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

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**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. Couldanythingbedonetoimprovemonitoring?**

* 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?**

**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.

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.

**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.4 **One in seven gay men on the London gay scene has HIV, compared with one in 14 nationally5**

**2. Prevention
a. IsGovernmentpolicysufficientlyfocusedonHIVprevention?**

* 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.6
* 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. Towhatextenthavepreventioninitiativestargetedatinjectingdrug 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.

4 Health Protection Agency, 2010 http://www.hpa.org.uk/web/HPAwebFile/HPAweb\_C/1237970242135. 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:

http://www.thisisleicestershire.co.uk/news/Mother-s-HIV-fear-pricked-dumped- needle/article-3562650-detail/article. html

* 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. Arecurrenttestingpoliciesadequateacrossthecountry?**

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

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

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

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

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

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

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

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

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

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

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

• 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. WhatimpactdoesstigmatisationofthosewithHIVhaveonthose 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. 7 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

7 Dodds C, Keogh P, Chime O, Haruperi T, Nabulya B, Ssanyu-Sseruma W et al. Outsider Status: Stigma and discrimination experience by Gay men and African people with HIV. 2004. London, Sigma Research.
8 What do you need? 2007-2008, Findings from a national survey of people with diagnosed HIV, Sigma Research.

**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”9*

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

9 Doyal L, Anderson J, Apenteng P. “I want to survive, I want to win, I want tomorrow” An exploratory study of African men living with HIV in London. 2005. Homerton University Hospital, Queen Mary University of London, African HIV Policy Network, Terrence Higgins Trust. p20.

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