



HOUSE OF LORDS SELECT COMMITTEE ON HIV AND AIDS IN THE UK

Submission from NAT (the National AIDS Trust)

Summary of Conclusions and Recommendations:

A National Strategy for HIV

- i. NAT recommends that the Government publish a national strategy for HIV which addresses HIV from the perspectives of sexual health, long-term condition management, and human rights and equality. The strategy should be multi-sectoral and there should be a consultation process before its finalisation. (para.8)

Monitoring and Advice

- ii. The resources dedicated to HIV and sexual health surveillance should be maintained, and indeed increased, given the level of need. It should be clearly stated that this work is a public health 'frontline service', rather than simply back office or administrative. (para.10)
- iii. The independence of this public health function needs to be protected, ideally in legislation. This extends to what is surveyed, the timing and content of published data and analysis, the initiation of projects and the interpretation of data/information. (para.10)
- iv. The Health Protection Agency (HPA) services once subsumed within Public Health England should remain open to external bodies to approach for advice and support around relevant data and their interpretation. The current transparent and helpful public service ethos is one which should be preserved. (para.10)
- v. The Government plans to establish an internal advisory group on sexual health and HIV. NAT hopes this body will work in an open way, able to publish its deliberations and advice should it wish to do so. (para.12)

Prevention

- vi. A consensus must be reached within the HIV sector and across the NHS and Government as a matter of urgency as to how to evaluate HIV prevention work focussing on outcomes (such as behaviour change or new infections), and as to what constitutes prevention success. We also need an appropriate level of investment in the monitoring of success. (para.17)

- vii. 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. It should be made clear that local authorities are expected to fund health improvement work around sexual health and HIV additional to the core GU service being commissioned. (para.20)
- viii. NAT strongly believes that a national HIV prevention programme situated within Public Health England must be maintained. (para.21)
- ix. The national HIV prevention programme should be managed by Public Health England with strategic advice from all key stakeholders, including the voluntary sector, epidemiologists, social/behavioural scientists and clinical staff. (para.21)
- x. NAT recommends that the HIV prevention needs of Caribbean communities be included within the remit of the national HIV prevention programme(s). (para.22)
- xi. Public Health England should re-examine HIV prevention work amongst IDUs, drawing on the expertise of staff from the HPA and the National Treatment Agency (NTA) who will have been brought into the department, as well as external experts. The national HIV prevention programme should address the prevention needs of IDUs, in particular gaps in HIV testing, safer sex advice and needle exchange within drug treatment services. (para.24)
- xii. NAT recommends that there be a pilot of prison needle exchange in an English prison at the earliest opportunity. (para.26)
- xiii. 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 (by contrast, the last DH television campaign for condom use, 'Essential Wear', did not mention HIV amongst the STIs to be prevented)
 - 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.
 - We should encourage more and better quality of reporting on HIV in the media. (para.30)
- xiv. Improved HIV testing, adherence to medication for those diagnosed positive and the avoidance of untreated STIs are now important prevention goals. (para.31)
- xv. UK prevention work must address not just condom use but also partner numbers as key factors in reducing risk of HIV transmission. (para.31)

- xvi. Renewed effort is necessary to educate people as to why HIV remains a serious life-long condition to be avoided, even with effective treatment available. Such information must not use fear or exaggeration, nor stigmatise people with HIV, but just communicate the facts. (para.31)

Testing

- xvii. It is important, given the success of the testing pilots, that the Government formally endorse the UK National Guidelines on HIV testing ('the UK Guidelines') as the testing policy to be implemented across the NHS. One reason for this is that responsibility for HIV testing will quite possibly be fragmented across different commissioning bodies – the NHS Commissioning Board, local authorities and GP consortia. Clarity in our HIV testing strategy is vital. (para.37)
- xviii. Interventions should be funded to communicate to MSM the importance of testing for HIV at least once a year, and more frequently according to risk. The HIV sector should also agree as soon as possible recommendations on frequency of HIV testing for African communities in the UK. (para.40)
- xix. More work must be done to increase knowledge of symptoms of primary HIV infection in most affected groups and encourage HIV testing where such symptoms occur. It is also important to increase knowledge of primary infection amongst healthcare workers, especially those in primary and emergency care, where currently symptoms are commonly missed. (para.41)
- xx. HIV testing should be routinely offered in high prevalence areas in general and acute medical admissions and to newly registering GP patients. These have been demonstrated to be cost-effective and acceptable to healthcare staff and patients alike. NICE Guidance should reflect the UK Guidelines on this point. The NHS Commissioning Board and GP consortia should commission accordingly. (para.45)
- xxi. It is essential that NICE Guidelines for relevant secondary care specialties include routine HIV testing as recommended by the UK Guidelines and that GP consortia consistently commission to these standards. (para.46)
- xxii. More consideration is needed of how to integrate community testing into the local 'health economy'. In particular, it is important to identify how community testing can not only provide convenience but also reach people for testing who would otherwise not seek an HIV test. (para.47)
- xxiii. Further exploration of home sampling within the NHS is needed – in particular, hard-pressed GU clinics could consider home sampling as a means of triaging those wishing to have an HIV test. (para.48)
- xxiv. Home testing for HIV should be legalised and regulated, and integrated into strategies to increase HIV testing take-up. (para.50)
- xxv. Mandatory HIV testing should not be introduced in any form. (para.53)

