNET feels that there is room for improvement in the current testing policies but is encouraged by the amount of effort that has recently been put into the DH HIV Testing initiatives.

In SWL we are working hard to increase testing and would like to highlight the work in Wandsworth between Primary Care and Secondary Care Physicians which has resulted in a 45% increase in new diagnoses to St Georges Healthcare NHS Trust between 2009 and 2010. St Georges Healthcare NHS Trust is currently involved with a number of additional initiatives on HIV testing at Accident and Emergency, primary care, termination of pregnancy and the colposcopy clinics.

Croydon is concerned that current HIV testing policies need to be improved 2 / 3 thirds of outpatients and 93% of our newly diagnosed inpatients at Croydon University Hospital are diagnosed late. The average inpatient stay for a newly diagnosed inpatient is 27 days and 16% require ITU/HDU care which is expensive and avoidable.

b. What can be done to increase take-up rates?
Further work needs to be done to normalise HIV testing across primary and secondary care. GUM services have a major role in education of other local providers to enable implementation of more widespread HIV testing. The evidence based from initiatives need clear and widespread dissemination to relevant specialties. HIV testing should be made routine and opt-out in all hospital admissions aged 16-59 especially in areas of high prevalence i.e. >2/1000 as per BHIVA guidelines Sept 2008. This needs to be made a national mandate / CQUIN in order to be effective. The same should be applied to all new patients at GP surgeries and in other situations outlined in the BHIVA guidelines.

We would also like to see increased testing of male partners, including partners of pregnant women. Partnership working needs to be increased which is difficult when organisations are competing to deliver services.

Treatment

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

The present system of commissioning and delivering HIV treatment in London is working extremely well. The London Specialised Commissioning Group is successfully purchasing antiretrovirals on behalf of 23 London providers and achieving sufficient gains
However we do have concerns that there may be some inequity of tariff and look forward to PbR. We have found Networks to be very successful in linking together providers and commissioners across the sector.

b. What impact might the proposed new commissioning reforms have on HIV treatment? There is some concern that commissioning nationally rather than locally means there is a lack of local knowledge, making local networks imperative for effective communication. These will need to be clearly funded.

c. In what setting can treatment most effectively be delivered?
Patients welcome the choice of treatment centre. Whilst there is a move for more centralisation the cost and time of travelling can affect the uptake of care. Centres are working more closely with Primary Care which is welcomed, but there may be a risk to the quality of care and increase in cost from fragmenting services which need to be carefully considered.

Cost

a. Have cost considerations been satisfactorily balanced with public health imperatives in HIV:
It is imperative that we are not forced to use more toxic drugs to reduce short term costs and some flexibility needs to exist in choosing optimum regimens for patients. HIV clinics provide comprehensive treatment, support, and partner notification, which will be difficult to duplicate if services are fragmented. These all contribute towards effective prevention and treatment policies which delivered through Primary Care may well be lost. Specialisation should not be under rated.

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

b. Is research funding correctly prioritised?

Stigma

a. What impact does stigmatisation of those with HIV have on those infected, and on addressing HIV as a public health problem?
Several decades on the amount of stigma for people diagnosed with HIV still remains high. Clinics in SWL report a high level of secrecy from their patients around their diagnosis this does nothing to support good prevention or increased HIV Testing. Your question highlights an area for more work.

b. Where are problems of stigmatisation most acute?

c. What measures are currently taken to tackle HIV stigmatisation? What more should be done?
There is a lot to be done, a lot to be addressed. There is a misconception that all healthcare professionals are comfortable with HIV. This is not always our experience especially in Primary Care. Sex is not always a comfortable subject at the best of times. Therefore more publicity, more education.

February 2011
Memorandum by Status (HAUK 33)

HIV prevention is failing gay men in the UK
Methods and approaches need to change
root and branch reform is needed

Summary

1. This a submission of evidence by Status, a new organisation concerned about the strategic neglect of HIV prevention for gay men in the UK in recent years.

2. The UK’s excellent surveillance data show that gay men continue to be disproportionately at risk, and continue to represent nearly half of all cases of HIV infection probably acquired in this country rather than abroad. Little headway can be made in reducing the incidence of HIV infection unless the continuing epidemic amongst gay and bisexual men is properly addressed. However, towards 3,000 gay men are diagnosed with HIV every year, which is more than three times as many as in the 1980s when this was seen as an immediate health crisis requiring urgent preventative action.

3. A Status mapping of national commissioning indicates that there is a strategic vacuum as regards the planning of dedicated HIV prevention services for gay men.

4. The bulk of national statutory funding meant to support HIV prevention for gay men goes to the national CHAPS programme. There is no transparency or accountability about how the money is spent, what it buys, what it achieves, or value for money. There is no fit for purpose independent evaluation.

5. As a proof of concept the concurrent pan London HIV Prevention Programme, has shown that it is possible to develop robust independent evaluation of agreed outcome measures and to influence service delivery through analysis of activity data. All future HIV prevention should be subject to equally rigorous scrutiny.

6. The HIV prevention sector has had a revolving door culture of informal lobbying by providers and decision-making that is neither transparent nor clearly linked to scientific evidence of effectiveness or best practice in programme contracting and management. Commissioning has been historically contingent and ad hoc rather than strategic.

7. As a result providers have been largely left to their own devices. There are many examples of disorganisation, wasteful duplication, leakage of budgets, lack of synergy between competing organisations, and a widespread failure to decommission failing services.

8. Conversely, a number of fundamental initiatives are highlighted, which are indicated by the scientific literature on effectiveness and by standard best practice, which do not exist in the UK.

9. Recommendations are made for a fundamental root-and-branch reform of HIV prevention for gay men in the UK. There is a once in a generation opportunity to promote this reform in the current transition to new structures of commissioning in the NHS and local authorities.
1 Scope of this submission

1.1 Status is a new not for profit social enterprise\textsuperscript{198} founded at the end of 2010. It brings together a group of evaluators, educators, researchers, clinicians, commissioners, journalists and gay community and business representatives. The impetus for another new HIV prevention organisation is mounting evidence of a systematic failure of HIV prevention for gay men in this country.

1.2 The mission of our new organisation, Status, is to monitor the state of HIV prevention for gay men and develop missing initiatives to revitalise gay community safer sex education and to promote community norms of responsibility. To this end, so far with no public funding, our young organisation has already developed a range of innovative functions, methods and projects:

• An ongoing mapping and review of HIV prevention services and how well they match findings of what is effective in the scientific literature.

• The beginning of a sequence of gay media campaigns providing: harder-hitting messages about the costs of HIV, promoting the revitalisation of community safer sex norms, and focusing on cases studies of responsible sexual behaviour. To our knowledge our gay media campaigns are the first in the UK to have gathered direct feedback from viewers (via a link to surveys on our website) that we can use to test the impact of current campaigns and fine tune future campaigns.

• We have begun a series of outreach campaigns, in close collaboration with a major central London clinic, using a bus in the heart of Soho, with high profile support from gay media and gay celebrities, and of the many hundreds contacted, this has already resulted in nearly 200 men testing, with some testing HIV positive.

• We are developing and expect to launch a comprehensive pack of HIV prevention and safer sex advice for newcomers to the London gay scene in April 2011.

• In order to shed light on how and why gay men are being infected today, in collaboration with clinicians we have begun piloting collaborative surveys with large samples of gay men to research a range of questions that have not been covered by recent research in the UK.

1.3 Our submission provides evidence that addresses the following questions:

• What groups are at particular risk from HIV?

• Is Government policy sufficiently focused on HIV Prevention?

• Have the right groups been targeted in recent HIV prevention campaigns

• How could prevention initiatives be better delivered and evaluated?

• Have cost considerations been satisfactorily balanced with public health imperatives in HIV prevention policy?

1.4 We recognise that in answer to these urgent questions, we paint a very different picture of what needs to be done. The select committee has heard from some of the

\textsuperscript{198} More information about the philosophy and approaches of Status can be found at www.statusprevention.com
main providers and players in the field, who have indicated that what is needed is more funding for business as usual. We disagree with this complacent picture. What is needed is a wiser use of the limited funding available for HIV prevention for gay men, through a complete root and branch reform of commissioning and provision.

1.5 In what follows we not only sketch out the broad outlines of how and why the organisation and working practices of HIV prevention are not fit for purpose, but also make recommendations for significant reforms based on scientific evidence of what is effective and standard best practice in commissioning and programme management. We argue that, at little or no cost to the public purse, HIV prevention services could be turned around to focus on achieving relevant HIV prevention outcomes.

1.6 We acknowledge that ‘extraordinary claims’ require extraordinary evidence. This evidence cannot be detailed in the requested short submission but is readily available, and Status would respectfully request an opportunity to present the necessary detail.

2 How do we know that HIV prevention is failing gay men?

2.1 In the UK HIV continues to very disproportionately affect gay men who continue to make up a large part of the epidemic: an estimated 1 in 20 nationwide, and up to 1 in 7 in London may be infected. By contrast, in the general population only 1 in 750 people are infected. For infections acquired in the UK, gay men remain the most at risk group. Unless you achieve prevention results with gay and bisexual men you can’t make any headway against what still amounts to nearly half the epidemic.

2.2 The epidemic amongst gay men is much larger now than it was in the 1980s, when, with fewer than 1,000 gay men diagnosed on average a year, it was seen as an immediate and urgent health crisis. Now nearly 3,000 gay men are diagnosed every year. Moreover this does not just represent the diagnosis of historical infection. Many were recently infected, and many are young gay men who have only recently begun sexual activities.

2.3 Part of the reason for this failure is that prevention is getting harder. Improving treatments mean that HIV is less feared. Nearly 30 years of familiarity with the virus has bred complacency. Well-intentioned but confused anti-stigma campaigns have had perverse side effects: they have played down the harm of HIV, and promoted the sense that it is no longer a particularly serious or life-threatening infection. ‘Bare-back’ pornography is now commonplace. There has been an explosive rise in recreational drug use on the gay scene and of sex-on-premises venues. The steady rise in prevalence means that each incident of unsafe sex is more likely to lead to exposure and infection.

2.4 But a more important reason for the failure, we submit, is that there has been complacency and systematic neglect. The ship has been drifting aimlessly, with no hand on the tiller.

3 Failure of strategic commissioning

3.1 There has been a casual neglect of the planning of national and regional HIV prevention for gay men.
3.2 There is effectively a strategic vacuum as regards reducing new infection amongst gay men, with no national or regional:

- planning body
- strategy
- needs assessment
- mapping of prevention funding
- mapping of prevention initiatives
- planning of care pathways or synergies between prevention organisations
- evaluation of the impact of HIV prevention initiatives.

3.3 Status has conducted an analysis of dedicated statutory funding available for HIV prevention initiatives with gay men. Exact figures are not published, but broadly:

- the bulk of dedicated statutory funding is a direct grant from the DoH to the national CHAPS programme administered by THT (~£2 million a year)
- most of the rest funds the gay men's part of the Pan London HIV Prevention Programme (PLHPP) (~ £1.5 million a year)
- in the rest of the country there is a postcode lottery, with a relatively small number of dedicated local projects supported by local commissioning, in e.g. Greenwich or Leeds, which between them account for less than £1 million per year
- there is no evidence of any significant charitable income going into HIV prevention for gay men to make good shortfalls in statutory provision (i.e. from charities such as THT, GMFA, NAT, EJAF, Crusaid, Avert, etc.)

3.4 There is no published rationale for the allocation of this strategic funding, and, perhaps unsurprisingly, patterns of HIV prevention activity are contingent and historical.

4 The failures of the national CHAPS programme

4.1 The directly DoH funded CHAPS programme probably represents up to half of all funding for gay HIV prevention in the UK. For the last 13 years the money has been given as a block grant to the THT to administer with no evidence of standard best practice in contracting, performance monitoring, transparency or accountability.

4.2 The CHAPS acronym begins with “C” for community, but there is no published record of there ever having been any community consultation. There is no published mechanism for polling community views.

4.3 The programme as a whole appears never to have been formally tendered, but has simply been repeatedly rolled over. There is no transparency about how CHAPS partners are chosen, how they are shed, or about the onward distribution of the money from the THT to those partners.

4.4 There is no record of any needs assessment process that underpins the work of the CHAPS programme. There is no evidence of any mapping of service provision to
minimise duplication and fill gaps in provision, and no rationale for prioritisation of one thing over another.

4.5 There is no public accountability about how the money is spent, or what it has bought, for what cost. There is no published list of CHAPS inputs or outputs, no map of what provision CHAPS offers, no forward schedule of what will be offered.

4.6 The programme collects limited demographic data from some of its clients, but does not collect evidence of those clients’ HIV-related needs. There is no record of how many gay men have been reached by the programme and no published record of client feedback about what they have got from the programme.

4.7 Over 13 years CHAPS has not managed to define any data sets to measure outcomes, and consequently cannot demonstrate any evidence of having delivered any HIV prevention outcomes. Despite the fact that this runs so contrary to the modernisation agenda, CHAPS has been rolled over year after year, with no requirement to show value for money.  

4.8 There is no published strategy or workplan, as commonly understood in programme management. There is only a strategic framework, *Making it Count (MIC)*, which, for a number of reasons, is unfit for purpose.

4.9 The consultation draft of the fourth version of *MIC* (2010) makes it clear that the driving purpose of the strategy is “having the best sex lives” and “to improve the quality of life for men who have sex with men”. In this context the reduction of HIV incidence is only one, and not even the most important, of a number of equally prioritised goals. Thus, astonishingly, there are no targets set for actual prevention of HIV infection. There is nothing in MIC to prevent the use of CHAPS funding on interventions which do not even directly address HIV. It is simply a permissive list of harm reduction activities, with nothing prioritised or de-prioritised. For example, the Select Committee may be surprised to learn that one of the suggested aims of work in MIC is encouraging withdrawal before ejaculation in penetrative sex, which is something that in our view is no more a reliable approach to HIV prevention amongst gay men than it is to the avoidance of unwanted pregnancy amongst heterosexual teenagers.

4.10 The construction of the *MIC/CHAPS* framework bears no obvious relationship to scientific evidence. There is little citation of the extensive peer-reviewed scientific literature on effective HIV prevention in any CHAPS documentation. Instead there is an over-reliance on the non-peer-reviewed research of a single agency, Sigma Research, which is also the evaluator of the programme.

