



UPDATING OUR STRATEGIES

**REPORT OF AN EXPERT SEMINAR ON HIV TESTING AND
PREVENTION 22 MARCH 2007**

9 July 2007

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Report of an expert seminar on HIV testing and prevention

1. INTRODUCTION

Deborah Jack, Chief Executive, National AIDS Trust

One of the most important milestones in the response in England to the HIV epidemic was the publication in 2001 of the National Strategy on Sexual Health and HIV, 'Better prevention, better services, better sexual health'.¹ That document, the result of extensive consultation with the sector and affected communities, has resulted in significant advances in an effective national response to HIV, many of which are identified in this report. But any strategy must from time to time be examined both to acknowledge achievements and also to see what still has to be done, and to adjust actions to changing circumstances. The Sexual Health and HIV Strategy is no exception. Six years after its publication, and with many of the timelines of the Strategy targets about to come to an end, the National AIDS Trust considered it time to facilitate discussion within the HIV sector of how the Strategy can be updated and refreshed for the next five years or so.

The Strategy covers a number of areas, prevention, testing, treatment and care, stigma and discrimination, and of course it is not exclusively concerned with HIV – it is a broader sexual health strategy also. In focussing on HIV we are not of course implying that wider sexual health issues should not also be looked at freshly. But NAT's remit is HIV-specific and we believe that recently there has been a loss of focus on HIV-specific concerns within the wider sexual health agenda. For that reason, in bringing sector representatives together at a seminar on 22 March 2007 to discuss 'Updating our Strategies', we decided to focus on HIV alone.

The Strategy covers only England and we therefore decided to limit discussion to England for the purposes of the seminar, though often UK statistics were used to make relevant and more general points. There will nevertheless be many issues arising from the seminar which will be relevant to the other nations of the UK and which we will pursue with our relevant partners.

Furthermore, even in relation to HIV the Strategy covered too many issues to address adequately in a one-day seminar. We therefore agreed to look at two issues in depth – HIV testing and HIV prevention. There may well be opportunity in the near future for NAT or another organisation to organise a similar meeting on other aspects of the Strategy. It could even be argued that there is significantly more to say around both testing and prevention than what we could cover in our one-day event. But the presentations and discussions of our seminar did raise a number of clear issues, conclusions and possible recommendations which I believe must form the basis of concerted future action.

We were pleased and grateful to have the support and cooperation of both the Health Protection Agency (HPA) and the Terrence Higgins Trust (THT) in our planning and delivery of this seminar. As respectively our public health agency and our largest voluntary sector HIV service organisation, the HPA and THT are uniquely placed to provide insights into the current state of the HIV epidemic in England. We were particularly grateful to Dr Valerie Delpech from the HIV and STI Department of the

¹ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003133

HPA and Paul Ward, Deputy Chief Executive of THT, for their presentations on the day and their contributions to discussions. The organisation of this expert seminar and the work on both preparatory material and outputs undertaken by the National AIDS Trust were made possible as a result of the generous support of Pfizer Ltd

A full list of those attending the seminar can be found as an Annex to this report. I would like to thank them all for their active and thoughtful contributions, which made the day such a great success.

What has changed since 2001?

The Strategy was published in 2001 but much of the discussion and drafting for the document would have taken place in the previous year. Since 2000 the HIV epidemic in England has changed significantly. In particular we should note:

- The unanticipated and significant increase in heterosexual diagnoses from people infected overseas, mainly in sub-Saharan Africa
- The substantial increase in risk-taking behaviour amongst men who have sex with men between the late 1990s and 2005
- The resulting increase in HIV prevalence – the Strategy estimated 30,000 living with HIV in the UK – there are now over 70,000

Such changes raise many challenges in terms of funding HIV prevention and testing, as well as adapting strategies to new communities with very different needs (faith issues, immigration issues, different forms of stigma and discrimination, for example).

The policy context has also changed considerably, much of it for the good. New protections against discrimination have been introduced by the Disability Discrimination Act 2005, and a Single Equality Act is promised. On the other hand, criminal prosecutions for reckless HIV transmission raise new challenges for prevention and testing messages and practice.

The Government's thinking on health provision has evolved through a number of key documents including '*Shifting the Balance of Power*', '*Choosing Health*', '*Our health, our care, our say*' and '*Commissioning for health and well-being*'. The emphasis is on maintaining and promoting health rather than solely tackling illness, and on providing what patients and local communities want how, where and when they want it, rather than imposing a single unresponsive model of healthcare provision.

There have also been developments in the HIV tests available, in particular the development of the rapid HIV test which significantly extends the flexibilities possible in HIV testing provision.

All these developments have been accompanied by continuous change also within the NHS itself. There has been restructuring (more than once!) with the arrival of Strategic Health Authorities and Primary Care Trusts; the establishment of the Healthcare Commission; the end of ring-fenced funding and the experience of funds available for sexual health being pressurised and in some cases lost; and a move away from national targets as a way of incentivising appropriate healthcare provision.

All these changes bear on the testing and prevention issues which formed the focus of the 'Updating Our Strategies' seminar. We did not wish at this stage to debate what form or process any 'updating' of the National Strategy should take. We felt it

more important to identify what have been our successes, areas where we might do better, and what our shared goals and ambitions should be going forward.