Treatment

- xxvi. The NHS Commissioning Board will inevitably be removed from experience at local and clinic level. If possible, some regional/'supra-local' based

structuring of its commissioning of HIV treatment would ensure flexibility and responsiveness to the situation on the ground. (para.57)

- xxvii. Healthcare planning will take place at the local level in the proposed Health and Well-being Boards. It is not clear how those whose healthcare is commissioned by the NHS Commissioning Board will have their interests and needs represented at these Boards around the country. (para.58)
- xxviii. There has been real progress of late in integrating sexual health services. Government proposals separate out the commissioning of HIV treatment and care (NHS Commissioning Board) from local sexual health services (local authority commissioning). The danger is a return to fragmented and uncoordinated (and thus more expensive) services - explicit and proactive steps will need to be taken to counteract such a consequence. (para.59)
- xxix. The NHS Commissioning Board's role in HIV commissioning should not be seen as a defence of the status quo in how HIV treatment is configured and provided. It may be the opportunity to implement real change. For example, the NHS Commissioning Board could require greater involvement of GPs in the care of stable HIV patients. (para.60)
- xxx. Performance of the NHS Commissioning Board in these responsibilities will need to be measured and assessed by the Secretary of State. Outcome measures should be agreed which demonstrate high quality HIV treatment and care, perhaps developing and applying nationally those developed for London with support from the HPA. (para.61)
- xxxi. There is a danger in the current 'drive to the local' that outcomes of care, whether healthcare or social care, for often marginalised minorities get lost in the bigger picture. It remains very unclear what 'must do' there is at the local level to ensure that there is the political will to meet the needs of groups such as people with HIV, or gay men or African migrants. (para.67)
- xxxii. A key support will be early development of NICE guidance for HIV healthcare and social care against which we can assess performance and quality. Such guidance should identify how HIV outpatient care and social care are provided and joined up, but also how these are integrated with other essential provisions such as appropriate psychological support, which is currently so patchy across the country. (para.68)
- xxxiii. With a high proportion of people with HIV within the immigration system, significant levels of severe poverty (between 2006 and 2009 one in six of all people with HIV had to access the charitable support of the Hardship Fund for emergency assistance), and disproportionately poor mental health, the planned national strategy must involve key relevant government departments. In particular for HIV treatment and care to be effective we need:
- An immigration system which consciously and proactively supports access to treatment and adherence (including during dispersal, detention and removal)
 - A benefits system which assesses people with HIV fairly and accurately, which supports those who can work back into employment, and which makes decisions on, and provides, benefits promptly and efficiently

- A healthcare system which acknowledges the elevated mental health needs of people with HIV, funds appropriate services and introduces joined-up commissioning and referral. (para.69)

Stigma and discrimination

xxxiv. The Government should as part of a national strategy for HIV develop a clear multi-sectoral approach to tackling HIV stigma and discrimination. This should include:

- commitment to anti-stigma training across all of the NHS, with a particular emphasis on primary care
- the inclusion of education on HIV and the unacceptability of stigma and discrimination in all schools' curricula
- support for people with HIV in knowledge of their rights and of protections against discrimination, in personally dealing with stigma as well as in disclosure of HIV status
- innovative work to improve public awareness, including -
 - better use of World AIDS Day to promote awareness and understanding,
 - identifying high profile 'champions',
 - supporting and empowering people with HIV to share their stories and experiences,
 - engagement with the media, and
 - regular surveys of public attitudes and understanding.
 (para.78)

xxxv. NAT recommends that the Committee support the exemption of people with HIV from NHS treatment charges irrespective of residency status. (para.81)

xxxvi. NAT recommends that as part of a wider and concerted effort to remove HIV stigma and discrimination from the NHS, that the current 'blanket' occupational exclusions are ended on HIV positive healthcare workers engaging in any invasive procedure. (para.83)

xxxvii. NAT believes that current occupational restrictions around the employment of people with HIV in the armed services are discriminatory and should end. (para.85)

A. Introduction

1. NAT (the National AIDS Trust) welcomes the inquiry of the House of Lords Select Committee into HIV and AIDS in the UK, and is grateful for the opportunity to provide written evidence to complement the oral evidence already given.
2. NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expert advice and practical resources. We campaign for change. All our work is focused on achieving four strategic goals:
 - effective HIV prevention in order to halt the spread of HIV
 - early diagnosis of HIV through ethical, accessible and appropriate testing
 - equitable access to treatment, care and support for people living with HIV, and
 - eradication of HIV-related stigma and discrimination.
3. This submission addresses issues for the most part in the order set out in the Committee's call for evidence. We comment only on those areas where we have, we trust, relevant points to make on the basis of our work. We do of course believe that all the issues in the call for evidence are of immense importance.