4.11 Representatives of CHAPS frequently make the claim that the programme is subject to independent pre-testing and evaluation. However, Sigma Research the programme’s evaluator for the past 13 years, has been a fully involved rather than independent partner in the programme for at least the last 10 years. There is an unavoidable

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199 For example, for most of 2010 CHAPS ran no campaigns in the gay press, even though ostensibly this is meant to be one of its main activities. However, this seems not to have affected the roll over of funding in any way for 2011-12.

200 *MIC* categorically states that “Since the purpose of activities is to improve the quality of life for MSM, it does not make sense to reduce HIV infection through means that reduce that quality of life [emphasis added]. Yet both the scientific literature and common sense tells us that you can’t have HIV prevention without changing unsafe sexual behaviour. For some men the use of condoms unavoidably reduces the quality of their sex life. That doesn’t make it any the more acceptable for them to infect others by not using condoms in anal intercourse. And the Status view is that it is irresponsible to prioritise the right of positive men to have sexual pleasure over the right of negative men to stay uninfected.
conflict of interest in evaluating a strategic framework, the MIC, that you have authored.

4.12 Further there appear to have been only 3 published reports evaluating the programme, the latest covering 2003-2006\(^1\). In these published reports a number of essential elements of standard independent evaluation are missing:

- no scrutiny of the theories of action of different initiatives in the programme
- no focus on whether the constituent elements of the programme are targeting those who might most benefit or even assessing the needs of their individual clients
- no cumulative account of delivery against output targets, if any, and no record of trends
- no focus in pre-testing of campaigns on what they are effective in achieving, only on whether they are ‘acceptable’
- no focus on the effectiveness of interventions, the impact on gay men, or the outcomes achieved by the programme\(^2\)
- no scrutiny of referrals, care pathways or concerted programme marketing and recruitment
- little or no evidence of findings critical of anything in the programme\(^3\), and consequently no record of recommendations that have led to any significant change in working practices over 13 years.

5 Developing outcome-focused evaluation in the PLHPP

5.1 Over the last 3 years, in parallel with the CHAPS programme, 11 London HIV prevention initiatives for gay men (most of them run by the same providers as those involved in CHAPS), have been evaluated in a very different way as part of the overall independent evaluation of the PLHPP.

5.2 This evaluation has demonstrated that it is perfectly possible to:

- define relevant and practical methods to collect robust data sets measuring clients’ needs and risks, and the outcomes achieved for them
- formatively scrutinise initiatives’ theories of action, together with their planning and quality assurance processes, so that some, at least, improve their working practices within the lifetime of the programme

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\(^1\) In addition to a later report which is merely an evaluation of a conference for CHAPS partners.

\(^2\) Typically, the evaluation of a particular media campaign found that, depending on the individual advert in question, only between 16 - 32% of gay men, even recognised CHAPS adverts published between 2003 and 2006. The evaluation did not recognise that this level of recognition would normally be viewed as a poor result in the context of gay community publications. More importantly, there was no attempt to find out how many gay men reported any change as a result. Even in its own terms this research was flawed since the researchers did not appear to have taken into account the phenomenon (well-attested in the scientific literature) of false recognition syndrome when research participants are first shown images and then asked if they recognise them.

\(^3\) It is just possible, reading between the lines, to make out veiled criticisms of the inadequacy of CHAPS programme planning processes, with brief references to ‘variable’ practice, and every variation from standard project management practice presented as an ‘opportunity’ or a ‘challenge’.
• evaluate the overall coherence and impact of a programme, including the targeting of those most at risk, the development of seamless care pathways, and value for money.

5.3 The evaluation culminated in an 18-month summative report, containing detailed performance data for each workstream as well as more than 100 recommendations approved by the Commissioning Group for improving the work of individual initiatives and of the programme as a whole.

5.4 We recommend that all future HIV prevention work for gay men needs to be subject to equally stringent independent evaluation.

6 Historically contingent commissioning and provision

6.1 We find that the overwhelming majority of HIV prevention projects and programmes for gay men have been poorly monitored and inadequately evaluated. Nevertheless there is now a growing body of robust evaluation for policy makers to consult.

6.2 The overall picture of commissioning of HIV prevention for gay men in the UK is that it is disorganised, duplicative, patchy, wasteful, and ill-focused on HIV prevention.

6.3 As in some other sectors of the health service, there has been a revolving door culture in the HIV prevention sector. Frequent reorganisation and churn has meant that key staff from providers have often taken leading roles in NHS commissioning, both in PCTs and as advisors to the DoH or a number of quangos. A relatively ‘cosy’ relationship has developed over recent years – with a number of prevailing assumptions:

• that providers are the experts in the field, know what is needed and can be left to get on with it;
• that projects expect to be able to depart from their original brief, without providers being held to account for delivering to their SLA, and in the event that SLA targets are not met, then all that is required is a process of negotiation with commissioners to reduce those targets;
• that independent evaluation ought to be non critical and should focus only on the positive.

6.4 As a result most commissioning has been provider-driven, with a tendency to continue commissioning historical services, even where there is no clear strategic rationale for them.

6.5 Perhaps the best example of this is provided by a ‘providers’ revolt’ in 2007, which effectively forced pan London commissioners to back down from new Commissioning Intentions that had sought to re-structure London HIV prevention services on the basis of the NHS modernisation agenda (i.e. with an emphasis on outcomes, value for money, service design based on needs assessment and best practice identified in scientific literature, etc.). Following a year-long turbulent consultation process existing providers in the former LGMHPP programme succeeded in having a number of old projects reinstated in the new programme without any clear strategic rationale.

204 In a review of recent commissioning, Status found little or no transparency as to processes to avoid cronyism.
6.6 A culture of informal decision-making and unstrategic, *ad hoc* commissioning has had adverse impact on the effectiveness of the HIV prevention work that is commissioned.

- There is much wasteful duplication of limited resources.
- Conversely many strategically important initiatives are missing altogether in the UK response to the epidemic.
- There is no reliable agreed system or standard for rewarding successful providers and restructuring or de-commissioning failing providers.
- In direct conflict with ‘world class commissioning’ there are significant barriers to new entrants to the market of HIV prevention providers.
- In the absence of national or regional needs assessment and service mapping, it is unnecessarily difficult to make a case for filling obvious gaps.

6.7 This is matched by a widespread lack of diligence in contract monitoring, and performance management.

7 **Examples of dysfunctional HIV prevention**

7.1 Is it possible that despite dysfunctional commissioning in this sector, somehow quality has emerged from the grass roots so to speak? The short answer is no. Apart from a small number of local projects which we would be happy to spotlight for the select committee, where evaluation has been published, there is a picture of disorganised and haphazard provision.

7.2 There is no space in this brief submission of evidence to detail the numerous examples of careless planning and implementation of HIV prevention projects. However, typical examples of leakage of budgets, waste and mismanagement include the following:

- One programme commissioned two gay men’s helplines with no rationale. The demand for one of these was so low, at less than 6% of its SLA target that it was de-commissioned after a year.
- During the swine flu scare of 2009, some publications about swine flu were substituted for gay men’s prevention publications.
- One project commissioned to deliver face to face interactive prevention work substituted on-line chatroom work of an unspecified nature with HIV positive gay men, which according to its own records appeared mainly to involve peer support discussions rather than discussions about safer sex.
- Recently two separate sexual health magazines were separately funded, with no obvious rationale.
- A number of projects that have delivered only up to a third of their SLA output targets have had those targets lowered instead of being given improvement notices.
- A number of projects that are supposed to provide training for gay men are unable to provide detailed written information about what their curriculum involves.
A number of projects claim to pre-test their offerings, but are unable to provide documentation of their piloting methodology, the samples they used, or any concrete changes made as a result of piloting.

A number of projects with a remit for running mass media campaigns have been unable to provide either basic distribution plans or even evidence of how and to whom their publications have been distributed.

8 Examples of key gaps in HIV prevention for gay men

8.1 Reviews of the scientific literature have consistently shown over the last 20 years or so that the HIV prevention interventions with the best evidence of efficacy are those that target men who are taking the most risks and involve a variety of 'talking therapies' led by clinicians and peers working in close collaboration, supported by appropriate media campaigns.

8.2 However, our mapping of HIV prevention provision shows that it is not constructed according to the findings of the scientific literature or the evidenced needs of gay men. On the contrary, a number of fundamental initiatives are missing:

- quantitative and qualitative research about how the latest 1,000 gay men got infected, so that trends in needs and risks can be identified and the results fed into the planning and delivery of HIV prevention services
- the timely use of activity data to ensure that programmes and projects are effectively targeting those most at risk and most likely to benefit
- a large-scale safer sex service for gay and bisexual men offering a variety of 'talking therapy' and relapse prevention services based on triage of each individual’s safer sex needs, with sufficient capacity and capability
- a large-scale outreach service to recruit men into the safer sex service
- a series of gay media campaigns: to remind gay men of the human, social and financial costs of HIV; to revitalise the social marketing of safer sex norms in the gay community; to counter the increasing peer pressure towards bare-backing; and to model the hidden persuaders that tempt gay men into unsafe sex, what they can do to pre-empt them, and where they can get help to practise safer sex consistently
- a well-targeted 'reception pack' with a comprehensive 'safety net' of advice for newcomers to the temptations of the gay scene (i.e. for young gay men, migrants to the big city, those with special sexual interests, etc.)
- last but not least, a large-scale project to offer all diagnosed HIV positive gay men safer sex education and support to maximise responsible behaviour.

206 Pilots of such services exist, but with insufficient throughput, typically in the dozens or hundreds rather than thousands. The aim has to be for such as service to have enough capacity to serve at least as many clients a year as are infected every year, or in the same order of magnitude.

207 There is very little work effectively targeting significant numbers of HIV positive men, and what there is tends to be generalised peer support (covering e.g. coping with treatments, side effects, or stigma), rather than about adopting or maintaining safer sex.
9 Recommendations

9.1 By contrast with many of the submissions the Select Committee will have heard from existing providers with a vested interest in the status quo, this is not an argument to increase spending in an era of austerity, but rather to use it wisely, and make it all count.

9.2 In an austerity era, where all services have to demonstrate that they are both essential and also value for money, we think the main risk is that funding for any significant gay men’s HIV prevention work is unlikely to be sustained without a fundamental shift of focus onto the target populations’ needs, methodological rigour, and outcomes achieved.

9.3 In the current re-structuring of the NHS and of Local Authorities, it is not yet clear precisely where the commissioning functions for HIV prevention will sit: GP consortia; public health (either centrally, or in local authorities); or some version of NHS specialised commissioning (with more than one model of what this might be on the table).

9.4 Many current providers will see this as a problem. We see it as a once in a generation opportunity to fix HIV prevention for gay men, but only if there is fundamental root and branch reform.

9.5 The recommendations below are made irrespective of future commissioning arrangements because they are based on acknowledged best practice in programme design and management and on scientific research, rather than the commissioning context in which these practices are applied.

9.6 If anything, demonstrable good practice is going to be even more at a premium in the commissioning context to come. Historically, the commissioning environment in the HIV sector has been less demanding and more amenable to informal lobbying on the part of providers finding it difficult to meet their targets. Whatever the new configuration of commissioning responsible for HIV prevention, it is quite possible that much stricter and less forgiving standards will be applied, not least because HIV prevention may be managed within a larger commissioning environment where it may be in direct competition with other sectors of work that can demonstrate that they have constructed services on the basis of clients’ needs, care pathways, and outcomes.

9.7 It is not difficult to know what to do. It simply requires the strategic vision leadership and diligence that has in the main been lacking.

9.8 The aim should be to reach the great majority of gay and bisexual men in the UK with messages that are effective in helping them:
   a. understand the personal and community costs of HIV disease
   b. know what they can do to avoid contracting or passing on HIV
   c. access interactive support services (information and advice, testing, counselling, mentoring and other talking therapies)
   d. change unsafe behaviour and sustain safe behaviour.
There needs to be a dedicated national strategy focused on achieving a reduction in new incidence of HIV transmission amongst gay and bisexual men.

The non-transparent and unaccountable funding to CHAPS should be ended and the funding used to commission new services transparently, accountably, and with a focus on outcomes, effectiveness and value for money.

There should be independent scrutiny of the sum total of all HIV prevention commissioned for gay men, and the gay community should be properly consulted in this process of scrutiny, in line with a ‘Big Society’ philosophy.

There should be independent outcomes-focused evaluation of all HIV prevention, with an emphasis on gathering evidence to prove that it is working rather than assuming that it is working because providers ‘know best’.

There needs to be a seamless safer sex service for the gay community, linking:

a. research about who is at risk and for what reasons
b. research about what could help them change
c. gay media campaigns designed to make gay men aware of the continuing risks, stimulate demand for, and pull them into, interactive services akin to smoking cessation advertising where the main point is to trigger reflection and achieve recruitment into interactive smoking cessation services.
d. enough interactive talking therapy work to meet the demand, and firmly focused on helping men change their behaviour and reduce unsafe sex.

Examples of good commissioning and patches of good local service provision can be found. What is needed is reform to publish the good practice, learn from it and use it to scale up effective work.

This submission is made on a corporate basis by Peter Scott, a Director of Status.

17 February 2011

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208 Superseding the Making it Count framework where nothing is prioritised or de-prioritised, and where there is no evidence-based rationale.

209 akin to smoking cessation advertising where the main point is to trigger reflection and achieve recruitment into interactive smoking cessation services.
Memorandum by Summit House Ltd, Paul Sheenan, PCT Sexual Health Commissioner and Diane McNulty, PCT Sexual Health Commissioner (HAUK 78)

Monitoring

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

The SOPHID system for collecting data does not provide timely information on numbers or stage of treatment for commissioning purposes. There needs to be a system that can give accurate timely data without compromising patient confidentiality to enable effective local planning of services.

Agree with comments above. SOPHID does give us quite a bit of depth in the areas it covers, but arriving a year late does not in any way help to plan in real-time. As a result interventions around HIV can be reactive, and can miss significant changes or developments which need an immediate response when they occur.

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

The decision to commission HIV treatment and the promotion of opportunistic testing and treatment outside of public health, when all the rest of sexual health services commissioning is a public health responsibility, could lead to fragmentation. There is no mention of the broader HIV prevention agenda and the commissioning of support services for HIV.