The international HIV testing context

Mention must also be made of two publications internationally which will have a big influence on the testing debate – one had already been published at the time of our seminar, the US Centre for Disease Control and Prevention (CDC) 'Revised Recommendations for HIV Testing of Adults, Adolescents and Pregnant Women in Health-Care Settings'² (Sept 2006) – the other has been published since our seminar but must be noted as we publish our report, the WHO 'Guidance on provider-initiated testing and counselling in health facilities'³ (May 2007). This is not the place to summarise both of these important documents in any detail. The CDC recommendation was for routine opt-out HIV testing in all healthcare settings (where HIV prevalence is 0.1% or above).

The WHO, having to make recommendations which were internationally applicable, has proposed different approaches depending on the nature of the epidemic (low-level epidemic, concentrated epidemic and generalised epidemic). The offer of the HIV test is recommended for all epidemics where people 'present in clinical settings with signs and symptoms or medical conditions that could indicate HIV infection'. Routine opt-out screening is additionally recommended in all healthcare settings only for generalised epidemics – for countries such as England with a low-level/concentrated epidemic, the recommendation is for routine opt-out HIV screening to be implemented in a more limited range of settings such as STI services, services for most-at-risk populations, antenatal, childbirth and postpartum health services, and TB services.

As we continue our discussions on how to develop a fresh HIV testing strategy in England, we will need to consider explicitly these proposals and our response.

This report contains introductory comments from speakers at the event, notes of the discussions which took place in the two breakout sessions (there was one on testing in the morning and another on prevention in the afternoon), and also summaries of key conclusions and emerging recommendations. The powerpoint slides of the three speakers are also available as a separate document on the NAT website.

The conclusions and recommendations are NAT's alone. It should not be assumed that they necessarily reflect the opinions of all participants or participants' organisations.

² <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm>

³ http://www.who.int/hiv/who_pitc_guidelines.pdf

2. TESTING STRATEGIES

2.1 *Updating testing strategies*

Yusef Azad, Director of Policy and Campaigns, National AIDS Trust

The issue of HIV testing is one which both demonstrates the value of the National Strategy for Sexual Health and HIV over the last few years, but also the need now, as its timelines come to an end, to think freshly on where we go from here and how we build further on past success.

Testing targets from the current National Strategy have included one on ante-natal screening, and one on offer and uptake of HIV test in GU settings. With regard to ante-natal screening it is hard to assess directly offer and uptake since these data are not centrally collected (and this difficulty of having targets which we cannot measure is found elsewhere in the Strategy) but 95% of HIV positive women in 2005 were diagnosed before delivery which is an effective proxy marker. There should of course be renewed effort to reach the undiagnosed 5% - but this success shows how effective in the right setting opt-out screening can be.

HIV testing targets from the National Strategy

- ⌘ In 2000 introduction of antenatal HIV screening with aim of a 90% uptake and an 80% reduction in the number of children with HIV acquired from their mother by the end of 2002 [4.53, 4.75]
- ⌘ By the end of 2004 all GUM clinic attendees should be offered an HIV test on their first screening for sexually transmitted infections (and subsequently according to risk) [4.77]
- ⌘ By the end of 2004 increase the test uptake by those offered it to 40%; and to 60% by the end of 2007 [4.77]
- ⌘ Reducing by 50% the number of previously undiagnosed HIV infected people attending GUM clinics who remain unaware of their infection after their visit by the end of 2007 [4.77]

There has been similar success in GU clinics with a significant increase in the number of HIV tests offered and in the percentage accepting the test. The target of reducing by 50% the proportion⁴ of previously undiagnosed HIV infected people attending GUM clinics who remain unaware of their infection after their visit by the end of 2007 seems to be reachable for heterosexuals [48% in 2001 to 27% in 2005] but more of a challenge for MSM [55% in 2001 to 43% in 2005].

What is clear is that there continues to be considerable unmet testing need with one in three unaware of their HIV infection. 34% of those diagnosed with HIV were diagnosed late in 2005⁵ and 11% with AIDS. We have also failed to make much

⁴ The target in the Strategy refers to the 'number' of previously undiagnosed being reduced but we assume 'proportion' was meant as a more meaningful measure of the effectiveness of the offer of the HIV test within GU settings.

⁵ Defined by the HPA as diagnosed with a CD4 cell count below 200 cells/mm³

further headway since the late 1990s in reducing the number of AIDS-related deaths. Not only is there an obvious benefit for those tested in being diagnosed earlier rather than later. It is also claimed by recent modelling from the States, cited by CDC in their recommendation for routine opt-out testing for HIV in US healthcare settings, that the undiagnosed are disproportionately responsible for onward HIV transmission (in the US the 25% undiagnosed are estimated to be responsible for 54% of infections).

More consideration is needed of MSM presenting with STIs in GU who do not test for HIV and how to encourage test take-up. There should also be discussion of how making rapid testing consistently available in GU would affect HIV test take-up, and how tests are currently offered. Is it still mainly an opt-in offer process or is there any growth in what is effectively an opt-out screen which includes HIV?

What is striking is how much of HIV testing still takes place in the very particular specialties of the GU clinic and in ante-natal care. Surely it is time to roll-out HIV testing far more widely if we are to reduce levels of undiagnosed HIV infection? There is well-researched evidence of continuing failure to test, despite recommended guidance, in other relevant secondary care specialties such as TB clinics. More should be done to ensure the offer of an HIV test (opt in or opt out) in response to a list of clinically indicated conditions, working closely with the relevant medical specialties and professional bodies to make sure this actually happens.