B. A National Strategy for HIV

4. The last national strategy for sexual health and HIV was published in 2001 and was in place until 2010. It was an extremely important resource and template against which sexual health activity in England could be planned and assessed. NAT welcomes the recent Government commitment to publish in the Spring a sexual health strategy, which will certainly address HIV. A great deal has changed over the last decade in the UK HIV epidemic, in testing and treatment as well as in the legal framework, and this must all be reflected in any new strategy. It is not, however, clear whether the Government's strategy will cover HIV in the breadth and depth required. A strategic approach to HIV must not only consider the condition from a sexual health perspective, but also as a long-term condition, and as a human rights and equalities issue.
5. Furthermore, an HIV strategy cannot simply be a strategy for the Department of Health but must be genuinely multi-sectoral, involving and securing commitments from such departments as the Department for Work and Pensions, the Department for Education, the Ministry of Justice, the Home Office, to name a few. We hope this submission makes clear why such a multi-sectoral approach is needed - it is also an explicit requirement of the UNGASS Declaration of Commitment on HIV/AIDS, to which the UK is a signatory.
6. A final essential component of any national HIV strategy is the involvement of civil society and, most importantly people with HIV, in its development and production. It is therefore very important that any strategy published by the Department of Health is in draft form and open to consultation to allow such involvement.

7. We also hope that the national strategy will take into account the findings and recommendations of the Committee, which given timings may be another reason to emphasise a consultation period for any strategy produced this year by the Department.
8. **NAT recommends that the Government publish a national strategy for HIV which addresses HIV from the perspectives of sexual health, long-term condition management, and human rights and equality. The strategy should be multi-sectoral and there should be a consultation process before its finalisation.**

C. Monitoring and Advice

9. The UK has one of the best HIV surveillance systems in the world. It is a vital tool in enabling Government (both national and local), the NHS and the voluntary sector to assess need, and identify trends over time (for example the proportion of people undiagnosed, or diagnosed late, and the relative burden of HIV on key communities such as men who have sex with men (MSM) or Africans). The Government plans to end the separate (and statutory) existence of the Health Protection Agency (the body responsible for this surveillance system) and subsume its functions within Public Health England, itself to be part of the Department of Health. This will be effected by the Health and Social Care Bill currently before Parliament.

10. A number of concerns need to be addressed:

The resources dedicated to HIV and sexual health surveillance should be maintained, and indeed increased, given the level of need. It should be clearly stated that this work is a public health 'frontline service', rather than simply back office or administrative.

The independence of this public health function needs to be protected, ideally in legislation. This extends to what is surveyed, the timing and content of published data and analysis, the initiation of projects and the interpretation of data/information.

The Health Protection Agency (HPA) services once subsumed within Public Health England should remain open to external bodies to approach for advice and support around relevant data and their interpretation. The current transparent and helpful public service ethos is one which should be preserved.

11. The work of the National Treatment Agency (NTA) is also being brought into Public Health England and we do of course hope that similar safeguards apply to their work supporting injecting drug users, particularly in relation to evidence-based approaches.
12. The Government has abolished the Independent Advisory Group on Sexual Health and HIV (IAG) which was an authoritative, transparent and highly respected source of advice to Government on sexual health and HIV, as well as an invaluable forum for key representatives in the sector to meet and share ideas and information. **The Government plans to establish an internal advisory group on sexual health and HIV. NAT hopes this body**

will work in an open way, able to publish its deliberations and advice should it wish to do so.

D. Prevention

13. The national strategy for HIV and sexual health in place from 2001 to 2010 included a section on 'Better Prevention' which had as its overall target a reduction by 25% in the number of newly acquired HIV infections by 2007. The relevant section of the national strategy contained useful and important commitments, including to target HIV prevention at groups particularly affected, not to allow discrimination to impede prevention work, and to address undiagnosed infection. For all that, new diagnoses of UK-acquired HIV in the UK have risen significantly over the last decade and it is estimated that overall expenditure on HIV prevention has probably declined in the same period.¹ Successive Governments deserve credit for maintaining national HIV prevention programmes for HIV and an evidence-based and ethical framework to address the epidemic.
14. There were, however, a number of problems with HIV prevention over the last ten years, which now need to be addressed as we move forward.

Lack of evidence of success:

15. The national strategy target was to reduce new infections, i.e. HIV incidence. It was agreed, however, at a time when there was no way of calculating new HIV infections year on year. New HIV diagnoses were not an accurate picture of new infections since people could have HIV for many years prior to diagnosis. Agreeing a target which was unmeasurable was not helpful. But it was symptomatic of a wider difficulty – how to evaluate and measure success. A decade later we still have not reached agreement as a sector on this point. The danger is, even if we have good reason to believe our work is effective, the absence of agreed measures of impact result in a wider loss of confidence in HIV prevention work. Evaluation of national prevention programmes, for example, has focussed on recognition of prevention materials rather than behaviour change.
16. It is difficult to measure the impact of HIV prevention work but more can certainly be done, and recently developed technologies, such as RITA testing, offer the prospect of a more accurate picture of incidence.
17. **A consensus must be reached within the HIV sector and across the NHS and Government as a matter of urgency as to how to evaluate HIV prevention work focussing on outcomes (such as behaviour change or new infections), and as to what constitutes prevention success. We also need an appropriate level of investment in the monitoring of success.**

Lack of local incentives for HIV prevention work:

18. There have not in recent years been national targets or measures to incentivise investment in HIV prevention at the local level. The result has been resources have moved away from HIV, which was not a 'must-do', to other services. Local PCTs disinvested over time from HIV prevention,

¹ 'Commissioning HIV Prevention Activities in England', NAT 2007

relying for funding on the national HIV prevention programmes which were only ever meant to catalyse and support HIV prevention work, not substitute for local action.² The draft Public Health Outcomes Framework currently out for consultation has no indicator which will incentivise HIV prevention work.