I understand why HIV treatment commissioning will rest outside public health, as this will enable cost savings to be made across geographic areas, and the buying in bulk of treatment. The risk with this, as described above, is that HIV might then appear to be “outside” or something separate to wider sexual health, when in fact it is a key component. My bigger worry is how we will get primary care to engage with opportunistic HIV testing, and respond to patients sooner, since HIV will sit outside of the remit of public health commissioning, and GPs themselves will administer their wider sexual health provision (for e.g. contraception)

c. Could anything be done to improve monitoring?

Information about social conditions i.e. poverty, poor housing, social situation should also be collated with existing data to ensure a clearer picture of the pandemic in the UK.

Information on housing, refugee status, and contact with social care services will all help to improve monitoring,. Also the creation of monitoring for those who specifically identify as commercial sex workers (both men and women)

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

Men who sleep with men (MSM) - this group does not use the ‘Gay scene’ or identify with the ‘Gay community’ therefore has little access to information + prevention campaigns targeted at the Gay population in gay venues. MSM often come from communities where homosexual behaviour is frowned upon because of religion, culture, poverty and poor education and therefore knowledge of transmission can be low or non-existent.
Late diagnosis – often men, often MSM.

The partners of MSM are also at risk of secondary infection particularly for individuals who have religious beliefs that prohibit condom use.

Bisexual men and their partners. Being bisexual is stigmatised amongst the gay community and the wider community and is often clandestine.

Men in prison where condoms/information/treatment or testing is not available or accessible.

Young gay men – HIV is no longer ‘in the news’. Because successful drug regimens are available and deaths from AIDS have decreased this can imply that HIV is an easily managed condition treated by simply taking medication.

M/F from African countries where HIV is prevalent.

Individuals sharing injecting equipment for drug misuse.

**Prevention**

a. Is Government policy sufficiently focused on HIV prevention?

No. The HIV agenda has not been the subject of a national campaign for some time and the public in general needs to be made aware, encouraged to test and to understand basic HIV information in an accessible and inclusive way. Late diagnosis of HIV is a particular problem as long term health problems are often more acute and long term with later diagnosis and recovery is more difficult.

No. HIV is not seen as part of wider sexual health, and the development of campaigns towards gay men and African people, although admirable and needed, has meant the message to heterosexuals, particularly white heterosexuals is non-existent. This is important as this group now makes up the bulk of all new HIV infections every year.

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

Gay men and Africans have been targeted as they are the most affected group but more widespread information needs to reach the whole population.

Agree with above.

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

Needle exchanges have made a significant impact on the infection rates of IDU’s and this service must continue in spite of the ‘abstinence agenda’ currently adopted by the NTA. They have been effective and largely responsible for reducing the number of new HIV infections seen in this cohort.
d. How could prevention initiatives be better delivered and evaluated?
By involving community and faith leaders in ‘spearheading’ campaigns working alongside local services that have access to ‘hard to reach’ groups. All health and social care workers should have mandatory basic training in HIV and schools/colleges must include sexual health and HIV education at a much earlier stage delivered by people who have a broad knowledge of HIV stigma, the effects and can challenge this.

As above. Also, involvement of strong peers who mean something to the target cohort – having a Coleen Rooney, Katie Price or whoever each cohort relates towards to propagate and support a preventative method would really help destigmatise and raise awareness. It worked successfully for Jade Goody and cancer, there is no reason why we cannot use another cultural icon/celebrity figure to do the same for HIV. We need to target, for heterosexuals particularly, the “OK” Magazine generation since it is those men and women who are becoming infected.

Testing

a. Are current testing policies adequate across the country?
Current DoH guidelines that recommend testing in specific circumstances i.e. high prevalence areas, country of origin - must be adopted for lower prevalence areas. If testing is only carried out in high prevalence areas then surely this is a ‘shutting the stable door’ approach? At current rates of increase in 15 years most areas will be ‘high prevalence?
As above. Change the definition of “high prevalence” before we all become one?

b. What can be done to increase take-up rates?
By encouraging people to test through public health campaigns that do not ‘demonise’ the virus.
Television campaigns about HIV testing shown at prime time that challenge the more usual media ‘hysteria’ approach to HIV
Community based testing outside of medical settings using voluntary providers and ‘Fast test’ kits.
Ensuring that people are aware of the confidentiality of having a test and who has access to the results as well as the health benefits to early testing.

HIV testing in G.P surgeries
Offering an HIV test during routine blood tests
HIV testing in colleges and higher education.
HIV testing in A+E
HIV testing for partners of pregnant women who are from a high prevalence group or country
Memorandum by Summit House Ltd, Paul Sheenan, PCT Sexual Health Commissioner and Diane McNulty, PCT Sexual Health Commissioner (HAUK 78)

As above, plus engagement with and support for, primary care practitioners including GP surgeries, A&E Walk in centres, Youth services and Childrens centres.

Encouraging delivery of opt-out rather than opt-in testing in a range of venues (has successfully worked in maternity provision)

**Treatment**

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

By ensuring that a dialogue is established with treatment and support providers (particularly outside of high prevalence areas)

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

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

Specialised HIV clinics that work with G.P's to deliver an ‘all round’ service. Outside of high prevalence areas people with HIV may be reluctant to inform their G.P or health provider about HIV fearing stigma or breach of confidentiality

Actively challenging pharmaceutical companies to reduce prices. By buying en block, the purchaser becomes more powerful. A powerful purchaser once assertive, can enable provision of treatment to be made more cost effectively.

Audit of services against treatment guidelines.

Regular engagement, consultation and dialogue with Consultants and GUM departments.

**Cost**

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

(i) prevention policy;

No. There is a lack of cost modelling around HIV prevention services, and often a lack of foresight from commissioners as to how effective the intervention might actually be. We need to start thinking about outcomes rather than outputs, define service specs correctly ensuring they are evidence-based, and highlight the cost savings that can be made by investing in HIV prevention.

and

(ii) treatment policy?

As detailed above, more could be done to reduce the costs of treatment by actively challenging pharmaceutical companies, and by block purchasing of HIV treatment drugs.

b. Is research funding correctly prioritised?

Perhaps it is, but how often do commissioners and public health practitioners get to see it? The issue for me is more of ensuring the research evidence is widely publicised and shared with key stakeholders – very often commissioners work from out of date guidance which bears no relation to current need and demand.
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 huge problem, the most challenging aspect of HIV after treatment adherence. Successful treatment can sustain the body but the problems that stigma presents the individual are debilitating and damaging. Stigma leads to isolation, depression, anxiety, health problems that include self harm and sometimes suicide.

Enormous, and stigma affects ALL groups. Not just the patient with HIV, but also the nurses, doctors, social workers and other health and social care staff who are working with the patient.

b. Where are problems of stigmatisation most acute?

Stigma is a particular problem for low prevalence areas where there may be no other visible HIV+ people and the disease is openly discussed in the community as a shameful and dirty condition that affects only those who ‘deserve it’.

Areas of deprivation where Asylum Seekers are dispersed can often be hostile and unwelcoming to immigrants and HIV is an issue that can divide communities.

Outside of big cities and affluent towns attitudes towards gays are far less tolerant and ‘AIDS’ is synonymous with unacceptable behaviour. People with HIV are often afraid to access services as they fear exposure in the community. Many people do not access support services for years after diagnosis. Children who have a parent or sibling with HIV are vulnerable to stigma as are people with HIV who are in employment and feel unable to share this information with their employers.

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

YES! Training and education programs rolled out across the UK – it’s not rocket science, we can ensure that people get the correct information for a ‘human’ perspective of HIV in a few hours and this can change attitudes for a lifetime.

People with HIV are considered under the DDA to be disabled from point of diagnosis therefore are protected from discrimination by law. But proving discrimination is difficult as it often means exposure of HIV status and many people will not risk this.

Passing on HIV is now a criminal act and carries severe penalties. Whilst no one would condone deliberately infecting someone with HIV, if the social stigma, self hatred and fear of exposure is overwhelming then an individual will either: not test, test and then deny the result, undergo medical treatment but not access any other form of social support, feel unable to discuss barrier contraceptives with sexual partners, particularly if there is no risk of pregnancy.

HIV is a public health issue but for the majority of the public that we as a charity interact with - it is a frightening condition and therefore people with HIV are often feared – like lepers. Public health campaigns need to ‘normalise and humanise’ HIV by allowing HIV+ people a chance to tell their stories rather than scaring people witless about the disease as this compounds stigma and prevents people testing. People with HIV accessing mainstream
media and openly HIV talking about living with HIV (not just on December 1st) alongside open dialogue about routes of transmission, treatment and the effects of stigma

Agree with above.

23 March 2011
Memorandum by Tcell (HAUK 43)

Who Tcell are?

1) Tcell is a wholly internet based campaigning and lobbying “grassroots” organisation known on the internet as www.tcell.org.uk.

2) In late 2007 the Department of Work and Pensions began a review of HIV+ people in receipt of higher rate DLA rates. The effects on the HIV+ community, especially those who have been positive for many years, often having had AIDS diagnoses, multiple HAART usage, and often suffering from multiple physical and mental problems was not hard to predict. Suddenly a community that has suffered loss on a catastrophic scale was told to expect another yet another predictable ‘hit’ but this time from the very establishment that is supposed to keep it safe. Many of us worried that we would see a repeat of the dreaded DLA review of the late 1990s, which saw many HIV+ people forced into poverty, and some to even take their own lives.

3) The community needed help, advice and support from those it trusted to act in its best interests. This was sought, both directly and indirectly but little was forthcoming. But, those very organisations that have for many years since the commencement of the AIDS crisis, who promised to protect the memory of those who have suffered and died and were entrusted to be working for the good of the living appeared to ‘drop the ball’ to many of us in the HIV+ community in a major way.

4) Tcell.org.uk was formed by people living with complex HIV who also lived the situation they faced at the time in an attempt to ensure that Social & Welfare issues for HIV+ people were not left of the agenda or ignored in future. Furthermore this has expanded to include additional issues faced by HIV+ people but suffer from insufficient activity and support namely mental health & HIV, Hepatitis C & HIV Co-infection, the impact of Human Papillomavirus (HPV) and to challenge the stigma suffered by the community.

5) It has grown, to a national organisation, thanks to the internet. It is largely self-funded by few volunteers all of whom receive benefits. The organisation receives no statutory or commercial funding.

6) We believe in empowering our community by sharing knowledge and experience amongst ourselves and across disabilities where the fundamental issues are shared. We believe that openness, transparency and visibility is a powerful tool to bring about the change, we that live the challenges and consequences of the campaigns we promote, face on a daily basis.

Author & disclosure of interests.

7) The author of this report is John O’Callaghan-Williamson, founder and director of Tcell.org.uk. He is a current member and former chair of the Frontline HIV Patients Forum (the HIV patients Forum at the Chelsea & Westminster HIV Directorate). He is openly gay & HIV+ and was diagnosed in 1999 and was employed in IT, mainly in
the City of London, until ill health lead to full time employment no longer being an option.

8) Submission of evidence here is based upon personal & peer experience. Schell concentrates on specific health issues not the broader HIV health debate as we recognise this field is full of very able people. Our focus is on social and welfare support.

Written Evidence

9) We have done our upmost to “spread the word” for this “Call for Evidence” to ensure that patient perspective and views are forthcoming to feed into a more balanced approach across the HIV Sector. It is, of course, important that the committee should seek evidence from the NHS & HIV Third Sector organisations that are funded commercially or governmentally. Some may argue however, that their own organisational self-interest may “taint” responses. Furthermore some organisations remain closer to PLWHA (People Living with HIV/AIDS) than others that are slightly removed. We certainly want recommendations from the committee to be based on full and broad experience across the spectrum.

10) Schell would like to see the committee not just look at issues around health prevention and provision but the broader experience of HIV+ people when it comes to employment issues, welfare & social care support and society. This broader scope would allow the main issue of Stigma to be more readily understood especially as it impacts on prevention, testing and accessing medical care. Health is a part of a “cake” that of itself doesn’t provide the sufficient scope to understand the broader issues that impact upon it.

11) Although HIV receives “special” treatment from a health perspective that would otherwise not have allowed such positive progression and better prognosis and health outcomes. The fact remains that the HIV+ population is small in comparison to society and the disabled community at large. In economic terms this means that in other avenues for which one health example, GP’s, is an exception. The cost/benefit of deploying the necessary resource to ensure equity of treatment and understanding for those with HIV/AIDS leads, outside of secondary health care, to an inherent lack of fairness &discrimination for PWLHA. This in turn “feeding the beast” that is the greatest challenge, of Stigma.

12) The Oral Evidence Session of 25th January 2011 Questions 76-137 was of particular interest as this represents the organisations that represent people PWLHA like us. I will refer to this on occasion throughout this submission in an attempt to provide, their Lordships, with information I hope they will find useful. The Oral evidence contained much that we agreed with.

13) We welcome and appreciate their Lordships efforts on the issues that matter to our HIV community.

Monitoring

14) The ability to monitor HIV infection rates within the UK is fundamental to all efforts in the UK to deal with the illness moving forward. We share the concerns raised by
your witnesses here. There may not be the need for more than a single independent advisory “panel” to address issues and give advice on HIV in the UK. However we would emphasise the need for political independence to ensure that advice is based on sound evidence not diluted by political expediency or ideology.

15) We would argue that the remit of any group dealing with HIV could facilitate through sub-groups broader issues facing those with HIV to advise across more of government other than health.

16) Mr Jabulani Chwaula, mentions the need for a “patient voice”. Part of the positive progress made thus far in the battle with HIV has been the involvement of the patient, “at the heart”, and part of the problem solving process. This is again fundamental to building trust between those providing care, policy & support and the HIV community as a whole.

17) As a patient I need to trust the data that forms a key part of the decision making process. This often reflects the funding available to the HIV Community ensuring an equitable “slice of the cake” when it comes to services for my community.

Prevention

18) Some people with HIV, from the groups and discussion I have been party to, within the gay community. Believe that the prevention messages have been to “soft”. The “tombstone” adverts are held up as being, for these people, the type of message that simply isn’t visible anymore. That people are not being “frightened” into thinking not twice but thrice about unsafe sex.

19) It is felt that the ‘softer’ messages are merely to encourage testing, give out a false message that HIV is no worse than merely taking a pill once a day and all will be fine.

20) What is clear however is different mixes of communities need messages that they can personally identify with. They require those messages in different formats and language appropriate to them.

21) Interestingly, regardless of political persuasion. The “tombstone” advert is remembered and had a huge impact. Active as I am within my community I cannot, as I write think of the last time I saw a prevention.