The recent Sigma Research study of the THT FasTest sites was an important assessment of one community testing service. Acceptability of the service related to receiving the test result at the same visit and the greater convenience of opening hours and location. More discussion appears to be necessary on costs and on the benefit of such provision in terms of new diagnoses. 3% of those who tested received a new HIV positive fastest result.

Only 5% of HIV diagnoses reported to the HPA appear to originate in primary care and there is evidence of significant lost opportunities to test and diagnose in this context. It has been an ambition of the DH to increase HIV testing in primary care since the National Strategy was published, if not before. We need to identify honestly the barriers to such primary care testing and discuss whether we plan to do anything about them. We should be aware of issues such as discrimination in primary care settings, the fact that primary care may not be accessible to all those vulnerable to HIV infection and the question of whether current GP surgery culture in terms of registration and opening hours is conducive to rolling out and making accessible the HIV test to a wider group of people.

It has become clear that the DH now interprets the HIV Testing Kits and Services Regulations 1992 as **not** prohibiting home sampling kits in the UK, and one private company are providing them. This raises the question of whether and how the HIV sector and health sector more generally might promote such sampling kits, issues of reliability, and indeed whether there is any argument for their being available on the NHS/from GU clinics.

In terms of testing targets, should we devise targets for testing in primary care or community settings? Or perhaps it would be better to identify targets which are less about the offer of the test (an input) and more about desired outcomes – a reduction in the proportion of late diagnoses for example.

It is all too easy to discuss testing simply in terms of service design. But another way to consider the issue is in terms of testing culture – research suggests 43% of gay

men in the UK have never tested and neither have 53% of Africans. There is a much higher rate of testing amongst, for example, gay men in the US. Do we want to change our testing culture in England, and if so what are we advocating? A regular check-up? Risk-based self-assessment?

Finally, we must take account of possible barriers in our current climate which could be deterring people from testing, be it criminal prosecutions, charging for HIV treatment and care, or more broadly experiences of stigma and discrimination in relation to HIV.

I would suggest the questions for discussion are:

- Is it time to change our 'testing culture' in the UK?
- Should we be aiming to extend substantially the availability of HIV tests in general practice and community settings? If not, why not? If so, how?
- Is there a case to roll out opt-out screening more widely, and if so in what contexts?
- Are there useful targets we could collectively work towards?

2.2 Key points from discussion groups on HIV testing

Testing cultures, routine opt-out screening and the CDC proposals

There was a consensus that the routine opt-out screening proposed by CDC for all healthcare settings in the US was not appropriate for the current English context, and would not provide the benefits to justify the costs. Instead we should increase the testing options for people – this did not mean reducing availability in GU clinics but expanding access elsewhere. Testing should become less complex and easier to access, focussing resources where the need was greatest and expanding choice.

The testing culture had to become less ‘controlled’, less ‘medicalised’ to a small area of medicine, less exceptionalist.

The current testing culture appeared to be that having an HIV test was something you did when you messed up. Maybe instead the emphasis should be on testing for the information it gives you, as was, for example, the message of the NAHIP ‘Better to Know’ campaign. There was, however, a worry that repeat negative testing might reinforce risk-taking behaviour, encouraging the sense that people could ‘get away with it’ and thus have more unprotected sex/more partners (see findings from the INSIGHT study).

Some thought ‘rapid’ testing should allow at least an hour between test and result to provide time for counselling and discussion, which might promote increased safer sex in the future, even where the test result is negative.

Many stressed the importance of accurate and detailed research to understand the needs of different groups, including incidence, undiagnosed rates and late presentations. There was concern over how to reach those who were infected with HIV from low prevalence groups such as white heterosexuals, and the need for greater understanding of the cost benefit argument for reaching out to such groups with HIV tests. Prevalence might also in some settings or contexts justify routine opt-out testing. But there were worries over disclosure of sexuality in relation to such demographic-based testing.

It was felt that we did not know enough about why people did not test. There was a suggestion that many gay men had not tested simply because they had not put themselves at risk. Improved HIV education and health promotion would reduce the numbers of ‘worried well’ seeking tests.

The CDC model of testing would involve testing a great many people who had never been at risk of HIV infection, though some thought this an acceptable by-product of the normalisation of the HIV test.

It was important to increase testing amongst those most likely to be HIV positive. On the other hand it was pointed out that those diagnosed late were often from outside the usual vulnerable communities. It was important therefore both to target testing services to groups most at risk but also improve the diagnostic skills of health professionals who see people with symptoms and fail to diagnose HIV.

There was more than one ‘testing culture’ in England. There was significant reluctance to test for HIV amongst African communities, and in many instances more pressing needs. It was important to think freshly about our testing messages to relevant communities.

Routine HIV screening in ante-natal care had been extremely effective in increasing the number of HIV diagnoses, particularly in African communities. There was, however, a significant disparity between the rates of undiagnosed HIV amongst African men when compared with the lower rates of undiagnosed HIV amongst African women. Current research into the effectiveness of 'couple testing' in ante-natal settings would be an important contribution to strategies for HIV testing in African communities in particular.

The sector had come to the view that it is good to know one's status but had not as yet communicated this view effectively to all gay men.

There was a fear that concerns over immigration status and over entitlement to treatment were acting as a barrier to some people coming forward for HIV tests. There were also fears around criminal prosecutions and the implications, especially in GP settings, of the electronic patient record. All these concerns had implications in relation to the ethics of opt-out testing.