19. 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 and so on. 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. GU services are an essential element of NHS secondary care provision. Putting aside arguments over whether local authorities should be commissioning GU services, it does seem wrong for funds for this service to be taken out of the ring-fenced health improvement budget, which was designed precisely to encourage longer-term preventive interventions and protect such investment in 'wellness' from the urgent demands of acute care.
20. **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. It should be made clear that local authorities are expected to fund health improvement work around sexual health and HIV additional to the core GU service being commissioned.**

The National HIV Prevention Programmes:

21. National oversight of targeted prevention to gay and African communities is entrusted to the two national HIV prevention programmes, CHAPS for MSM and NAHIP for African men and women. At the time of writing it is unclear how they will go forward in the context of current public health reforms. With the current emphasis on localism there is some concern as to their future – **NAT strongly believes that a national HIV prevention programme situated within Public Health England must be maintained.** At the local level HIV numbers always remain low compared with more common health conditions. Although HIV may be severely affecting certain minority groups it is unlikely they will have a strong political voice, both because of their minority status and because of issues of stigma and prejudice. Furthermore, there are immense advantages to the national 'economy of scale' when it comes to expertise and resources to analyse need, plan models of intervention and develop resources. Whether there should continue to be two separate national HIV prevention programmes or a single programme with various elements is something for further consideration – a single national HIV prevention programme would have the advantage of also addressing other emerging elements of prevention need (see below). **The national HIV prevention programme should be managed by Public Health England with strategic advice from all key stakeholders, including the voluntary sector, epidemiologists, social/behavioural scientists and clinical staff.**

Caribbean communities:

² See 'Building on progress: enhancing the response to HIV in England', Independent Advisory Group on Sexual Health and HIV 2009

22. HIV prevalence amongst black Caribbean communities is much lower than for example in African communities, but is nevertheless three times that of the wider British population. There are also elevated rates of other STIs. This disproportionately high prevalence of HIV is found amongst both heterosexual and homosexual Caribbeans, and is partly acquired overseas but also driven by ongoing infection in the UK. There is currently no strategic approach to meeting the HIV prevention needs of these communities nor are there dedicated funds for such a purpose.³ **NAT recommends that the HIV prevention needs of Caribbean communities be included within the remit of the national HIV prevention programme(s).**

Injecting Drug Users:

23. HIV prevalence amongst injecting drug users (IDUs) has remained low, particularly when compared with that in other countries. This is in large measure because from the outset of the epidemic there was a strong emphasis on such harm reduction measures as provision of clean needles and injecting equipment, and of opiate substitution treatment (OST), for example methadone maintenance. Recent studies have identified areas for improvement – in particular more consistent accessibility of HIV (and other BBV) testing, and clean injecting equipment, in drug treatment services, and also the provision of safer sex advice in these services.⁴
24. Moreover, HIV prevalence amongst IDUs in London is approaching 4%, the threshold at which UNAIDS considers there are real concerns of an expanding epidemic, and equivalent to prevalence in MSM and African communities nationally. It is important therefore to avoid complacency. **Public Health England should re-examine HIV prevention work amongst IDUs, drawing on the expertise of staff from the HPA and the NTA who will have been brought into the department, as well as external experts. The national HIV prevention programme should address the prevention needs of IDUs, in particular gaps in HIV testing, safer sex advice and needle exchange within drug treatment services.**
25. There is a current Government emphasis on recovery from addiction which, though well-motivated, needs to be considered with care. Pressure on IDUs to move on from OST can result in a return to addicted and chaotic lifestyles. For those diagnosed with HIV, moving off OST can undermine adherence to HIV treatment and thus harm the individual's health and increase their risk of infecting others.
26. There is also a serious failure in HIV prevention for those IDUs (a significant proportion) 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. At present provision of clean injecting equipment is forbidden in UK prisons. Disinfectant tablets are available but they are acknowledged to be inferior as means of preventing BBV transmission from shared injecting equipment. The principle of comparable healthcare in prisons to that in the community is breached in denying prisoners this essential preventive intervention for those who inject drugs. Experience of such prison needle exchange programmes, for example in

³ For more detail see 'HIV and black Caribbean communities in the UK', NAT 2010

⁴ For more extended consideration of these issues see 'Injecting drug users and HIV', NAT 2010

Spain, shows decrease in drug use, decrease in harms and no instance of attacks with needles. **NAT recommends that there be a pilot of prison needle exchange in an English prison at the earliest opportunity.**

Prevention and the wider public:

27. It is also increasingly apparent that we need to look again at HIV prevention for the public as a whole. Of course HIV prevalence outside those groups most at risk remains very low. But it is estimated that in 2009 of all UK-acquired infections diagnosed, approaching a quarter were neither amongst MSM nor African men or women. In other words, they were of people who are not currently served by either of the two national HIV prevention programmes.
28. It does not seem to be cost-effective to undertake, for the whole population, the sort of intensive work being advocated for gay and bisexual men and for African communities, given the low prevalence amongst the general public. But for those infected HIV will be a lifelong health burden and the costs to the public purse of these HIV transmissions are significant. We have to identify 'smart' ways of reaching the general public with HIV prevention messages.
29. The need for this is underlined by the surveys undertaken by Ipsos MORI for NAT of public understanding of, and attitudes to, HIV. 20% of people do not know that HIV is transmitted by sex without a condom between a man and a woman. This is a decline of 10% from ten years ago, when 90% knew this fact.⁵
30. **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 (by contrast, the last DH television campaign for condom use, 'Essential Wear', did not mention HIV amongst the STIs to be prevented).**
 - **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.**
 - **We should encourage more and better quality of reporting on HIV in the media.**

Developing our prevention strategies:

31. Improving HIV prevention is not just about incentivising action and funding, identifying outcomes, and targeting the right people, it is also about looking innovatively at our interventions themselves. The increasing awareness that HIV treatment reduces viral load to levels which make transmission extremely unlikely is profoundly changing prevention strategies - **improved HIV testing, adherence to medication for those diagnosed positive and the**

⁵ 'HIV: Public Knowledge and Attitudes, 2010', NAT 2011

avoidance of untreated STIs are now important prevention goals.⁶ In addition,

- **UK prevention work must address not just condom use but also partner numbers as key factors in reducing risk of HIV transmission.**⁷
- **Renewed effort is necessary to educate people as to why HIV remains a serious life-long condition to be avoided, even with effective treatment available. Such information must not use fear or exaggeration, nor stigmatise people with HIV, but just communicate the facts.**

E. Testing

32. As with HIV prevention the high rates of late diagnosed and undiagnosed HIV in the UK strongly suggests that more needs to be done in terms of testing for HIV. The HPA estimates that 26% of people in the UK with HIV are undiagnosed.⁸ 52% of those diagnosed in 2009 were diagnosed 'late', that is after the point at which they should have started treatment, and 30% were diagnosed 'very late' with a CD4 count of less than 200 (roughly equivalent to eight years undiagnosed on average). 73% of those with HIV who died in 2009 had been diagnosed late. NAT is part of the 'Halve It' campaign, which brings together voluntary and private sector organisations, clinicians and epidemiologists with the aim of campaigning for a national response which will halve the proportion of people diagnosed late and the proportion of those with HIV who are undiagnosed.
33. The approach to HIV testing has been revolutionised by a number of factors in recent years. One is the increasing effectiveness of HIV treatment in keeping people well and enabling a near normal life expectancy – but this crucially depends on the individual being diagnosed in time, before their immune system is irreparably and seriously harmed by HIV. Late diagnosis makes an early death more likely, as well as serious and complex illness, which it is much more difficult and costly to treat. Moreover, we now know that HIV treatment can reduce infectiousness to near zero – early diagnosis and treatment is thus a vitally important preventive measure. Finally, developments in testing technology make HIV testing faster, more reliable and less invasive, increasing the accessibility and acceptability of the test.
34. The primary model for HIV testing in the UK has traditionally been 'opt-in' where the person must proactively agree to any offer of an HIV test. Furthermore, most HIV testing was sought out at sexual health clinics by those wanting a diagnosis. Therefore, historically, testing has been predominantly restricted to sexual health and community clinics.
35. Change began in 2000 with routine opt-out HIV testing in ante-natal care. Research has shown this approach to be acceptable and very few women opt out.⁹ The result has been earlier diagnosis of women with HIV and the prevention of mother-to-child transmission.

⁶ 'Towards a UK consensus on ART and HIV transmission risk', NAT 2010

⁷ 'Partnership Patterns and HIV Prevention amongst MSM', NAT 2010

⁸ 'HIV in the United Kingdom: 2010 Report', HPA 2010

⁹ 'Time to test for HIV: Expanded healthcare and community HIV testing in England, Interim report', HPA 2010

36. The model pioneered in ante-natal care of a routine opt-out HIV test in a healthcare setting was picked up and applied more widely by the UK National Guidelines for HIV Testing 2008, developed by BHIVA, BASSH and BIS, which recommend that HIV testing should be routine and opt-out in specific healthcare settings such as STI clinics, antenatal services, drug dependency programmes and healthcare services for those diagnosed with certain clinical indicator conditions including tuberculosis and hepatitis. They also recommend that testing should be offered to key at-risk groups and in communities with high prevalence, and repeat testing should be offered to those most at risk. Importantly, they recommend that in high prevalence areas (diagnosed prevalence of 2 or more per 1,000) routine opt-out HIV testing should be provided to all new GP registrants and in general medical admissions in hospitals.
37. Whilst the Department of Health has been supportive of the UK Guidelines, and helpfully funded some testing pilots of this new approach, the Guidelines are not formally 'endorsed' by the Government. **It is important, given the success of the testing pilots, that the Government formally endorse the UK National Guidelines for HIV Testing ('the UK Guidelines') as the testing policy to be implemented across the NHS. One reason for this is that responsibility for HIV testing will quite possibly be fragmented across different commissioning bodies – the NHS Commissioning Board, local authorities and GP consortia. Clarity in our HIV testing strategy is vital.**