22) With T₅Cell having an interest in Hepatitis C and co-infection with HIV I do find myself offering views to others, whether they are HIV and sero-sort their sexual partners or not. That HIV isn’t the only illness they should now be concerned about catching. As Hepatitis C gathers more and more victim’s it would seem to me that prevention messages may well need to be less about the specific illness and more broadly about several that can lead you, through unsafe sexual practice to an immune disease, a liver disease and unable to have children.

23) Looking at the data on potential Hepatitis infection in the UK. Those that are projected as being undiagnosed. It may be time that HIV didn’t single itself out but was part of a broader campaign about Sexually Transmitted Infection’s more generally, more of part of the information and part of a broader strategy of safer sex generally. I have some sympathy with Baroness Tonge’s observations here.
24) I accept the points made by your witnesses. The need for evidence to support prevention initiatives needs to be more readily available and analysed for cost effectiveness especially in an austere time.

25) Localism can play a huge part with prevention. This is not a new concept. I am sure everyone will agree that certainly the gay community does contribute to the prevention cause within itself. Local Patient Forums can play a part but they are typically poorly funded. However there connections with local health provision i.e. GP surgeries etc, and their communities I believe is a resource that hasn’t been fully exploited here. The “top down” approach doesn’t always deliver better outcomes or results. Here I can only reflect my broader experience.

**GP Consortia**

26) In the oral evidence funding and the reorganisation of the NHS has been a big issue. Ultimately it’s “patient choice” and its exercise that is the solution. Positively Women now Positively UK undertook a study into the issue surrounding more use of GP’s by HIV+ patients. I understand they may well refer to this in there submission. The web address for the project is [http://www.accessgp.org.uk](http://www.accessgp.org.uk). This looked at both the GP and patient side.

27) Within London with centralised purchasing of services and drugs. Where some would prefer to deal with their GP for routine blood tests and prescribing HIV drugs the structure doesn’t facilitate this. The point is that some people would like their GP to be a provider of some parts of there care. Others have little trust in the knowledge of the GP and many more either don’t register with a GP or use a London Clinic and don’t disclose GP details as the require protection from perceived discrimination and stigma. In some cases this can be very real.

28) It is correct that the commissioning and provider are two different things. There should be no structural issue with Secondary care or GP consortia commissioned to provide care top down. Essentially it comes down to the confidence of the patient with the service they access. One for which a path needs to be laid. Where the patient can lead the way. As more confident patients defer parts of their treatment to the GP and are happy, they will talk about this with their peers. “Word of mouth” is very powerful and needs to be recognised. This is certainly a “work in progress”. I trust my GP on many matters personally except my HIV. Merely because at the own admission they lack the skill though the conversation is open and constructive and an interest demonstrated.

29) Looking at the London HIV Consortium model. This is understood to provide “economies of scale” in certain purchasing it undertakes. Devolvement to GP consortia may see the end of this type of structure simply meaning that the cost of care in London increases with the savings lost. GP consortia is a bottom up solution that may not deliver the cost efficiency savings of a top down approach. I would caution, especially in this climate, not to take a regressive step.
Testing

30) Testing should be encouraged where possible. This can be achieved in some areas by specifying it within GP contracts as a measure against payment. Local pharmacies can be incentivised to offer testing. Local community settings can run testing clinics i.e. it seems gay nightclubs and bars from my own community is a good idea. I know the Dean Street Clinic has been innovative in Hepatitis C awareness campaigns and it seems innovation is a key here.

31) Opt out/in has issues. If a GP asks a patient if they want a test and they opt out. I have concerns about how this may be recorded in the individuals medical notes and if it may ever be reported indirectly or in answer to a direct question on a request for a medical report by a third party. The ramifications of a opt out in this example may give rise to un-necessary suspicion. I also believe this may impede work as far as dealing with stigma is concerned.

32) Mandatory testing is an absolute no. This would cause more harm than good. I do not see how on the one hand you can be against it on Human Rights reasons and then make an argument for some mandatory testing. We would caution this approach for many reasons not least the Human Rights issues involved. It seems to me that we do not give due credit to medical professionals here. It would seem to me that an informed and specialised medic in the field of TB would be more than aware of the link to HIV and would, using their experience and knowledge, discuss with their patient a HIV test.

33) Any form of compulsion or “mandatory” requirement is always a regressive and highly damaging approach.

34) In the modern world, Home Testing kits available in the UK would ensure a product of a UK recognised standard and not a “cheap knock off” from a site outside the UK. It cannot be beyond such kits to carry clear information on who to call in the event of a positive result. Terrence Higgins Trust could be funded to handle referrals or the new replacement for “NHS Direct” could also take a part. As this would be a commercial venture I see no reason why any license granted couldn’t include the type of information required and from whom. There is a wealth of support out there. This passes control to people, important as control can be an issue with HIV.

Criminalisation

35) Criminalisation is the “elephant in the room” for some of the issues raised. This I would argue has created additional fears for people to test. Not only have we seen convictions for the transmission of HIV but also Hepatitis C. The coverage of this in the media and stance of the government in continuing to keep this a criminal offence has taken the efforts to combat stigma backwards not forwards.

36) Baroness Masham mentions ‘contact tracing’. I would suggest that this can be difficult for a person newly diagnosed and coming to terms with it. Contact tracing can also bring to the fore fears of criminal prosecution. I am not arguing against Contact tracing merely that criminalisation does play a role.

37) Finally the impact, driven by media coverage that criminalisation has upon HIV stigma.
Treatment

38) Moving forward to ensure treatment flexibility and cost effectiveness, encouraging local GP consortia to partner to purchase may bring about savings. We have seen for some time now, reported, patients having less say in their treatment options with preference given to migrating to newer, less pill overhead, combinations. Driven by cost rather than reasoning based on adherence and toxicity. I myself was told I should be on a newer combination by a leading professor in HIV at a recent meeting, even though the combination I am on has worked for years and I can adhere to it, and I ideal with the side effects.

39) Adherence has seems to have been replaced, in the HIV jargon as ‘toxicity’. Either way I think most would agree that adherence is the goal to achieve with any therapy. The difference is that with “adherence’ you may change your anti-retrovirals until you find a combination you can take and can commit to taking. “Toxicity” is managing the side effects of prescribed antiretroviral often by prescribing even more medications. At least that’s how I see it.

40) Adherence clearly saves money in the long term. I would like to see this back as a leading issue when it comes to treatment options.

41) I remain concerned that “cost saving” is placing the patient further from the decisions about their health. Unless a patient especially a HIV patient can co-own or own the decision the battle to adhere becomes more difficult.

Cost

42) We know that the NHS has been saving money and cost cutting for over a year. The Chelsea & Westminster HIV Directorate itself subject to cuts. Governmental and commercial money will be squeezed to deal with an economy focused on saving money and with little current growth. Personal donations will be squeezed by increased general living costs and job fears.

43) As a patient, potential receiver of services and critical friend of the HIV sector. Outcomes are important. I want to know that money given whether in health care, support service, prevention campaign or testing. Is delivering value but more importantly for every £1 received the majority goes to the “frontline” effort.

44) There are a few hundred HIV organisations around the country some national, the majority more local. There will always be a need for HIV to be represented at a national level. Further rationalisation is inevitable as money becomes more scarce. Organisations such as T’sCell, that although national will be unaffected. Many of the smaller organisations will continue because to use the rhetoric they are the “Big Society”. Existing to meet a local demand or HIV issue not covered elsewhere.

45) Localism is good news for these smaller organisations often much closer to the “grassroots” and people living with HIV on a daily basis. Of course this emphasis to the “bottom” will no doubt be at the detriment of the “top”.

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46) For any organisation, group, innovation is going to be a key constituent of delivering quality measurable outcomes for less money. Partnership will be another. Patient involvement and patient ownership the most fundamental.

47) Money is the driving factor and of course larger organisations have an interest in protecting their employee’s and status. I am not arguing this is wrong. Merely that there is a voluntary sector that could and would be invigorated by being able to raise more funds for local initiatives, initiatives they can identify as unique to their communities but not necessarily others. For Testing and prevention campaigns this may be the untapped solution thus far eluding broader prevention strategies.

48) We believe that HIV+ people, once doing much for themselves, recently less active. Can individually and in groups contribute more. They simply need the support. The funding models are perverse in that they seem to rely on client dependence rather than bringing about client independence.

49) I have often believed that the larger sector bodies could do more to bring people together around there illness across communities. Funding I think prevents this but at a local level I have witnessed people coming together because the only thing they have in common is HIV. Larger charities are in a position to aid and assist smaller groups, affiliation need not be a fear. Protectionism also pervades and doesn’t help transparency though progress has been made by some in recent times.

50) Within the NHS, patients can accept and work with HIV health providers to ease “change”. In fact introducing them into discussions of cost can ease “cuts” as in some cases the patients may actually agree. They can quickly and cheaply solicit views form there peers. With some funding they can survey more widely with overheads kept down due to no staff overheads, they work voluntarily. Patients can even contribute but suggesting cost saving issues.

51) The NHS remains very protectionist. In my experience trying to work with them to deliver a patient survey proved extremely difficult on many levels. The right encouragement was given but the action was slow to follow if indeed it followed at all. Training up volunteers to offer some of the supplementary services may be a way to reduce cost, maintain service and offer some a first step back to work.

**Stigma**

52) This remains a huge topic that one could go into at length. I would make the following points in addition to those already touched upon.

53) Stigma is often referred to as a singular and isolated issue. As a form of discrimination or prejudice it is often merely part of a compound of discrimination or prejudice. Before your HIV status is known you may already be subject to prejudicial judgement on the basis of your colour, culture, ethnicity, religious belief, sexual orientation or visible disability. In oral evidence the AHPN gave an example.

54) Therefore I would ask that consideration is given to the cumulative effect with HIV stigma as part of the mix.
55) In my personal experience I do think that there has been progress on HIV stigma but there is much further to go. There are legal protections but this can involve expensive legal processes for which the stress has a negative impact on the health of the individual. That is of course if the person feels able to expose their HIV status by placing it in the public domain in this manner. Alas many still fear exposure for the reasons given in oral evidence. We know through our work in social and welfare campaigning that many are not challenging adverse decisions as the fear of exposure is greater than the further slide into poverty.

56) The Chair maybe interested in the MAC AIDS FUND Survey albeit from 2007 and I submit the Executive summary from the findings of the global survey of public perceptions and attitudes around HIV/AIDS.

57) Empowering individuals and involving them in the decisions and dialogue around the illness they live with is a factor to help overcome Stigma. Often those that live with the illness see decisions and policy made that is remote to them. If they want to become more active they can find that the barriers exist within the healthcare and support structures that claim to advocate for them.

Summary

1) It is important that there Lordships are aware of the impact of the criminalisation of HIV on the areas under consideration.

2) Current, broader governmental changes for PWLHA impact on the existing relationships between doctor and patient. The requirement for medical reports in support of benefit or housing applications, for example, can see the trust so vital for maintaining good health, being damaged. In fact we have already seen some evidence of this.

3) Health provision and cost may need to factor in the real potential for increased medical intervention if given current changes to the whole welfare system, people decide to give up on the medication that keeps them well. We saw some evidence of this in the DLA review of 2007/2008. Again we are seeing this subject being raised however the scale and pace of change is much greater. The accompanying stress on people with HIV will effect their general wellbeing and physical and mental health that may require more clinical interventions.

4) Mental health remains the poor relation to physical health for those with HIV.

5) Testing should be made available in manner that individuals want to engage with proper guidance where such testing takes place away from a clinical setting.

6) Independent and detailed data collection and analysis with an Independent Advisory Panel to advise on policy are fundamental to ensuring needs are properly reflected in resource provision.

7) Compulsion and “mandatory” requirements are regressive concepts whose application should always be avoided. They have negative impact and lead to less use of medical interventions more generally as well as have a negative impact in the HIV community and the stigma felt as whole. Consensus, education and trust achieve
much more over time. When it comes to HIV these concepts or “solutions”, again, make HIV a more “special case”, are authoritarian in nature and don’t aid ‘normalisation’.

8) Localism we believe will hold some of the solution to cost reductions across the board. Better targeting of local communities understood by local people will produce better local outcomes. Encouraging more activity locally will have a positive impact on local NHS provision, better targeting of prevention campaigns given local knowledge and relationships, unique and specific local issues addressed. Overall putting people at the heart of the solutions to their problems and issues but the successful delivery of local campaigning initiatives. Localism raises the visibility of HIV with in communities and attacks stigma.

9) HIV+ care in GP settings or commissioning by/to GP consortia is a sensitive issue. The approach needs flexibility but more over patient control and leadership. A top down edict will only lead to more people removing their involvement with primary care. It is the direction of travel, the right direction for normalisation but needs to be done with extreme care and gradually. Again localism and local groups have a huge role in delivering on the progression of this aspect of HIV care provision in the future.

10) Innovation will be key to delivering HIV service moving forward, and cost reductions moving forward.

11) Living with HIV positively is considerably more than just dealing with the health aspect.

12) Cost reductions, health strategies and third sector programmes all require PWLHA at the “heart” of the process.


14) Finally, solutions borne out of a London experience don’t necessarily work in the rest of the country and local complexities needs more consideration.

February 2011
Memorandum by the Time2Know Partnership (HAUK 16)

1. The Time2Know Partnership

1.1 The ‘Time2Know’ partnership is a multi-disciplinary collaboration between frontline HIV prevention practitioners; commissioners; partnership specialists and evaluation and data strategy experts. The partnership leads each have over 20 year’s experience of commissioning, delivering and/or evaluating HIV prevention at the local, London wide and national levels.

1.2 The partnership would like to present the following evidence, drawn from our extensive practical experience of working with HIV prevention, for consideration by the select committee in relation to HIV prevention work with African communities.

2. Background to our submission

2.1 The aim of the Time2Know partnership is to deliver new HIV prevention ‘products’, which have the scope and capacity to overcome the main barriers to effective HIV prevention with African communities, namely:

- The failure to target HIV prevention to people in most need and, therefore, the failure to tailor HIV interventions to meet the needs of each individual
- The failure to address the gaps in the evidence base or to build a more balanced picture of effectiveness based on impact and outcome evaluations
- The failure to develop systems and opportunities to support innovation and continuous improvement

In addition, the partnership is jointly writing a detailed specification to develop the capacity of outreach projects to collect, analyse, and disseminate evidence of clients’ HIV prevention need including: knowledge; beliefs; attitudes to personal risk, sexual risk taking; and self evaluation of HIV status and STI testing history.