Some were sceptical of the argument from CDC in the US of a significant benefit for incidence from a reduction in the proportion of people undiagnosed. It was pointed out that increased testing might not reduce transmission. The CDC approach would probably capture few people in the acute infection stage where the majority of HIV transmission may well be occurring. There was evidence of modification of risk taking behaviour following a positive diagnosis but some were sceptical of this research which was not always conducted under conditions which encouraged candour. More research was needed on the impact of the test on behaviour but prosecutions meant it was more difficult to gather evidence.

Testing standards

Some said it was important to ensure there were consistent high quality standards for testing in all settings, and that if we were to roll out testing into new settings it was especially important to ensure quality was maintained. Whilst testing should be 'normalised', good care and support after a positive diagnosis remained extremely important. Quick, appropriate and well-informed referral must be in place. Others felt testing was the most important thing to focus on at the moment.

Concerns were expressed that the push in GU for increased test take-up had not been matched by the resourcing of HIV support organisations who are expected to follow-up effectively those diagnosed HIV positive. THT's research suggested that even when diagnosed HIV positive in GU settings, individuals are not getting the support they require.

With regard to rapid testing, there was an important issue of confirmatory results in the case of a positive result. This posed challenges for follow-up – one statistic cited was that 25% of people did not return for a follow-up test.

Testing in GU clinics

There was agreement that testing in GU was going well, given the recent significant increase in both test offer and take-up. GMSS 2005 suggests that amongst gay men 85% of GU attendees are being offered and accepting HIV tests.

It had to be noted, however, that not everyone accessed GU services and it was therefore essential that HIV testing was available elsewhere.

It appeared that the increase in test take-up in GU was driven mostly by the routine offer of an HIV test, on an opt-in basis, but there was also evidence from BASHH that opt-out testing was beginning to happen in GU clinics. Further action was needed in GU clinics if the target of reducing by 50% the proportion of those who left a GU clinic undiagnosed was to be reached. This was particularly the case for MSM. There was a need to make rapid testing much more widely available in GU and clearly identify routine opt-out HIV screening as GU policy.

Testing in other secondary care specialties

One person thought it extraordinary that no target had been set for the offer of an HIV test in TB clinics. There were questions about the clinical guidelines for HIV testing of people in hepatology clinics.

There was considerable support for the identification of certain secondary specialties, where conditions often also indicated possible HIV infection, as appropriate settings for opt-out HIV testing, for example TB, hepatology, dermatology, GU.⁶

More also had to be done to make HIV testing readily accessible to injecting drug users, in particular through greater availability of on-site HIV testing at needle exchange sites.⁷

Testing in general practice

Some argued for routine HIV testing in general practice whilst others considered this to be a waste of resources. The consensus seemed to be that whilst routine testing would be inappropriate in this setting and some 'boundaries' were needed, it was difficult to identify other criteria, such as HIV prevalence in certain groups, which could be an acceptable basis for the routine offer of a test. There was agreement that there should be testing available in general practice on the basis of possible symptoms of HIV infection, or on request, and that training was necessary in order to enable GPs to recognise signs, symptoms and risk factors, as well as take sexual histories and assess risk.

It was suggested that more research was necessary into why HIV diagnoses were not being made in primary care. There was a need for a Sexual Health/HIV module in GP training if it was not in place already. GPs also needed to know how to offer an HIV test and give an HIV positive diagnosis. Indeed simply mentioning HIV seemed to be very difficult in some GP surgeries.

Discrimination in primary care setting, whether actual or perceived, was itself a significant barrier to both offering and requesting a test.

There were also continuing and misinformed concerns about insurance despite the fact that it is now only a positive diagnosis (rather than having a test or a negative result) which needs to be reported to a prospective insurer.

⁶ See 'HIV testing for patients attending general medical services, National Guidelines'. Royal College of Physicians concise guidance to good practice number 3, 2005.
<http://www.rcplondon.ac.uk/pubs/books/hivtesting/HIVguidelines.pdf>

⁷ See HIV testing recommendations in Turning Point report 'At the Sharp End: a snapshot of 21st century injecting drug use' Turning Point 2007

There was an issue of the 'culture of the GP surgery'. Is it a place one simply goes when ill or is it a resource for regular health checks? Is there the possibility of making the HIV test somewhat like a cervical smear or breast screening? Screening of particular vulnerable groups such as Africans or gay men for HIV in general practice would be controversial and difficult to implement. Many gay men, for example, do not disclose their sexuality to their GP and would not be happy with their sexuality being on their medical record. The difficulty was that the alternative of HIV testing on the basis of risk behaviour was more difficult to capture through regular reminder and check-up processes. In any event, doesn't the culture of a 'regular' HIV test almost condone or support continued risk taking behaviour as normative?

There were concerns about confidentiality in certain primary care settings, especially in rural areas. Primary care was not an anonymous open access service. It was also pointed out that a significant percentage of Africans were unable to access primary care, whether because of an absence of GP surgeries with open lists in deprived areas or because undocumented residency status meant there was no right to free NHS primary care.

More research was needed on the acceptability of HIV tests for African communities and the place of primary care. Some felt there were advantages for African men and women in having HIV testing more readily available in primary care settings. But others spoke of concerns over confidentiality when healthcare workers were from an individual's own community.

It was possible that the costs of an HIV test were deterring GPs from providing the test in GP settings and this was something which had to be looked into further. There was a need for a QOF framework or, if that was inappropriate, alternative financial incentives to test. More policy research and discussion were needed on this issue.