Increasing testing 'demand'

38. Currently over a quarter of MSM have never tested for HIV,¹⁰ and approximately 40% of black Africans have never tested for HIV.¹¹ Both these statistics are improvements on past years. But that still leaves a significant minority who have never tested in both at-risk groups. Furthermore, 'ever tested' is only a minimal measure of testing effectiveness. For those who are sexually active within high prevalence populations it is not enough to test just once. Regular testing is necessary.
39. Sexual behaviour is difficult to change but testing behaviour seems more susceptible to health promotion messages. There has been progress in recent years and this momentum must be maintained. One recent development is of a consensus in the HIV sector around messages to MSM on how regularly to test. A similar consensus has still to be developed for testing advice to African communities.
40. **Interventions should be funded to communicate to MSM the importance of testing for HIV at least once a year, and more frequently according to risk. The HIV sector should also agree as soon as possible recommendations on frequency of HIV testing for African communities in the UK.**

¹⁰ 'Tactical dangers: findings from the UK Gay Men's Sex Survey 2008', Sigma Research 2010

¹¹ 'Bass Line 2008-09: Assessing the sexual HIV prevention needs of African people in England', Sigma Research 2009

41. One of the difficulties in encouraging demand for an HIV test is the fact that for many years HIV can be asymptomatic – there is no apparent ‘illness’ which might motivate someone to seek medical advice. However, for between 70% and 90% of people infected with HIV there is a short period soon after infection where symptoms of ‘primary HIV infection’ are evident – usually a combination of fever, rash and sore throat. This is an important opportunity to seek and/or be offered an HIV test.¹² **More work must be done to increase knowledge of symptoms of primary HIV infection in most affected groups and encourage HIV testing where such symptoms occur. It is also important to increase knowledge of primary infection amongst healthcare workers, especially those in primary and emergency care, where currently symptoms are commonly missed.**
42. There are additional barriers to those at risk accessing HIV tests. BASS Line found that a high proportion of African men and women simply do not know where to get an HIV test. More work also needs to be done in at-risk communities around assumptions of monogamy, and more generally on the prevalence of HIV in their communities and of undiagnosed HIV in particular. There has also been a reluctance to emphasise the effectiveness of timely treatment because of a worry that somehow this will undermine prevention messages. This is not true – accurate knowledge of HIV and the effectiveness of treatment will encourage testing, reduce transmission of undiagnosed HIV, contribute to the reduction of stigma, and enable people to consider HIV risk reasonably and responsibly.
43. For people in African and other migrant communities there is a particular worry as to whether if diagnosed HIV positive one will be able to access HIV treatment. In fact though certain migrants are liable to charges for HIV treatment, the treatment itself should in any circumstance be accessible as ‘immediately necessary’ – but the prospect of unpayable bills and debt collectors is enough to deter many, including those who in fact can access free treatment but who are confused over the rules. The intrusion of immigration issues into public health has a wider and harmful impact. The BASS Line Survey in 2007 found that 42% of African respondents did not know that you could not be deported because of your HIV status. One implication of course is for further work communicating the facts around NHS access and immigration policy. But another must be for the Government to detach HIV services from immigration policy. That means providing free HIV treatment for those living here who need it, just as is done for all other STIs and infectious diseases. It also means dropping plans in the UKBA/DH consultations last year for the NHS to inform the UKBA of NHS debtors so that future requests for entry, visa extension or citizenship might be refused.

Increasing testing ‘supply’:

44. The HPA have recently evaluated a series of DH-funded HIV testing pilots which were designed to expand HIV testing and increase take-up.¹³ These pilots, most of which were either hospital or primary care based, rolled out HIV testing as routine and opt-out. There were high levels of uptake of tests in both primary care and hospital settings, which indicates that such an

¹² See 'Primary HIV Infection', NAT 2008

¹³ 'Time to test for HIV: Expanded healthcare and community HIV testing in England, Interim report', HPA 2010

approach to testing is acceptable to people. They proved cost-effective in terms of numbers diagnosed HIV positive (where this is estimated as a diagnosis rate of at least one per 1,000). The pilots also included community HIV testing projects focused on high-risk communities. These pilots saw a lower level of uptake, but again positive diagnoses. A further demonstration of cost-effectiveness is that many of the pilots are now continuing with local PCT funding.