2.2 Our project has been in development for 20 months, during which time it has completed two pilot phases. We have screened over 1,500 individuals from sub-Saharan Africa aged 18 and over to identify those who have two or more sexual partners. We have delivered full interventions with over 200 people who meet these inclusion criteria.

2.3 The project has developed good working relationships with local managers of 45 businesses and services used by African people in Enfield and Haringey. It also has close working links with St Ann’s Sexual Health Service, especially the team who provide community HIV testing in Wood Green Library.

2.4 The evidence we wish to present addresses the issues covered within HIV Prevention b) have the right groups been targeted for HIV prevention campaigns? and d) How could prevention interventions be better delivered and evaluated?

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210 Identified in ‘HIV Prevention: a review of reviews assessing the effectiveness of interventions to reduce the risk of sexual transmission, Ellis, S. Barnet-Page, E. Morgan, A. Taylor, L. Walters, R. Goodrich, J. March 2003
3. **HIV Prevention and African Communities**

3.1 HIV is a preventable disease. During 2004 the Health Development Agency was commissioned to produce an Evidence Briefing Summary to ascertain the effectiveness of STI prevention interventions. This stated that there is sufficient review-level evidence to conclude that interventions are more likely to be effective if they are based on theoretical models; are targeted and tailored (in terms of age, gender, culture, etc.), make use of needs assessment and formative research; provide basic accurate information through clear unambiguous messages; and use behavioural skills training including self efficacy.\(^{211}\)

3.2 While some examples of good practice in local commissioning and delivery have been realised, very few opportunities for shared learning to support the development of effective larger scale programmes have occurred in the UK recently. As a result, much commissioning of HIV prevention work targeting African communities lacks a common and coherent theory for action. At best, it is process or output driven (i.e. only monitored for numbers of interventions delivered, hours worked or individuals engaged) as opposed to being focused on better sexual health and HIV prevention outcomes for the individual.

4. **Targeting African people at risk of HIV infection**

4.1 The African Handbook, the implementation guide for ‘The Knowledge, The Will and The Power’ (KWP) planning, policy and action framework developed by the National African HIV Prevention Programme (NAHIP) partners tries to resolve some of these problems by offering clear and concise descriptions for a broad array of HIV prevention interventions. It also recommends that for HIV prevention purposes, African people are grouped under five target priorities:

- People living with HIV
- The sexual partners of people living with HIV
- People with multiple sexual partners
- The sexual partners of people with multiple sexual partners
- All other African people who are sexually active

4.2 Some work to promote safer sex among African people living with HIV and their sexual partners has been developed at the local level. A good example is the Newly Diagnosed Pregnant Women’s Service, delivered by a partnership between the midwives and other health professionals at the N Middlesex University Hospital Trust and the PACSH (Pan African & Caribbean Sexual Health) Project based at Embrace UK. However, these isolated services can only deliver fragmented provision to African people living with HIV and their sexual partners, even though people diagnosed with HIV are a relatively easy group to target for health promotion.

\(^{211}\) Prevention of Sexually Transmitted Infections (STIs): a review of reviews into effectiveness of non-clinical interventions, Ellis, S and Grey, A. (2004) HDA
4.3 **HIV prevention which targets African people with multiple sexual partners does not exist.** In our experience, many commissioners and providers of community HIV prevention assume that African people will not find frank discussion of numbers of sexual partners or other sexual risk factors ‘culturally appropriate’ or ‘personally acceptable’. To our knowledge, there is no published evidence to support this assumption.

4.4 Time2Know has screened 1,500 Africans in a range of settings including hair salons, bars, restaurants and clubs by asking them if they come from sub-Saharan Africa, are aged over 18 and have two or more sexual partners. This intervention has been approved by managers of 45 venues, many of whom have also been clients of the service. Originally planned to last between 45-60 minutes, outreach workers report that many clients are requesting longer and/or repeat sessions. Not only have we found no resistance to discussion about multiple sexual partners and sexual risk factors, we have found that many people are very keen to discuss sex, STIs and HIV in considerable detail. In practice, Time2Know demonstrates that there is both need and demand from the community for services targeted to this priority group.

4.5 While there is consensus that ‘outreach’ provides the core activity within HIV prevention, many service specifications only vaguely define outreach processes and what they are supposed to achieve. As noted in the African Handbook, outreach interventions are often carried out by pairs of workers to ensure their own safety and to protect themselves from accusations of misconduct. We have found that discussions about sex and sexual risk of HIV, while feasible in public places are best carried out one-to-one. This requires careful planning and management of the relationship with the venue managers. It is, however, not difficult to achieve this level of commitment with people who support the aims of the project.

4.6 In the light of these findings; the reduction in public investment in HIV prevention anticipated over the next five years and the need for every HIV prevention project to make maximum impact on undiagnosed and late diagnosed HIV infection levels we **conclude that all HIV prevention targeting African communities can, and should, target people who have multiple sexual partners. We also believe that clear expectations for HIV prevention targeting African people with HIV needs to be set at a national/regional level.**

5. **Tailoring HIV prevention to people at risk of infection**

5.1 Time2Know clients include people from 19 sub-Saharan Africa countries; they are aged between 18 and 54 and have been in the UK between 1 year to 10+ years (average 4-5 years). Roughly equal numbers of men and women have used the service. Over 5% report same sex relationships as well as heterosexual relationships. They also include people with education attainment levels spanning ‘no formal education’ to university level.

5.2 The intervention is structured in five sections: personal and demographic details; knowledge of HIV and attitudes; sex and sexual relationships; HIV and STI testing; learning and impact on future behaviour. The delivery toolkit enables outreach workers to rapidly assess key variables such as knowledge levels, relationship circumstances, attitudes and beliefs, and to tailor the spoken and written information they provide accordingly. These variables are recorded on the questionnaire
alongside the advice and information given. The record provides both a log of each client’s HIV prevention needs and evidence of how these needs were identified and met. **It is this dual purpose data record, linking the delivery of the individually tailored intervention with action research into needs, impact and outcomes that makes Time2Know unique.**

5.3 The intervention goes on to record whether or not the client has understood and learned anything new. Where appropriate, the outreach worker can reinforce key messages with small media resources developed by NAT, NAM, the Heal Partnership, NAHIP, FPA, local providers and others. Monthly analysis and review of the data allows the team to share common themes and barriers to learning for their clients.

5.4 One common scenario, encountered by all of the outreach workers, concerns clients who have a reasonable knowledge of the risk factors for HIV; report multiple sexual partners; have had unprotected sex in the last three months and condom failure on at least one occasion, and who have never tested for HIV but who ‘just know’ that they are HIV negative. The reasons given for this assumption include: ‘I have no symptoms’ or ‘Only dirty people get HIV’ or ‘I know what to look out for and don’t have sex with those kinds of people’. Time2Know allows the outreach worker to identify these complex, contradictory and deeply held beliefs and respond effectively.

5.5 For many clients, Time2Know is the first time that they have had these assumptions about their HIV status challenged. The intervention records high numbers of clients stating that as a result of the discussion they will always aim to use a condom with every new sexual partner. The numbers of clients who report that they will either definitely (56%) or probably (22%) go for an HIV test as a result of taking part in Time2Know indicates that this intervention is highly effective.

5.6 The Time2Know project is already recording successful referral into HIV testing both at St Ann’s and at the community testing service at Wood Green Library. In pilot Phase 3 the Time2Know partnership will include St Ann’s Sexual Health Service. This will facilitate better tracking of referrals to testing, including anonymised test results, CD4 count and viral load.

6. **Building the evidence base for effective prevention targeting African people at most risk of HIV**

6.1 It is our view that a strategy for setting national expectations for HIV prevention targeting African people living with HIV and their sexual partners should be drawn up as a matter of urgency. This strategy should seek to increase opportunities for shared learning across local commissioning and provider teams in order to identify best practice and best evidence based interventions.

6.2 Time2Know has applied for a DoH Innovation grant to roll the project out in other locations, assess the feasibility of delivery in French and other languages and disseminate learning nationally. If successful, in Phase 3, the Time2Know project will deliver a programme of shared learning events to present the findings from the action research and the outcomes achieved for our clients as a result of participating in the intervention. These will be published on the NAHIP KWP website, (www.kwp.org.uk).
6.3 The Time2Know service specification provides a blueprint for commissioning outreach services with integrated evaluation targeting people from sub-Saharan Africa with multiple sexual partners. Key steps to the successful replication of this type of targeted, tailored and outcomes focused intervention include:

- Development of the data strategy to guide the collection, verification and analysis of client reported data from the inception of the project
- Commissioning a cycle of pilot phases to allow the intervention to evolve and the outreach workers to develop new skills
- Recruitment of highly skilled outreach workers – many Time2Know workers are current or recent graduates wishing to secure field experience as well as committed HIV prevention professionals
- Strong partnership working at all levels but especially with testing services, community businesses and other specialist providers
- Longer term funding with an emphasis on continuous and shared project learning and product improvement
- A rigorous focus on HIV prevention outcomes at all levels of delivery and strategic partnership working

6.4 In our experience, multi-disciplinary African HIV prevention partnerships working at a local level are more likely to complete these steps successfully. Several examples of strong commissioner/provider partnerships have been established in London, indicating that models similar to Time2Know could be rolled out in the Capital. These relationships are much more difficult to create in a top-down regional or national model.

6.5 We conclude that African HIV prevention interventions would be better delivered and evaluated if they were a) designed to build on the achievements of local commissioner/provider teams; b) sought to scale up those models which demonstrate successful targeting and tailoring of their interventions and c) underpinned with a clear data strategy linked to a published plan for the dissemination of learning.

Catherine Pearson, Time2Know Partnership Manager on behalf of:

- Mesfin Ali, Health Services Manager at Embrace UK and Time2Know implementation Manager
- Joan Badcock, Joint Enfield & Haringey Lead Commissioner and Commissioning Manager for Time2Know
- Dr Simon Sandberg (Phase 1) and Peter Scott (Phase 2) Directors Ergo Consulting and Time2Know Data Strategy Leads
- Jabulani Chwanla, NAHIP Programme Manager and T2K/NAHIP Link Lead

February 2011
Memorandum by Tuke Institute (HAUK 45)

Summary

The Tuke Institute is an organisation of scientists, service-providers, and organisational-development professionals pursuing scientific research, policy, and civil capacity-development to create truly patient-centred medical services with the focus on health-effectiveness. It uses these methods to promote solutions to problems in the delivery of services in medicine and medical science and focuses on new methods of promoting and enabling civil participation in the design, delivery, and governance of such services. The fundamental goal is to make medicine about what ill people need to get well and to stay well.

HIV-related illness in the UK continues to be a significant burden to the public in terms of its financial, social, and personal costs. Despite the obvious fact that the HIV pandemic is driven by behaviour, expertise in behavioural science and behavioural medicine is inadequate or even absent in all areas of policy and service-delivery, and policy-setting is often a function primarily of political considerations within professions or provider-organisations, with the evidence-base informing these as a secondary concern.

There is also a primary problem in the lack of public participation in policy-setting, service-delivery, and governance, which relates to the themes common across all problem-areas: of complacency, a loss of vision, and a lack of leadership, particularly fresh leadership.

This submission consists of an expert opinion that identifies a number of problems and both individual and systemic solutions thereto. These include the development of:

1. an organisation that can represent the interests of people with HIV in terms of medical (including social) and scientific services delivered on behalf of people with HIV to people with HIV

2. Health-Outcome Delivery Standards for medical services, so that the health-effectiveness of medical services can be measured in reference to how they help people with HIV live healthy and productive lives

3. integrated medical services in reference to Health-Outcome Delivery-Standards that address the comprehensive physical, mental, and social health-needs of people with HIV, facilitated by case-management, to which behavioural medicine is key and which have been shown to be cheaper than the current physician-centred model

4. a new framework for HIV prevention, focusing on health-effectiveness and the measurement of health-outcomes in both those with HIV and those at risk for infection

5. a common and consistent message and approach for public education about HIV, to avoid the systemic problems inconsistent messages have caused to date

6. new means of public participation so as to ensure representativeness of solutions

7. a review of the representativeness of civil and provider-organisations in service-delivery generally and in medical practice and in scientific research in particular.
8. a blueprint for translational science in HIV research so as to ensure the validity and value of funded research done for the public benefit, including a system for surveillance of illness-burden and health-outcomes in HIV treatment

9. a coherent policy on criminalisation that might shift it from criminalising HIV-transmission to criminalising disability-discrimination

10. a strategic 10-year plan for a coherent, national response to HIV in the UK.

These solutions would facilitate great progress towards a modern and cost-effective national response to HIV in the 21st century and refresh the vision and model that HIV provided historically for the response to other costly chronic illnesses that burden society today, including breast cancer and neurological disorders.

Monitoring

a. Monitoring systems in the UK are among the best globally in terms of surveilling the incidence and prevalence of HIV-infection.

b. The knowledge of HIV-prevalence and of the dynamics of HIV-transmission in the UK has never informed the size of the prevention-programmes, reflecting a lack of political will in funding and/or a loss of knowledge-translation from science to policy.

c. Despite the current excellence of surveillance systems of this sort, there is also a lack of knowledge of how to translate such good data into effective interventions, due in part to the failure to use the expertise of social and behavioural scientists in developing evidence-informed interventions in a coherent and national programme.

d. There is no adequate surveillance of illness-burden: i.e., how HIV affects the ability of people to live healthy lives or not. Such systems exist in other countries for certain chronic conditions. These data are essential if services for HIV are to be designed to deliver health-outcomes and the services are to be bench-marked and assessed for health-effectiveness and cost-effectiveness. Most assessments to date have been small-scale surveys initiated by community-groups that have then been used for advocacy and have entailed significant struggles with service-providers. Large-scale surveillance needs to be implemented.

e. Surveillance systems of this type need to use metrics that are also used in the clinic, also requiring a change in the way clinical services are delivered and how ‘health’ is defined as something more than a suppressed viral load and CD4 counts above 400. This means a new effort to join up public health with medical services in order to create more efficient synergy towards health-outcomes.