UCL research and the popularity of the MedFASH 'HIV in Primary Care' booklet suggests there is some enthusiasm out there for greater HIV testing and STI management in primary care settings.

There was a related question of the management of people diagnosed with HIV in primary care settings. There was a move to restrict the use of HIV specialist services for non-HIV specific healthcare – instead encouraging people living with HIV to access such care in general practice. This was a challenge for general practice in terms both of professional expertise and non-stigmatising attitudes. As a general practice treated people living with HIV in an expert and supportive way, it was likely it would become more 'HIV-friendly' and more likely both to offer HIV tests and to be a place where people would feel comfortable to request one.

Primary care was an opportunity to transform testing culture and not just transfer it, in particular through local enhanced services. So there should be consideration of out of hours provision and weekend testing, for example.

Some thought testing in pharmacy settings was inappropriate given the impact of a positive result whilst others thought testing should be available there for those who wanted it.

Testing in community settings

Some thought the offer of a test in many community settings – a gay pub for example – was simply inappropriate (others disagreed), though it might be a good setting to disseminate information on testing.

The Sigma Research study of the THT FasTest sites suggested that accessible rapid testing in the community was acceptable for Africans and gay men who had never tested though it did not encourage those who did not want to test to change their minds.

It was questioned whether community sites for HIV testing knew how to refer on those who tested positive to specialist HIV care. Service networks with agreed pathways were vitally important.

Home sampling kits

A majority of participants appeared to be in favour of greater use of home sampling kits. It was felt home testing kits would help normalise HIV testing and be of particular benefit in low prevalence areas and where GU access was difficult.

Commissioning

There was discussion of possible tensions between acute and community providers of testing, one seeing the other as 'competition'. There was also discussion of what we should be expecting in terms of community 'demand' for service provision in this area. Testing strategies needed to be tailored to the local population and be responsive to the most up-to-date evidence. There was a need for a commissioning guidance which addressed these issues, and which supported community involvement. Local strategies were needed with effective champions/advocates to secure funding.

Targets

It was important when considering testing targets not to focus simply on numbers being tested, still less on numbers being offered a test. Relevant outcomes were the important measure of success. Amongst those mentioned for consideration were a reduction in the number of HIV-related deaths; a reduction in the estimated percentage of people undiagnosed; a reduction in the average time between infection and diagnosis; a reduction in late diagnoses; and a reduction in diagnoses accompanied by presentation with AIDS. There was also interest in targets around partner notification, in particular in ante-natal settings. And possibly the percentage of people with indicated conditions offered an HIV test in primary care or in relevant secondary care specialties. There would need to be further discussion of which of these possible targets are most appropriate and which could be effectively measured at the local level.

Reference was made to the MedFASH audit indicator on the percentage of GPs who undertake HIV testing on patient request (see Standard 2). These standards needed to be promoted to the RCGP and to GPs. There could be financial incentives for enhanced sexual health services and for HIV testing, as an alternative to targets.

It was pointed out that there was less control over the timing of diagnosis for those infected overseas.

2.3

HIV Testing

National AIDS Trust Conclusions and Emerging Recommendations

Research/Information

There are a number of areas for further research/information, including:

- **Barriers to testing in specific groups/communities and the acceptability of various testing options, for example, rapid testing, home testing, testing in community settings**
- **Current availability of rapid testing and community testing, with evaluations**
- **The impact of criminal prosecutions for reckless HIV transmission on willingness to test for HIV**
- **The availability of HIV testing in General Practice, current rates of 'missed diagnosis' in General Practice, effectiveness of referral processes to GU, and the cost-effectiveness of making HIV tests available in General Practice in relation to local prevalence**
- **The potential of 'couple testing' in ante-natal, GU and other healthcare settings**
- **Current rates of HIV testing and diagnosis in relevant non-HIV secondary care specialties**
- **The cost-effectiveness of a comprehensive roll-out of rapid testing in all GU settings**

A new Strategy

Success in expanding HIV testing in GU clinics and ante-natal settings must be maintained and further developed. But there is now a fundamental need to extend HIV testing well beyond such medical specialties and make the test readily accessible to meet the significant amount of unmet need. **A fresh strategic approach to the provision and roll-out of ethical, appropriate and accessible HIV testing should be agreed over the next twelve months by the Department of Health, HIV and other relevant clinical and professional bodies, and the HIV sector.** Such work will need to be integrated into any wider revision of the National Strategy for Sexual Health and HIV.

Stigma and Discrimination

HIV-related stigma and discrimination remain the most significant barriers to people testing for HIV. **The Department of Health must commit itself to effectively funded action to eliminate HIV-related stigma and discrimination from all NHS healthcare, and as a priority from primary care and those secondary care specialties where HIV tests may be offered or recommended.** The current DH 'Implementation Plan' on HIV stigma and discrimination is inadequate in this regard.

Maintaining current success

Recent success in expanding HIV testing in GU needs to be acknowledged, maintained and further developed, with clear strategies to reach the continuing significant proportion of MSM who remain undiagnosed after GU visits.

Extension of HIV testing in other settings should aim to complement this provision and reach those not attending GU services.

Increases in the numbers tested and diagnosed in GU clinics should be accompanied by adequate resourcing and funding for post-test follow-up and support.

Routine opt-out HIV screening

The right approach for England is not the CDC road of routine opt-out screening in all healthcare settings.