45. **HIV testing should be routinely offered in high prevalence areas in general and acute medical admissions and to newly registering GP patients. These have been demonstrated to be cost-effective and acceptable to healthcare staff and patients alike. NICE Guidance should reflect the UK Guidelines on this point. The NHS Commissioning Board and GP consortia should commission accordingly.**

HIV testing in non-HIV secondary care specialties:

46. An important element in the UK National HIV Testing Guidelines is the need for consistent opt-out HIV testing in relevant secondary care specialties where other conditions indicate the possibility of HIV infection – for example, TB, hepatitis and lymphoma. HIV tests are still performed too rarely in many of such settings, resulting in HIV being missed and the person being diagnosed far too late. This is in NAT's view tantamount to clinical negligence and a sometimes deadly example of how HIV stigma can undermine effective healthcare. Most of these secondary care specialties will soon, according to Government plans, be commissioned by GP consortia according to NICE guidelines, which will be developed in the near future. **It is essential that NICE Guidelines for relevant secondary care specialties include routine HIV testing as recommended by the UK National HIV Testing Guidelines and that GP consortia consistently commission to these standards.**

Community testing:

47. There is also a fundamental need to extend HIV testing beyond clinical settings and make testing more accessible to reach the significant amount of unmet need. Testing strategies must offer people real choices which meet their different and changing needs, and community testing may well extend accessible testing to those who might not otherwise seek an HIV test. Community testing is often provided by the voluntary sector but could as well be provided by NHS services. **More consideration is needed of how to integrate community testing into the local 'health economy'. In particular, it is important to identify how community testing can not only provide convenience but also reach people for testing who would otherwise not seek an HIV test.**

Home testing:

48. Home sampling for HIV could be an innovative method to increase up-take of testing, as it removes the necessity to go to a clinic or GP and therefore may be less daunting to many people. Home sampling involves the individual taking their own blood sample, sending it to the laboratory/service for testing, and then receiving the result and relevant counselling from the service. Studies have shown that it is acceptable to people at risk and to those who

would not normally access testing.¹⁴ Home sampling is legal in the UK and is offered by some private companies. One of the DH testing pilots was also of home sampling amongst MSM. **Further exploration of home sampling within the NHS is needed – in particular, hard-pressed GU clinics could consider home sampling as a means of triaging those wishing to have an HIV test.**

49. More radical, but possibly more popular, would be the legalisation of home testing kits for HIV, where the result is available there and then to the individual. Self-testing could expand the reach of HIV testing and increase test take-up. US studies have indicated that self-testing for HIV is acceptable among those who have never tested before and among people at risk.¹⁵ However before self-testing could be considered the HIV Testing Kits and Services Regulations 1992 (Statutory Instrument 1992 No. 460) would have to be amended so as to permit and regulate self-testing kits. This would allow the Government to ensure proper quality control and management of self-testing.
50. **Home testing for HIV should be legalised and regulated, and integrated into strategies to increase HIV testing take-up.**

Mandatory testing:

51. In the early days of panic around AIDS there were some calls for mandatory HIV testing as a response to the epidemic. Happily in the UK no such policy was pursued. Mandatory testing breaches the human rights of the person tested¹⁶ and the ethical obligations of the healthcare worker. It singles out HIV as in some way especially to be feared, thus perpetuating and entrenching stigma (no other condition in the UK is tested for on a mandatory basis). It thus is counter-productive, driving the epidemic underground. It is also unnecessary – all the recent HIV testing pilots 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.
52. It should also be noted that HIV testing as a condition for certain goods, services, employment or privileges can be effectively mandatory and should only be applied in rare and absolutely essential circumstances. The recent ILO Recommendation on HIV/AIDS and the world of work, for example, prohibits the use of HIV testing for those seeking employment, those in work or those migrating for work.
53. **Mandatory HIV testing should not be introduced in any form.**

F. Treatment

Commissioning HIV treatment and care:

¹⁴ 'Home testing for HIV', NAT 2008

¹⁵ 'Home testing for HIV', NAT 2008

¹⁶ See Guideline 3 'International Guidelines on HIV/AIDS and Human Rights', OHCHR/UNAIDS 2006

54. Current NHS reforms have put a spotlight on how HIV treatment is currently commissioned and delivered and our vision for the future. NAT considers that there are a number of possible commissioning models which could work (and indeed there are different models in different parts of the UK). It is as important to ensure any particular approach is given time to bed down and for the necessary commissioning expertise to develop in the responsible organisations. NAT has been providing administrative support to the HIV and Sexual Health Commissioners Group for England in the conviction that such a peer network can be invaluable in developing best practice and sharing experience. In the few years during which we have been supporting the Group there has been evidence of such progress. The proposed reforms are inevitably going to result in loss of skilled staff and of institutional knowledge.
55. In the NHS White Paper proposals, most NHS commissioning was to be undertaken by GP consortia, though there was an alternative for certain conditions and services of central commissioning by the NHS Commissioning Board. NAT, along with a number of HIV sector organisations, argued that HIV outpatient care should be commissioned by the NHS Commissioning Board rather than GP consortia. There were a number of reasons for this preference, including the complexity of cross-charging for patients between GP consortia, the advantage of national commissioning for drug procurement, the distorting impact of an even small increase in HIV positive patients for GP practices, the lack of experience of HIV and HIV services amongst many GPs, and the fact that open access HIV clinics have meant that the advantages cited for GP consortia do not as obviously apply in relation to this condition.¹⁷
56. There are a number of high cost/low volume conditions which are in a 'national definition set' for specialised commissioning and these conditions were in any event all to be commissioned by the NHS Commissioning Board, including HIV paediatric care and HIV inpatient care. HIV outpatient care had been removed from the specialised commissioning national definition set only a year previously, and on a consensual basis much of the regionally based arrangements to commission such services remained in place. The Government in its response to the NHS White Paper consultation agreed that the NHS Commissioning Board would commission HIV outpatient care, citing as one reason the advantages for drugs procurement. NAT are of course pleased with this outcome. But challenges remain.
57. **The NHS Commissioning Board will inevitably be removed from experience at local and clinic level. If possible, some regional/'supra-local' based structuring of its commissioning of HIV treatment would ensure flexibility and responsiveness to the situation on the ground.**
58. **Healthcare planning will take place at the local level in the proposed Health and Well-being Boards. It is not clear how those whose healthcare is commissioned by the NHS Commissioning Board will have their interests and needs represented at these Boards around the country.**
59. **There has been real progress of late in integrating sexual health services. Government proposals separate out the commissioning of**