Prevention

1. Prevention is conceived primarily as a public health (i.e., population-level) issue, rather than being equally a medical (i.e., individualised) issue. Furthermore, it is framed almost exclusively in terms of primary prevention: i.e., preventing uninfected people from becoming infected. Secondary prevention—of infected people becoming ill from related or unrelated illnesses—is not adequately conceptualised or implemented and this needs to be remedied.
2. Most people at risk of HIV-transmission are seen already by medical services and the translation of knowledge about prevention into clinical practice remains an unsolved problem. Prevention-efforts provided by clinicians in the UK are widely considered to be ineffective. This may be reasonably ascribed to the lack of trained competence in behavioural medicine and a lack of comprehensive services to back prevention-efforts up and to make them credible to recipients.

3. The targeting of interventions to specific groups (i.e., in public health) or specific individuals with certain risks (i.e., in medicine) is necessary. Yet, within public health, there is a need to recognise that there is no community as such within at-risk groups, especially following the introduction of effective pharmaceutical management in 1996 and the collapse of the gay community’s participation in the response to HIV. Stereotyping of people with HIV as though we are behaviourally homogenous, due to a purely epidemiological perspective, has led to poor policy, poor decision-making, and inadequately sophisticated interventions. Social identity is not an predictor of community-identity and individuals can span communities; other at-risk groups have never had a community as such yet are still amenable to interventions based on social-group—e.g., injecting drug-users. Targeted interventions need to be responsive to these realities. The lack of expertise in social and behavioural sciences in understanding diversity of target-groups for prevention has hindered the design and efficacy of interventions through poor knowledge-translation.

4. The role of business in facilitating the effectiveness of interventions is underestimated. In the gay ‘community’, businesses have the greatest potential for impact on prevention. Yet professional, paraprofessional, and even some community-based organisations do not engage with them.

5. There has been a failure to deliver a balanced and consistent prevention-message to the public through a problem of competing and incompatible interests between public health and medicine, neither of which has helped meet the needs of people with HIV in the long-term. The first message has emerged through an effort to use public health to reduce discrimination, such that “HIV affects everyone”. Data are interpreted in such a way as to meet the needs of the media and the funding bodies, due to a lack of governmental leadership in curtailing discrimination through more direct (i.e., legal) means. The second, conflicting message is that ‘HIV is easy to treat’, which promotes a pharmaceutical solution to the socio-behavioural problem of HIV-transmission, a misperception that HIV is curable, and has thus led to increasing costs through a failure to integrate preventive interventions with medical services. A consistent and rational approach to responding to the problems of HIV needs to be developed.

6. Prevention and treatment requirements have become much more complex, but many conceptual frameworks are still essentially the same as in the 1980s, despite the use of newer technologies. First, ‘harm-elimination’ ceded to ‘harm-reduction’ as a framework; this should now move towards the more comprehensive framework of health-effectiveness encompassing prevention, diagnosis, treatment, and rehabilitation and resulting in meaningful health-outcomes, not simply the avoidance of HIV-transmission.

7. Rather than being grounded in scientific evidence within a health-effectiveness framework, prevention has moved instead to the lowest common denominator typical of the NHS: commercialism and commercial methods that promote the balkanisation of
services through out-sourcing. It is symptomatic that, for example, within the now-quasi-commercial organisation, the Terrence Higgins Trust, of which I am deeply proud to be a Founder and Patron, prevention services are organised under Marketing. This is indicative of the challenges facing this sector and of the distance we have to travel in order to put the affected communities first.

8. Using more modern techniques (e.g., social media) does not mean that the techniques are more effective; the use of fashionable methods without understanding the theoretical and determinative issues in achieving and measuring health-outcomes means that such methods are often little more than good PR. The lack of expertise available in scientifically measuring health and health-outcomes in both public health and medicine (i.e., at multiple levels of the problem) is a primary concern. Again, measuring these factors is an area of expertise exclusively within behavioural science and behavioural medicine and input in these areas of expertise are lacking.

9. It should be noted that pharmaceutical companies have “health-outcomes” experts; however, these individuals are almost exclusively economists, measuring cost-outcomes, which are quite different from health-outcomes. The latter refer to how well a person is, how able s/he is to live a healthy life filled with meaningful activities of daily living, not the offsets of financial costs in medical services provided by the use of a commercial product. This confusion is an unfortunate result of PR-initiatives by commercial providers in selling their products to commissioners without adequate input from behavioural and social scientists and without awareness of critical theory in medicine and health. Again, this points to a need for the input of scientists—not just technical researchers.

Testing

1. There are very significant problems in the uptake of testing for HIV-infection. The uneven and less than wholly salutary response to HIV in the 1980s created an approach to HIV that we are still struggling with, primarily with the problem of discrimination on the one hand and the perception that HIV-infection is trivial on the other (vide supra).

2. The “Halve It” initiative is an excellent and notable one with broad support, aiming to reduce the number of people diagnosed with HIV when they have already progressed to AIDS. Again, an emphasis on introducing social and behavioural science into policy and delivery-formulation is necessary in order to deliver the hoped-for outcomes.

3. A synergistic initiative should focus not solely on reducing the number of late diagnoses but on reducing the time between infection and diagnosis in those, particularly, who acquire HIV within the UK. This latter is yet another issue within the purview of behavioural medicine, as it relates to self-managed health and awareness of symptoms and behaviour within the affected.

4. Similarly, programmes promoting testing need to communicate the benefits of diagnosis as early as possible, consonant with the emerging framework of health-effectiveness. However, these benefits need to be more than just the availability of pills.

5. A primary problem lies in getting clinicians to adhere to standards and to change their behaviours within clinical practice. Creating incentives in both public and providers is a behavioural issue and is amenable to expertise held by applied behavioural scientists (e.g.,
organisational health psychologists) and clinicians qualified in behavioural medicine. Thus, interventions need to be targeted to both the public and to providers, to ensure the latter's adherence to testing-guidelines.

6. Criminalisation of HIV-transmission is counter-productive and socially damaging. As with many others in positions of responsibility—politicians, for example—deniability of knowledge is a tool for self-protection; for someone at risk of having HIV infection, this means avoiding testing. Criminalisation may have a role in the response to HIV (vide infra: “Stigma”), but not in reference to HIV-transmission and personal responsibility.

Treatment

1. It is significant that the health of people with HIV is not cited in the call for evidence, only treatment. This may reflect a belief that, as long as a person's viral load is controlled and his/her CD4 count is above a certain level, then that person will be healthy. Relatedly, a prevalent perception that HIV is simple to treat and is even curable: all one has to do is take some pills. Neither is true.

2. A related perception is that people with undetectable viral load and a CD4 count above 400 are therefore fit to work. In tandem with the fact that the Department of Work and Pensions’ process of assessment for Disability Living Allowance is not based on clinical judgement of function but on a legal definition of disability, it is clear that the reality of living with HIV in designing and delivering health-effective services is inadequately considered.

3. These perceptions are grounded in the failure to deliver a balanced and consistent message to the public about the nature of living with HIV and are typical of a physician-centred approach to clinical services. Physician-centred medicine as a service is defined by what physicians do rather than by what people suffering from illness need in order to get and to stay well. “What physicians do” may be characterised by the diagnosis of physical disease and the prescription of pharmaceutical products or surgery for the resolution of that disease. However, corollaries of this definition of medicine are: that only the services that are provided by a physician are actually necessary to create health; if a disease is treated, then the person is necessarily healthy; and, if a physician has provided his services, then either the patient is healthy or the condition is not treatable. There are decades of critical literature on this approach and definition of medicine.

4. The diagnosis and treatment of physical diseases does not necessarily include an inability to assess or treat losses of function that result from those disorders. Losses of function relate to illness in a person, rather than disease in a body and getting people well requires addressing the person, not just their body. Physician-centred services (as provided by both general and specialist clinics) are inadequate to help meet the challenges of living well with chronic conditions in general, due to the pervasive and enduring effects that such conditions have on physical, mental, and social ("biopsychosocial") function and the way in which they interact. Consequently, health-effective services need to reflect the needs of the person in overcoming the consequences of disease, not just the presence of disease.

5. Relatedly, there is a pervasive culture of amateurishness in service-provision: competence in the clinical delivery of both primary and secondary prevention can not be taught on a weekend course attended by clinicians acting outside their area of
professional expertise any more than the competent prescribing of pharmaceuticals for HIV can be taught to hospital porters by their attending weekend courses. The issue of physician-centredness underlying this problem is the same as that underlying health-ineffective medical services generally.

6. HIV as a condition (not just an infection) is managed health-effectively—and therefore cost-effectively—by a comprehensive service-model that includes behavioural medicine, nurse-led clinics, case-management, and integration with social services. Such integrated, biopsychosocial service-models have been shown in American research to deliver highly significant savings in financial costs. It is also noteworthy that this research on cost-savings has been done in the privatised system of American medicine; a partially public system of medicine such as the NHS provides could be expected to deliver even greater cost-savings due to its potential for integration with publicly-owned social services.

7. Prior to the introduction of effective pharmaceutical management of HIV infection in 1996, various low-level versions of a biopsychosocial service-model had emerged and relied heavily on the participation of the affected public in providing services of this type. After 1996, in tandem with the collapse of the gay community’s participation through burn-out, the physician-centred model regained precedence with a consequent loss of many of the medical and public health gains achieved prior to 1996.

8. The problems caused by physician-centred practice has resulted in costly and unnecessary secondary problems such as co-morbidities and excess disability, which have left individuals in desperate situations that have been amplified by their lack of access to adequate community-based services as these latter have become increasingly commercial and balkanised.

9. The balkanisation of services (i.e., where they are neither comprehensive, integrated, nor co-localised geographically or temporally) promotes loss in follow-up and reduced health-effectiveness, and this is amplified by a pervasive lack of case-management.

10. Commercialism has occurred due to the absence of any significant vision or leadership and the loss of valid community representation and participation in service-design and delivery. As with prevention, a commercialist approach has resulted in organisations cherry-picking services that maximise their funding streams without reference to a larger plan for meeting the needs of people with HIV.

11. Providing over-the-counter tests and cost-defined pharmaceutical management has a negative effect on the government’s ability to deliver adequate health-outcomes, especially when it is viewed by providers or the public as a replacement for health-effective medical services.

12. It is expected that the physician-centred model will be promoted by the new GP-based commissioning framework set out in the British Government’s White Paper “Equity and Excellent: Liberating the NHS”. A short critical analysis of these problems in terms of a failure of patient-centred practice and health-effectiveness has been published by the Tuke Institute (Reference 1). Most obviously, the problem of physician-centred practice and its relatively poor health-effectiveness will be promoted.

13. While it is inevitable that some services for HIV will be delivered in primary medical practice (be that physician-centred or biopsychosocial), it is important to consider other
models such as the provision of general medical services within a specialist unit. Scientific research needs to be done on the health-effectiveness of all service-models and should form part of a rational and evidence-based approach to the design and delivery of medical services in HIV. Such models should be developed on the basis of Health-Outcome Delivery-Standards.

14. Health-Outcome Delivery-Standards—i.e., standards of services that are developed in reference to what a person with a chronic condition needs in a clinical service in order to get and stay well—have not been developed to date, only treatment-standards for disease, such as the British HIV Association (BHIVA) Standards and the NHS Quality Improvement Scotland Draft Clinical Standards for HIV Services (References 2 and 3). These are symptomatic of the core problem, reflecting physicians’ perceptions of what people with HIV need and on what physicians deliver, and based on a purely NHS model of what can be done within the current organisational design rather than what needs to be done, and without reference to the reality of living with HIV or to the relevant scientific evidence base in social and behavioural sciences or in social or behavioural medicine. Clearly, more meaningful standards need to be developed.

Cost

1. In a nationalised system of universal medical services, one can not consider cost-effectiveness without reference to health-effectiveness.

2. Cost-assessments must include financial, social, and personal costs of programmes or their absence. Purely financial assessments are no longer credible, even when illness-burden is translated into financial losses to society.

3. Financial costs, most obviously, are driven by behaviours that cause new HIV infections and promote illness, that reduce the effectiveness of pharmaceutical management of infection through inadequate adherence or other behaviours that complicate pharmaceutical management through co-morbid infections, and—most importantly—by a failure to help people with HIV become and/or stay healthy. Costs are of immediate concern due to the rationing of services.

4. A physician-centred model of services is known to be poorly health-effective and also poorly cost-effective. Comprehensive, integrated services reduce the need for medications and increase their efficacy, thereby reducing unnecessary financial and social costs and extending the reach of budgets in providing services to an expanding patient population.

5. In terms of current surveillance practices, it is not possible to judge the adequacy (and therefore cost-effectiveness) of services in public health or medicine using just indices of incidence, prevalence, morbidity, and mortality. All cost-analyses should be based in auditable health-outcomes as part of medical records gathered by a national system of surveillance. Such health-outcomes need to relate to credible clinical measures, not administrative or legal ones.

6. Short-term approaches to funding, framed by the needs of the financial controllers in government at all levels, has been counter-productive in developing long-term solutions. Provider-organisations are therefore reactive, not proactive and solutions are typically based on consumerist models (e.g., patient-choice, market-surveys; customer-service
approaches to complaint-handling), rather than health-effective models (i.e., comprehensive, integrated services). This increases costs by reducing the effectiveness, sustainability, and reach of solutions.

7. A failure to ground services in the needs of people with HIV in reference to an overarching and evidence-informed framework—and to maintain it through participative governance—means that the only way to change service-delivery is to shut down particular services provided by one organisation and start them up again through another organisation. This is burdensome to people with HIV and incurs undue financial and social costs in the long-term. Participative governance is a method to prevent this, if suitably implemented.

8. Research and research-funding is considered separately, below, and is considered separately from surveillance-research.

**Scientific Research**

1. There is a general lack of adequate scientific expertise used in applied research into HIV in the UK. Much clinical research is methodologically low-level and, cost-wise, consists primarily of me-too pharmaceutical trials that translate poorly into health-effectiveness of services.

2. Phase-IV (post-marketing) studies of pharmaceuticals are inadequate and often absent, especially in reference to long-term outcomes. This results in a reduced health-effectiveness of services and, thus, excess financial, social, and personal costs when people become sick from medications. The majority of illness in HIV requiring medical attention is related directly or indirectly to the toxicity of medication, although this is not necessarily the cause of most financial costs.

3. Other research is often akin to market-research and provides results of questionable scientific rather than political value. The exceptions are the methodologically rigorous research by Sigma and, increasingly, research done in partnership by civil and scientific organisations.