Routine opt-out screening for HIV should be the agreed norm in GU clinics.

Routine opt-out screening is also one option to be considered in certain relevant secondary care specialties. **As part of a fresh HIV testing strategy, clear guidelines for routine HIV testing in secondary care must be developed, implemented and audited for an agreed group of indicated conditions, with buy-in from the relevant professional bodies.** The current MedFASH project looking at this issue in detail will be an important step in achieving this outcome.

General Practice

There was significant support at the expert seminar for HIV testing being much more widely available in primary care, with attention to the financial incentives necessary to leverage such provision and much improved medical school and continuing training. **HIV testing in General Practice should be available on the basis of request or in response to possible symptoms/reporting of risk. The significant barriers of stigma and discrimination in primary care, poor diagnostic skills, difficulties in registration with a GP, lack of skills in sexual history taking, and of inappropriate opening hours must be addressed as a matter of urgency by the Department of Health and relevant professional bodies.**

Commissioning

Commissioning has to work to some consistent assessment of testing need in a given area, and **work underway to support Commissioners in accessing reliable and relevant statistical information should include guidance on the identification of local HIV testing 'need'.**

Targets

New strategy targets need to be identified for HIV testing. These should be specific and outcome-related, for example in relation to a reduction in the proportion of late diagnoses.

3. PREVENTION STRATEGIES

3.1 *Prevention in a changing context*

Paul Ward, Deputy Chief Executive, Terrence Higgins Trust

It is clear that there has been an increase in HIV diagnoses over the past few years and that these have been largely confined to communities at greatest HIV risk. It is unclear, however, whether there has been a corresponding increase in HIV transmission in the UK.

A review of the behavioural and epidemiological research suggests that levels of HIV risk taking are lower in UK African communities than in UK gay male communities. This evidence also suggests that there has been a worsening more broadly in the sexual health of some groups of gay men, particularly men living with HIV.

Research evidence suggests there has been limited success at reducing undiagnosed HIV infection, and that people with undiagnosed HIV may account for a disproportionate level of ongoing HIV transmission. Despite the publicity given to recent cases of criminal prosecution for HIV transmission there is little evidence of intentional HIV transmission. Research also shows that factors such as proximity to HIV, availability of treatment and cultural attitudes/norms affect people's decision making about HIV testing.

Levels of expenditure on HIV prevention activities have fallen in both absolute and relative terms over the past decade, and this places additional importance on the continuation of national HIV prevention programmes.

There is a clear and reasonably robust evidence base for HIV prevention interventions, as well as a strong cost effectiveness case for these interventions.

There are a number of challenges which need to be faced in renewing the UK's HIV Prevention strategy including a low individual and public visibility of HIV, low funding priority by many statutory bodies, and a need to tackle levels of undiagnosed HIV as a means of helping reduce ongoing transmission.

A renewed strategy should have the following components:

- maintaining an emphasis on what works and expanding the evidence base through innovation and evaluation
- integrating prevention and testing programmes
- increasing the amount of work with people diagnosed with HIV
- maintaining national support and coordination

Within this work should continue to be targeted at communities at greatest HIV risk, principally African communities, gay men and injecting drug users. Within these communities work should be further targeted so that it reaches those people who are at greatest HIV risk, for example people in sero-discordant relationships, people with high numbers of sexual partners, or people who find it difficult maintaining safer sex or injecting behaviour.

In conclusion there is much to be proud of in the UK's response to HIV but there is a need for the UK to renew its prevention strategies if it is to avoid a major increase in the numbers of people with HIV over the next decade.

3.2 Key points from discussion groups on HIV prevention

Incidence data and Prevention 'Success'

Incidence data through use of the STARHS test⁸ would be very valuable for commissioning. It would be interesting to look at how such STARHS testing goes in the US.

There was concern over the accuracy and gaps in country of infection data collected by the HPA. STARHS could possibly be useful to assess and cross-check such information.

There was discussion of whether 3 per cent incidence was unacceptably high or not. One view would be that this is simply how things are – and comparable to incidence in other major cities around the world, all of which also have active HIV prevention campaigns. Maybe this is what it looks like for prevention to be working. It was pointed out that with an increasing 'positive pool' of people, incidence would rise even if condom use remained the same. Thus an incidence of 3% was perhaps only to be expected.

Some questioned the estimated incidence rate and the extrapolations made from GU clinics for the gay male population as a whole.

There was evidence from San Francisco of incidence levelling off or declining whilst STI incidence increased, which could possibly be explained by serosorting.

There was certainly no prevention magic bullet nor any one answer as to why transmission was occurring at current rates.

Particular issues around transmission risk

Treatment certainly had a significant impact in reducing risks of transmission. There should be concern over possibility of transmission during the acute infection period, when co-infected with an STI and in the late disease stage (though less unsafe sex might be taking place in this latter period; and many African migrants are unlikely to be in the UK during their acute infection period).

There was some discussion as to whether the data suggested that most transmission took place in casual or more settled relationships, and the extent to which there was a difference between heterosexual and homosexual transmission in that regard.

Improving our data

Not enough was known about incidence in African communities in the UK. One problem, as previously stated, was the frequency with which boxes were not filled in for HPA data on probable country of infection. There was also missing data when it came to contact tracing and partner notification from HIV positive diagnoses in ante-natal settings, data which would be very useful for assessing incidence in African communities.

There was concern that criminal prosecutions would undermine the ability to research reliable and useful data for future prevention work.