4. There is a common perception that a low-level, undergraduate education in a field of science (e.g., physiology) provides an adequate view of the theoretical and methodological issues in translational science and policy-setting. There is a related failure to understand the difference in training and expertise between clinicians, research-clinicians, clinician-scientists, clinical scientists, applied scientists, and basic scientists, with an assumption that they are interchangeable. This allows professional politics to dominate the way in which policy is framed and set; hence the reason why we have bodies informing medical and public health priorities formed primarily by physicians—rather than by qualified scientists and policy-makers assisted by consultative input from clinicians as one among several providers.

5. A review of all the bodies considered to address the needs of people with HIV (BHIVA, CHIVA, NHIVNA, MedFASH, THT, NAM and AIDSmap, EAGA, IAGSHH, etc.) suggests a worrying lack of qualified scientific input, particularly in the social and behavioural sciences. In some—e.g., EAGA—there has been overt resistance to the inclusion of social and behavioural scientists due to the lack of fresh vision and leadership. In most, there is also a lack of input from a balanced sample of clinicians, including nurses,
physicians, psychologists, and social workers. It is worth noting that the National AIDS Trust is an exception to this rule in general due to the way in which it develops ad hoc expert consultation.

6. Such groups represent the perceptions of the constituents and funders—i.e., physician-groups promote physician-centred solutions, nursing-groups promote nursing-centred solutions, etc. Relatedly, the pervasive political need for physicians' buy-in biases the outcomes of policy-setting away from the needs of people with HIV and becomes, once more, about physicians’ needs. This is why the model of clinical services in the UK is not based on current scientific knowledge and may be said to be at least two decades behind leading-edge service-designs in the USA.

7. A comprehensive review of the translation of HIV-research from patient-needs to science and back to patient-needs is necessary to create an adequate blue-print for research that can deliver health to people with HIV and at-risk for HIV. An overview of such a framework for health-research in general, predicated on the delivery of public benefit, has been published by the Tuke Institute (Reference 4) and relates to work done by its Executive Chairman for the National Institute for Health Research in designing a national clinical research infrastructure that delivers public benefit and ensures translation from science to health-outcomes. A similar one needs to be done for HIV. Needless to say, it should be led by qualified scientists not just clinician-researchers.

8. Such a blue-print would allow a more reasonable assessment of the prioritisation of funding into research, and in relation to the quality of research, than is feasible now.

Stigma

1. The burden of stigma (as an experience or a perceptual filter on others) has reduced over time generally, but it is still very high within black African and West Indian communities. The separate burden of the discrimination as an overt act has remained unacceptably high throughout society.

2. The failure to implement appropriate methods to prevent discrimination has meant that criminalisation has been allowed to emerge and cause significant problems. Relatedly, there is a lack of access to justice in instances of discrimination, as it requires being able to pay for legal services in order to uphold the law; when the majority of instances of overt disability discrimination in employment, for example, do not even come to the notice of the legal system and when a typical incident can cost £30,000 in legal fees, it is reasonable to say that the current protection against disability discrimination is tokenistic at best.

3. Similarly, the lack of a coherent and credible policy on the immigration of people who have or may have HIV is counter-productive to national efforts to address the problem of HIV. This requires political leadership informed by vision within the communities affected.

4. The majority of stigmatisation experienced by most people with HIV currently continues to be within medical services; for instance, long-term survivors who have a history of participation dating from pre-1996 are called pejoratively “professional patients” by physicians while efforts by affected communities to create patient-advisory boards have met with significant resistance by clinical providers. This has fed into the problem of
5. Discrimination against people with HIV cannot be separated from discrimination based on related social issues, such as ethnicity, sexual orientation, or indeed other unrelated medical conditions. For example, in the Kobler clinic in London, gay and lesbian patients seeking assisted conception services to raise a family have been told to go abroad “where they don't care so much about child-welfare”; only heterosexuals are allowed access to assisted-conception services. There is no significant recourse in these instances and they form part of a larger and pervasive problem of the blaming of patients for shortcomings within providers and of overt discrimination.

6. Blaming ‘others’ and dis-identifying with people who have HIV is a primary causative problem in stigma and discrimination; initiatives promoting the criminalisation of HIV-transmission have amplified this. Marketing-based health- and welfare-promotion is unable to address this and a new framework is needed.

Participation and Representation

1. Any review of the state of the response to HIV in the UK needs to emphasise the need for both participation by and representation of the affected part of society. British governmental initiatives have slowly moved towards participatory values, although participatory democracy has a history of over half a century. The value and methods of such participation has also developed significantly over this period and new frameworks—such as the Big Society—represent efforts to expand its reach. While public participation in the formulation and delivery of civil services has struggled most in the areas of medicine and medical research, it has an essential function in creating meaningful and useful services to the public.

2. Public participation lies in three distinct but linked domains: participation in clinical and scientific practice; participation in the review of such services, including in their audit and governance; and participation in commissioning and policy, right up to the national level. A thorough review of this and its role in delivering health-effective medical services has been published by the Tuke Institute along with a briefing on the role of public participation in science (References 5 and 6).

3. There is no credible participation in the audit and governance of any clinical HIV services. This is generally true also of educational, research-, and outreach-services too, although rare instances may exist.

4. As noted above, most of the bodies considered to address the needs of people with HIV (BHIVA, CHIVA, NHIVNA, MedFASH, THT, NAM and AIDSmap, EAGA, IAGSHH, etc.) do not receive input that is actually representative of the needs of people with HIV. Despite the positioning of some highly knowledgeable and experienced advocates on various boards, it is not possible to ensure that these bodies represent the needs of people with HIV due to the lack of comprehensive medical and scientific input as to what those needs are. Furthermore, many such advocates labour against tokenism, especially in clinician-dominated groups, due to problems of stigmatisation and discrimination (see above).

5. The move towards quasi-commercial service-provision by non-profit sector bodies has resulted in a lack of access by people with HIV, a consequent lack of representativeness,
a lack of responsiveness to their needs, and services no longer being driven by those needs but purely by funding priorities—priorities that are set in the first place by organisations with non-representative involvement in funding bodies.

6. As a consequence of these factors, there has been a significant move towards quasi-commercialisation and balkanisation of services within a franchise-model, a lack of integration of service-delivery across the sectors, a lack of collaboration, and competitive monopolisation of funding-streams by providers rather than a broader civil capacity-development and skills-transfer across a variety of organisations. This means that the geographical location and type of services available are constantly changing and can shift dramatically in the face of funding-losses to the leading organisation providing a particular service. This causes excess burden on people already living with a burdensome illness and can result in the failure to access necessary services for long-term health, which is financially and socially costly. Appropriate methods of public participation can prevent these problems from occurring.

**Systemic solutions**

It is unhelpful to identify isolated solutions (as above) without reference also to larger, systemically effective solutions; individual solutions are inadequate because no problem exists in a vacuum. Systemic solutions include the following:

1. The development of an organisation that can represent the interests of people with HIV in terms of medical (including social) and scientific services delivered on behalf of people with HIV to people with HIV. Such an organisation would have three themes:

   1.1 a civil capacity-development theme, that develops a representative and advocacy-oriented body for all people with HIV and provides scientifically sound (not market-survey) evidence to inform policy in medicine and public health. The Tuke Institute has developed a model for this.

   1.2 a medical theme that provides a balanced representation of services focusing on health-outcomes; this would mean scientists and policy-experts working in consultation with primarily nurses, physicians, psychologists, and social workers equally who have expertise in providing services in the clinic and in the community to the young, adult, and elderly. Providers with HIV themselves have a special role in such an organisation as they bridge the experience of being a patient and being a provider (be that a scientist or a clinician). Here, it is worth noting that ‘science’ is used in its original, continental sense that includes all the human sciences, not just the biological, behavioural, or social sciences.

   1.3 a civil health theme that focuses on developing common and targeted interventions in public health, civil policy (e.g., on immigration), and consists of scientists, educators, media-professionals, lawyers, etc.

   1.4 This organisation would be built on thorough participation by the HIV-positive public and be governed participatively by HIV-positive advocates with expertise in HIV-related scientific, medical, or civil health themes.

2. This organisation would replace the stated need for professional advocacy bodies such as BHIVA, CHIVA, NHIVA, etc., and for advisory bodies such as EAGA, etc.
service-providers or independent policy-organisations. The remit for such a task, with sufficient funding, could feasibly be given to the National AIDS Trust as the only independent organisation with evident expertise in policy in tandem with a comprehensive approach. Its primary products would include:

2.1 Health-Outcome Standards for medical services to people with HIV, including those relating to disability and its assessment; the purpose of this would be to frame medical services in terms of what people need to get and/or stay well with HIV and would be informed by international evidence.

2.2 Standards, methods, and policy for public participation in medical and scientific HIV services, including in audit and governance so as to ensure the continuing relevance and adaptiveness of putatively representative organisations.

2.3 Standards, methods, and policy for the design and delivery of medical services in reference to §2.2

2.4 Standards, methods, and policy for the design and delivery of public health services in reference to §2.2 and §2.3; this would include sizing public health programmes according to need.

2.5 Standards, methods, and policy for the design and delivery of scientific services in reference to §2.2, §2.3, and §2.4, delivering a blue-print for translational scientific research and ensuring that both advocacy and policy are based on adequate reasoning and evidence.

2.6 Standards, methods, and policy for civil capacity-development among community-based organisations, including service-providers of various sorts; this would include a review of the value and design of service-delivery organisations in the civil sector and might recommend, for example, the separation of service-providers from advocacy functions in needs-assessment and priority-setting, due to conflict of interest.

2.7 Governmental policies, such as a credible, balanced, and humane immigration policy in order to enhance prevention and testing up-take; policy on the role, if any, of criminalisation in HIV—e.g., in disability-discrimination—ensuring the government takes responsibility for addressing discrimination by moving it, for example, from the category of a luxury-law (i.e., for those who can afford civil litigation) to a criminal one in certain or all instances; etc.

2.8 A 10-year strategic plan for a coherent national response to HIV, drawing together all these strands.

3. In the absence of the development of such an organisation, the following should be developed independently as a priority:

3.1 Health-Outcome Delivery-Standards

3.2 policy on the design and delivery of health-effective medical services

3.3 a blue-print for translational scientific research in HIV, in reference to the Health-
Outcome Delivery-Standards

3.4 a large-scale surveillance system of health-outcomes in HIV, in order to assess illness-burden and inform policy-setting and funding. The metrics need to be based in measures that are used clinically, which requires a shift in the model of delivery of clinical services as physician-centred practice is unable to provide this.

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February 2011
Letter from the UK Border Agency (HAUK 96)

Medical Testing for Infectious or Communicable Diseases

I welcome the opportunity to assist the House of Lords Select Committee on HIV and AIDS in the UK. You raised three questions with the UK Border Agency on migrant health screening.

1. Are there any mandatory testing or screening policies for any communicable or infectious disease for those entering or re-entering the UK and, if so, how do such policies operate?

All persons subject to immigration control seeking entry or entry clearance (visas) to the UK are liable to medical examination at the discretion of an Immigration or Entry Clearance Officer (rules 36 to 39 of the Immigration Rules). A medical examination may be commissioned where a person is clearly unwell, has mentioned ill health as a reason for their journey, are travelling here for medical treatment, or where screening is required as a matter of policy. The Agency’s officers may refer such cases to medical officers to allow for consideration as to whether the applicant suffers a condition that may pose a public health risk, or in other instances, for advice as to whether the applicant’s condition suggests that they may be unable to maintain or accommodate themselves whilst in the UK.

The UK Border Agency conducts mandatory pre-entry screening for TB for visa applicants wishing to come to the UK for more than 6 months across 15 high incidence Tuberculosis (TB) countries. This is delivered through the International Organization for Migration (IOM) and is part of a large scale pilot assessing the efficacy of TB screening. Persons who wish to travel to the UK for over six months from these countries are required to present a certificate from the IOM confirming that they have successfully completed this screening, which is conducted using a combination of x-rays, sputum and culture tests, when making a formal application for a visa. The UK Border Agency is presently reviewing the arrangements for screening visa applicants and arriving passengers for TB.

In terms of arriving persons, a medical examination may be conducted by a Port Medical Inspector (PMI, who is appointed by the Health Protection Agency). Passengers arriving into Heathrow and Gatwick airports from a country with a high incidence of TB (an incidence rate of 40 cases or more per 100,000 population) and intending a stay for over six months may be referred for screening by x-ray conducted by the PMI. In other ports, data on passengers arriving from high incidence TB countries is collected and shared with the local health authorities. NICE guidelines advise healthcare professionals to consider screening in the community for TB using data from ports of entry, new GP registrations and from data provided by educational establishments. Where there are public health concerns, the Immigration Officer can, at the PMI’s discretion, serve notice requiring the passenger to report to the local NHS for further assessment or treatment.

Recognised refugees resettled to the UK through the Gateway Protection Programme, through referral from the United Nations High Commission for Refugees, are also required to undergo comprehensive health screening before they can travel to the UK so their needs can be fully assessed before resettlement. This screening includes chest x-ray screening for

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212 Bangladesh, Cambodia, Ghana (which also takes applications from Burkina Faso, Cote d’Ivoire, Togo and Niger), Kenya (which also take applications from residents of Eritrea and Somalia), Pakistan, Sudan, Tanzania, and Thailand (which also takes applications from Laos).
TB for those over 11 and HIV tests (including pre- and post-test counselling) for those aged 15 years and over. Other than the Gateway Protection Programme, the UK Border Agency does not screen migrants for HIV. The UNAIDS position (which the UK Government supports) is that HIV related travel restrictions have no public health justification and restrictions based on its presence alone considered discriminatory.

2. What is the consequence of a positive diagnosis in any such testing or screening programme for communicable or infectious disease, for example, does it impact on a person’s entitlement to enter or remain in the country and what follow-up arrangements result, such as access to NHS treatment and care services?

Persons who are found to be suffering from a disease that may create a public health risk, such as those screened abroad for TB, are advised to seek medical treatment. Save in exceptional circumstances, an application to travel to the UK would be refused until it is considered safe for the individual to travel and safe for those whom they may come into contact with. Where active pulmonary TB is detected in a visa applicant abroad, the visa will not be issued. The applicant may return for further screening having completed treatment. As they will not have made a formal visa application at that stage, they will not have been refused entry clearance. IOM data suggests that over 90% of those they have detected with active TB have subsequently returned for re-screening after treatment, indicating they still intend to apply for a visa.