⁸ The STARHS test ('serological test algorithm for recent HIV seroconversion') is used to determine whether someone has seroconverted in the last four to six months, or if they have been infected for a longer period of time.

MSM

Expanded access to GU and testing initiatives such as those discussed earlier in the day would both be valuable. Continuing education around and access to PEP was also important.

It was especially important to do more work with HIV positive gay men. It needed to cover a range of ages, to tackle issues of control, negotiation skills, self-esteem and depression. GMFA pointed out that sometimes service provision most effectively attracts HIV positive gay men when it isn't 'labelled' as such. They had most success attracting positive men to a general course for gay men on assertiveness. More broadly it was agreed that treatment services should be offering health promotion – diagnosis by itself did not change behaviours. CHAPS had been working with HIV positive men for many years.

Some thought there might be some complacency as to the implications of HIV infection for gay men in their 40s.

The INSIGHT study⁹ was an important source of information on decision-making with regard to risk amongst gay men, the use of repeat negative tests to affirm risk-taking behaviour, the link between risk-taking and questions of depression and low self-esteem, as well as of machismo behaviour and treatment optimism.

Different prevention campaigns were needed for different groups – young men/older men/BME gay men, but at present there was insufficient money to engage in this kind of work.

There was a need for more attention to the 'imported' epidemic amongst gay men – 15% of gay men were infected abroad and this rose to 40% amongst black gay men. Furthermore, gay men moving to the UK were more at risk once they had arrived. There was still much to research around the needs of BME gay men who are at higher risk and whose needs are not being met by current interventions.

The sector/GU clinics were not dealing with the MSM who repeatedly presented for STIs without ever accepting an HIV test.

Gay men should be provided with information on all prevention options – condoms, 'strategic positioning'¹⁰, partner reduction. There was a worry from some that the partner reduction message might fuel the view that only promiscuous people were infected with HIV. There was evidence from GMSS 2005 that positive men were engaging in 'strategic positioning' choice to lessen the risks of transmission.

Some thought we were not as yet using effectively and innovatively the evidence we already had around gay men.

⁹ For more information on the INSIGHT study go to http://www.hpa.org.uk/infections/topics_az/hiv_and_sti/behavioural/insight.htm

¹⁰ Decision-making on whether to be the insertive or receptive partner in anal sex on the basis of serostatus (there being a significantly lower risk of infection to an HIV insertive partner with an HIV positive receptive sexual partner, than if the HIV negative individual is the receptive partner).

African communities

The epidemic in African communities was very different from that amongst MSM. There was evidence of significant difference in the rate of partner change and the number of partners. Africans were invariably in a much worse economic situation, with many cases of serious deprivation. There were sometimes problems of sexual coercion and rape in relationships. There were many 'African communities' in fact, and prevalence was of course linked to prevalence in country of origin. There was a real problem of fear of officialdom.

New communities outside London are only now establishing networks. It was important to have engagement with these groups and with HIV issues amongst African communities from local authorities and public health officials. It was pointed out by a number of people that there had been significant investment in African capacity building but without necessarily the success which had been hoped for.

It was important to be sensitive to the distinct needs of those who had recently arrived in the UK.

There was also a need for more work on transmission within settled relationships, where we could learn from interesting work done overseas. Much more work should be done with Africans living with HIV.

Work with faith communities remained important but other leaders and champions should also be identified. There were difficulties with working in the faith context.

The forthcoming research 'African HIV Prevention Needs Assessment' to be undertaken by Sigma Research would provide important information for African prevention work. There was agreement that at present too little was known about the epidemic amongst Africans in the UK. More information about for example sexual behaviours and attitudes to testing would provide scope for greater success in prevention. How successful were current campaigns around condoms and disclosure in African communities?

It was important to have the vision to invest in pilots and innovation, especially in relation to African communities.

Sex and relationships education/Young people

There was agreement on the need for sex and relationships education in schools, and on the importance of tackling homophobic bullying and providing information on homosexuality. There was also currently little or no provision for young HIV positive children/teenagers as they became sexually active, advising and supporting on sexual behaviour, risks of transmission, disclosure of HIV status, the relevance of the criminal law and other difficult issues. With regard to young people from African families growing up in the UK, it was important to have prevention strategies which recognised that their culture might be significantly different from that of their parents.

Injecting drug users and prisoners

Injecting drug users were a vulnerable group not directly represented at the seminar but whose interests had also to be considered. DAT workers had to be linked in to issues of HIV and issues of sex, rather than always simply referring those issues on

to the HIV sector. PCTs and working groups engaged on prisoner health should also be involved in wider HIV prevention efforts. Migration from Eastern Europe (and Southern?) had also to be considered in this context.

Targets and the politics of prevention

Prevention was happening but it was not being evaluated consistently and those evaluations disseminated. It was important to both fund evaluations/research and disseminate the results widely. Funding to test and evaluate prevention was currently inadequate. Evaluation had also to be continual because effectiveness of interventions change over time. Evaluations of prevention interventions in the US should also be analysed for relevance to the UK.

It was clear that incidence can decline in response to prevention efforts and there could well be a value in having incidence targets if only to maintain some kind of political focus on the issue. But reducing incidence would always be a challenge with an ever increasing number of HIV positive people and an increase in the number of men who have sex with men. Furthermore, there had in the past been real difficulties in measuring incidence for target purposes. With the roll-out of STARHS testing such measurement might be possible but it would be important to have a reliable process identified and in place before any such target were adopted.

Buy-in was necessary into the aims of Making it Count¹¹, the agreed theoretical framework for HIV prevention amongst MSM, which was about unmet need, not incidence. The realistic aim of prevention should be increasing information levels and support in people having the skills to act on that information. There was also a need for more outcome focussed targets (for example, the access of gay men to condoms). Targets had political value – perhaps it should be behaviour rather than incidence. Resources would then be necessary to ensure proper evaluation.

Commissioning was key to the success of prevention efforts. But currently many commissioners did not understand the issues and needed to be upskilled as a matter of urgency. They needed to be able to understand local needs and undertake local needs assessments. It was important they understood the data and invested in the long-term in evidence-based prevention. Again, the ethic and rationale of Making it Count had to be properly explained, and better use made of evidence in prevention interventions. There was also a need for better communication amongst commissioners, a better relationship between the Commissioners Group and the DH, and internal guidance for Commissioners.

Commissioners needed an improved understanding of their populations, including their African populations. And Africans needed to be more involved in local decision-making. Perhaps there should be a 'target' in terms of the education of commissioners?

There was a need for 'champions' for HIV prevention at both national and local levels. It was also important to engage with faith leaders. Government department activities, and clinical and non-clinical sectors all needed to be better integrated to achieve the best results.

It was important to have a consensus as to what prevention looks like, how well we are doing and the key, consistent messages. There was also considerable support for a return to some form of protected funding for HIV prevention work which was not

¹¹ <http://www.sigmaresearch.org.uk/downloads/report03e.pdf>

at the mercy of other short-term budgetary needs. MPs also needed to be shamed into action.

3.3

HIV Prevention

National AIDS Trust Conclusions and Emerging Recommendations

Past successes and future priorities

Whilst there is room for improvement, development and innovation, **more should be done to communicate, especially to relevant decision-makers and to the NHS, the *achievements and effectiveness* of what is currently being done in maintaining HIV incidence rates at a fairly low level.**

Areas for further HIV prevention efforts include:

- HIV positive gay men and HIV positive Africans
- Migrant gay men
- BME gay men
- Contact tracing/Partner notification/Partner testing through the antenatal screening process
- Transmission in settled/regular relationships (in both gay and African communities)
- Recently arrived migrants

Funding

Evidence suggests HIV prevention funding has stagnated or declined over the last ten years in real terms, and recent attempts to provide greater resources for sexual health through 'Choosing Health' monies have not on the whole been successful.

The case for ring-fenced funding available for HIV prevention needs to be revisited. If prevention funding had kept pace with the HIV epidemic over the last decade there is good reason to believe more could have been achieved in reducing incidence rates. The best approach may well be to argue for ring-fenced funding for public health and health promotion objectives, rather than specifically for HIV alone.

Information

More funding needs to be made available for evaluation of prevention work and for pilot/innovative projects.

Improved data collection is needed to support HIV prevention – in particular in relation to likely country of infection, contact tracing data, transmission in African communities in the UK, incidence data (through STARHS especially), and in relation to migrant gay men.

Commissioning

More needs to be done to communicate the rationale behind 'Making it Count', especially to the wider health sector, including to PCT Chief Executives and HIV Commissioners.

There is an urgent need to improve the local commissioning of HIV prevention, based on a better understanding of local sexual health needs and of the evidence on effectiveness of interventions. **Guidelines for Commissioners in assessing local HIV-related prevention need should be drafted and agreed as a matter of urgency.**

Targets

New prevention targets are needed – possibly around incidence, possibly around behaviours, certainly around outcomes rather than only inputs. Such targets would require a commitment to fund evaluation/data collection.

Attendance List

Dr. Jane Anderson - Homerton University Hospital
Yusef Azad – National AIDS Trust
Alison Begley – Crescent Support Group
Carl Burnell - GMFA
Gus Cairns - UK Coalition of People Living with HIV
Tim Chadborn – Health Protection Agency
Magda Conway – National Children’s Bureau
Ben Cromarty – Yorkshire AIDS Action
Sheonaidh Cumming – National AIDS Trust
Valerie Delpech – Health Protection Agency
Matt Dixon – Croydon Primary Care Trust
Gillian Elam – Centre for Sexual Health and HIV Research
Prof. Jonathan Elford – City University
Amanda Evans – Royal Free Hospital
Ibi Fakoya – African HIV Research Forum
Bernard Forbes – UK Coalition of People Living with HIV
Walter Gillgower – National African HIV Prevention Programme
Robert Goodwin – Department of Health
Matthew Hodson - GMFA
Deborah Jack – National AIDS Trust
Kalex Kalialia – Tower Hamlets PCT
Ruth Lowbury – Medical Foundation for AIDS and Sexual Health
Chris Morley – George House Trust
Peter Nieuwets – West Sussex PCT
Will Nutland – Terrence Higgins Trust
Kay Orton – Department of Health
Lisa Power – Terrence Higgins Trust
Dr. Audrey Prost – Centre for Sexual Health and HIV Research
Brian Rice – Health Protection Agency
Murad Ruf – Health Protection Agency
Fraser Serle – Health First
Rhon Reynolds – African HIV Policy Network
Dr. Ann Sullivan – Chelsea and Westminster Hospital
Caspar Thomson - NAM
Paul Ward – Terrence Higgins Trust

Peter Weatherburn – Sigma Research
Dr Chris Wood – North Middlesex Hospital
Steve Worrall – Positive East