Those arriving into the UK at Heathrow and Gatwick and suspected of suffering active pulmonary TB may, on the advice of the PMI, be granted temporary admission, and the local health authority alerted to undertake follow up assessments and treatment or the person hospitalised immediately. A refusal on public health grounds will only follow where the PMI considers that there is a significant risk to public health. Removal in these cases could only follow competent medical advice that it is safe for the individual to travel having received required treatment, any risks to others have been managed and removal would not contravene the International Health Regulations 2005. The same procedures (on or pre-entry) would apply in relation to other infectious or communicable diseases where, in the opinion of a competent health or medical authority, there is a risk to public health.

Resettlement under the Gateway Protection Programme should be not offered when, in the opinion of the medical examiner, the individual has a disease or illness, which, for the individual’s own health, or for public health reasons, currently precludes travel, or requires treatment before travel. However, resettlement may be offered to such individuals once, in the opinion of the medical examiner, this ceases to be the case. Under the Gateway programme, the UK has the discretion to refuse resettlement on a range of grounds including disproportionate cost, resettlement need, and whether the individual poses a danger to public health. All decisions to accept or refuse a refugee for resettlement to the UK, where they may pose a risk to public health or a disproportionate cost to the programme, must be referred to Ministers. No one identified with HIV/AIDS has been rejected from the Gateway programme. In conjunction with local authorities and Primary Care Trusts, refugees resettled in the UK are provided with accommodation and registered with a general practitioner ahead of their arrival in the UK. The UK’s immigration related screening programmes do not directly effect the screened individual’s entitlements to NHS and care arrangements.
3. Are there any voluntary or mandatory arrangements which target for testing those screened on entry or re-entry to the UK subsequent to their passing through the border?

There are no powers in immigration legislation to require persons who have permission to be in the UK and who have already entered the country to undergo health screening or testing, but there are services available to immigration detainees and asylum applicants supported by the UK Border Agency. At Immigration Removal Centres, arrangements are in place to ensure that new arrivals have a medical screening within 2 hours of admission, with a follow-up appointment with a doctor within 24 hours, if appropriate. These assessments are made to establish any immediate health needs and will include identifying the potential presence of infectious or communicable disease. Where healthcare needs are identified, arrangements are in place to ensure that all are able to access specialist care, including TB screening.

All new asylum seekers who need full accommodation and funding support from the UK Border Agency are offered a health assessment including TB screening, which almost all accept, while they spend three to four weeks in UK Border Agency provided initial accommodation. This happens in the early stages of their asylum application, prior to dispersal into other accommodation within the community. The health assessments, which are funded by the Department of Health and have been established since 2002, aim to identify and address immediate healthcare needs, recognise on-going issues, and, where necessary, refer for treatment including those relating to infectious or communicable diseases.

I hope the committee finds this information helpful.

May 2011
The Wellcome Trust is a global charitable foundation dedicated to achieving extraordinary improvements in human and animal health. We support the brightest minds in biomedical research and the medical humanities. Our breadth of support includes public engagement, education and the application of research to improve health. We are independent of both political and commercial interests.

As one of the largest HIV/AIDS philanthropic funders based in Europe, spending approximately £26.3 million on HIV/AIDS research both nationally and internationally, the Wellcome Trust is pleased to respond to this call for evidence by the House of Lord’s Select Committee on HIV and AIDS. In developing this response we have consulted experts in the field and are grateful for the inputs received from our funded researchers. Given the Trust’s remit, our comments will focus on areas where research may be utilised to strengthen the control of HIV and AIDS. While our response focuses on the UK, HIV/AIDS does not respect national borders and the impact of what is occurring internationally must be considered by the committee.

1. Monitoring of HIV and AIDS in the UK provides important information for conducting public health research. While HIV monitoring across Europe is generally poor, the UK’s system is an exception. It is comprehensive and largely focused on those most likely to be exposed to HIV. We support the continued use of behavioural and biological surveillance among high-risk groups such as men who have sex with men and communities of people from HIV-endemic countries. We believe that work in this area should be increased, for example by introducing surveillance in prisons, and that better methods for measuring HIV incidence should be developed to assess the population impact of public health interventions.

2. Regarding the proposed health reforms, we are concerned about how the new arrangements for commissioning of sexual health services and HIV will impact a) the cohesion of the existing national network of Genito-Urinary Medicine/HIV services, and b) the maintenance of ability to provide robust surveillance and outcome monitoring.

3. We are pleased that despite the dissolution of the Health Protection Agency (HPA), health protection features prominently in the proposed health reforms. Our main concern is how the transfer of health protection functions into the Department of Health will impact the dissemination of data. While surveillance should be carried out on a national level, information on local populations will need to be made available to local authorities in a timely manner. There is concern in the community that the integration of the HPA into the Department of Health will result in the loss of its independent advisory functions.

4. Interventions introduced to increase testing and early detection of the virus need to be based on evidence of their efficacy. Several methods to increase testing have been proposed, including the introduction of home testing, contact tracing, partner notification and opt-out HIV testing for people with indications of high likelihood of exposure (including people with other sexually transmitted diseases, those with TB, those recently admitted to gaol or drug treatment, and people who belong to high risk groups). Further research needs to be conducted into the efficacy of behavioural
and biological interventions and how best they can be implemented, specifically in terms of different risk groups.

5. It is important that research is context specific, as methods for increasing testing may not be suitable for all risk groups. For example, targeted prevention efforts for high-risk groups are often difficult due to discrimination and stigmatisation. Alternative methods for increasing testing among high risk groups such as geographically targeted universal testing may provide an excellent pathway for reaching risk groups without discrimination, and should be further investigated. Specifically, targeted testing of African and Caribbean-born heterosexuals is difficult because stigma is often acute among people from HIV-endemic countries.

6. A large-scale trial is currently being planned in South Africa at the Wellcome Trust funded African Centre for Health and Population Studies on ‘treatment as prevention’ of HIV. The trial is based on evidence that the early use of antiretroviral drugs (ARV’s) may decrease transmission of HIV. While the current guidelines in the UK advise placing a patient on ARV at a CD4 count <350 cells/mm³ the trial is placing all HIV infected patients within a specific population on ARV immediately, regardless of their CD4 count, and monitoring transmission across the population. Since the epidemiology of HIV in the UK is different from South Africa, we suggest that a similar trial be considered to determine if earlier treatment is an effective form of prevention in the UK.

7. Efforts must also be placed on improving inadequate behavioural change messages. The balance between the warning approach (HIV as a something you want to avoid getting) and the anti-stigma approach (HIV as something you can contract and continue to live a normal life) is a difficult one, and we suggest further research be conducted on how best to achieve this.

We would be happy to elaborate on any of these comments and look forward to the report that will be published this summer.

18 February 2011

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Letter from Dr Chris Wood MRCP, Consultant HIV Physician, North Middlesex University Hospital (HAUK 44)

Thank you for this opportunity to provide input into this process. I have been an HIV specialist for over 20 years and work in a socially deprived area of north London with a high HIV prevalence. I have only provided a few comments and these are by no means comprehensive. I am gravely concerned about the future of the NHS and HIV care is an area that requires a strong and robust integrated NHS and social care and voluntary sector provision as it is still a very dangerous condition if undiagnosed and not treated correctly. Many HIV+ve patients in the UK are very disadvantaged and vulnerable, and HIV is still heavily stigmatised in many communities, and to a lesser extent in society at large. With correct care and support the outlook for HIV+ve individuals can now be excellent in many cases. With inadequate care and support it is still a devastating, disabling and fatal disease, even in the UK in 2011. There is much work to be done and the current climate of re-organisations and cuts in the NHS, Local Authority care, benefits provision and the Welfare state and the voluntary sector are providing a ‘Perfect Storm’ of threats and disruption to HIV care as optimal HIV care and prevention it relies on the integrity and co-operative working of all of these entities.

I/ Monitoring of the HIV Epidemic in the UK:

I believe that it is imperative that the Health Protection Agency (HPA) remains independent, properly resourced and staffed and that it is not sub-sumed into a government department. It has been classed as a ‘Quango’ and as such I believe its role is to be brought into the Department of Health. The HIV Sector relies very heavily on the HPA for much of the national HIV data without which monitoring, prevention, evaluation of treatment, etc etc would all be much impaired.

In addition, I strongly believe that the future of the ‘The National Study of HIV in Pregnancy and Childhood’ (NSHPC) http://www.nshpc.ucl.ac.uk/, which is based at the University College London Institute for Child Health, needs be ensured. This project is co-ordinated by Dr Pat Tookey and has provided Internationally respected data for many years and has been an integral part of helping to develop and maintain standards in the diagnosis and management of HIV+ve pregnant women and their children in the UK, as well as HIV+ve children themselves. I know their funding is under severe threat but they have been an invaluable source of information, research and data on antenatal and paediatric care in the UK. The quality of their work is of international importance and they have been a major drive in maintaining and driving up quality standards for both antenatal and paediatric care and as such their funding needs to be secure.

Treatment:

HIV Care should continue to be provided by specialist HIV units. I believe that it is very important, for the foreseeable future, that the majority of outpatient HIV care is provided from specialist HIV units and that this should remain the default position for now. I think that this should be the paradigm for at least the next five years. Units such as ours at the North Middlesex University Hospital (NMUH) NHS Trust have many patients with multiple ongoing medical and psychosocial needs and these are most efficiently met by providing services in the setting of a ‘one stop shop’ where we can get multiple specialties at
the same site including medical, dietitian, pharmacy, liaison nurse, peer support workers, citizen advice bureau, housing and other social services workers, etc. This is much more efficient than having to move the team around. Our own experience at the NMUH of trying to set up satellite clinics, in our setting where we have very few spare staff sessions and very few juniors to cover senior colleagues to work off site, is proving very difficult.

There are some centres and some patient groups where providing care close to homes when GP services may well be feasible but I think it as a general rule across the country, where most care is provided in non teaching hospital settings, that moving any substantial proportion of HIV care out of specialist centres is not currently viable and would be counterproductive. There are some areas where this model may work depending on patient complexity and demographics, staffing levels and the HIV experience of GP practices but I am sure they will be the exception. I also believe that there is a danger that this policy could be driven by several very atypical units placed in the centre of London with very good GP supporting practices in the areas. However, I believe, that these settings are not typical of the UK as a whole and to model service development on a few exceptional cases would be to put many other clinics and indeed patients at a disadvantage where a GP and community services are just not ready to deal with the change in patient flow.

**HIV should clearly be an area of maintained specialist commissioning** and the London HIV Consortium I think is a very good model. It is clear from my own experience of my patients and other patients generally that they are still very frequent problems for many patients with general practice including an increasing loss of continuity of care that patients receive from general practice and this is a common cause of dissatisfaction of patients talking about their GPs.

**Treatment** The drastic reductions in hospital budgets and need to generate efficiency savings are putting pressure on Anti-retroviral prescribing. Increasingly guidelines are being developed at local and national level, that are based on cost rather than cost-effectiveness or patient experience. There is pressure to return to more cumbersome regimens, involving more tablets taken multiple times per day. The UK is in danger of becoming subject to postcode HIV prescribing of newer safer, but perhaps more expensive, antiretroviral agents, depending on the local circumstances. The UK is also likely to continue using older more cumbersome anti-retroviral regimens with more side effects, whereas most other developed nations are moving to some of the newer, more convenient, better tolerated, less toxic drugs (which unfortunately cost more!)

**Cost:**

Spending Cuts in NHS reorganisations impact on HIV care in a number of ways. It is clear from local discussions in Haringey and Enfield that local authority cuts and health cuts are going to drastically affect the provision of voluntary sector support services including community groups and other areas of voluntary sectors and peer support sectors for which many patients of ours rely heavily. I am sure this will be replicated everywhere. In addition services such as social services, community nursing and the Citizens Advice Bureau, all appear to be moving away from providing dedicated HIV services and moving all the specialist care into the general pool of generic work. This invariably leads to loss and dilution of local HIV expertise and advocacy, thereby reducing the level of services to patients, and
increasing difficulty in accessing specialist HIV knowledge in these various community based services.  

Funding cuts affecting HIV care and prevention include: health cuts, local authority cuts, and reduced funding in the charity sector. As increasing pressure is felt by social services or community nursing and provision of other community services such as dietetic, physiotherapy

I am not sure what the situation is with the AIDS Support Grant but I understand that it still exists but is now mainstreamed and not ‘ring-fenced. In the absence of ring-fencing there is a real danger that a lot of the specialist knowledge and provision will be swallowed up in the general scrabble to provide general and generic services and this could have a major impact on patient clinical outcomes and experience.

Certainly in my experience many of our patients need a lot of support and advocacy and it is getting harder and harder for them to access this. Also services designed to help get people back into work such as Living Well and other initiatives are gradually being cut so it is likely to be harder for people living with HIV who are reasonably well to get back to work or to do retaining and so on.

**General impact of NHS changes** The ensuing chaos and uncertainty of the NHS re-configurations and changes will be detrimental to providing high quality medical and social care for HIV+ve patients. Prevention efforts will also be seriously affected. The changes will affect the continuity of medical care and planning of medical care as we all work hard to respond to the changes in NHS funding and organisation. This takes up an inordinate amount of time for senior clinicians and managers and will do so for years to come. At the same time HIV cohorts are increasing inexorably 9a good thing!) but with reducing resources rather than expanding resources. HIV treatment and prevention in the UK relies heavily on the voluntary sector for advocacy and peer support. The current re-organisations and reduced funding due to the spending cuts will devastate this sector with severe consequences for patient care and quality of life.

The speed of the NHS and Local Authority Social Care re-organisations and funding cuts are making it very difficult to provide ongoing and future HIV care at the level to which it has been. Even before this’ Re-organisation and Funding’ crisis there were major problems in the UK approach to HIV prevention and Care provision. The speed and recklessness of the current multiple changes are making it much harder to deal with these pre-existing problems including HIV testing, retention in care, social care provision, and stigma. For example, 25-30% of HIV+ve people in the UK are currently unaware of their HIV infection.

In addition, the rapid and severe changes in welfare funding, including the Employment Support Allowance, disability and housing benefits, are causing much confusion and distress to many patients. Levels of destitution among HIV+ve patients are already noticeably greater now than it was a few months ago.

I would be happy to provide further information if required.

18 February 2011