¹⁷ See <http://www.nat.org.uk/News-and-Media/Consultation-Responses.aspx> and NAT response to the NHS White Paper consultation: Commissioning for Patients October 2010

HIV treatment and care (NHS Commissioning Board) from local sexual health services (local authority commissioning). The danger is a return to fragmented and uncoordinated (and thus more expensive) services - explicit and proactive steps will need to be taken to counteract such a consequence.

60. **The NHS Commissioning Board's role in HIV commissioning should not be seen as a defence of the status quo in how HIV treatment is configured and provided. It may be the opportunity to implement real change. For example, the NHS Commissioning Board could require greater involvement of GPs in the care of stable HIV patients.**
61. **Performance of the NHS Commissioning Board in these responsibilities will need to be measured and assessed by the Secretary of State. Outcome measures should be agreed which demonstrate high quality HIV treatment and care, perhaps developing and applying nationally those developed for London with support from the HPA.**
62. There are a number of issues which financial pressures will make more acute. In relation to drugs, one emerging concern, as some drugs in the near future come off patent, is that decisions will be made to take patients off single pill prescriptions and instead placed on different pills for the different drugs for cost reasons. It will be important to set such proposed savings against the impact on quality of life and adherence for people with HIV themselves, as well as the potential public health impact of reduced adherence.
63. In relation to the configuration of services, further work needs to be done to assess how we can develop services for most people with HIV which are not exclusively provided in acute care but where there is some sharing of provision with more cost effective primary and community care settings and providers. There are opportunities for GPs to have more of a role in monitoring of stable patients, for home delivery of drugs and greater virtual communication. This will all have to be under appropriate specialist clinical oversight and with stringent quality standards and protocols.

Social care:

64. Social care can cover a wide range of interventions, funded by local authorities, and designed to help people in their daily lives so as to play a full part in society. Until last year social care for people with HIV was separately funded through a ring-fenced grant to local authorities in England known as the AIDS Support Grant (ASG). NAT conducted a survey of the use of the ASG in 2009 and found that HIV social care was mainly spent on such services as counselling, peer support, staff training, support for adult and for young carers, personal care, children and young people, and some respite and residential care.¹⁸ Such services can clearly be vital in enabling people to come to terms with a diagnosis, and secure support around adherence and care needs.
65. The AIDS Support Grant and its ring-fence ended in 2010. It was, however, good to see the Government in the Comprehensive Spending Review both increase the amount provided in the Formula Grant to local authorities for social care, but also retain, albeit no longer ring-fenced, a distinct allocation

¹⁸ 'The AIDS Support Grant: Making a difference?', NAT 2009

for HIV social care based on local HIV prevalence (the only condition-specific allocation to continue). We are under no illusions as to the pressure for cuts being experienced in local authorities. Across the country people with HIV and organisations supporting them are making the case for HIV social care being an essential preventive intervention, supporting for example adherence to medication, self-management, social inclusion, and thus avoiding physical and/or mental deterioration which is so distressing to the individual and of course increases costs.

66. The Government has earmarked £1 billion for integrated NHS/social care provision but details are as yet unclear. One focus will certainly be 'reablement' of those leaving hospital. NAT hopes that funds for NHS/social care coordinated interventions will look also at those with serious long-term conditions who are living in the community.
67. In responding to the recent Government consultation on a social care outcomes framework,¹⁹ we made clear our concern that proposed outcome measures will fail to capture the experiences of people with HIV. **There is a danger in the current 'drive to the local' that outcomes of care, whether healthcare or social care, for often marginalised minorities get lost in the bigger picture. It remains very unclear what 'must do' there is at the local level to ensure that there is the political will to meet the needs of groups such as people with HIV, or gay men or African migrants.**
68. **A key support will be early development of NICE guidance for HIV healthcare and social care against which we can assess performance and quality. Such guidance should identify how HIV outpatient care and social care are provided and joined up, but also how these are integrated with other essential provisions such as appropriate psychological support, which is currently so patchy across the country.**²⁰

Wider determinants of successful treatment and care:

69. Challenges to successful treatment and care rarely relate to HIV clinics themselves, which provide services to a high standard. However good one's direct HIV-related treatment, an individual's health and well-being can nevertheless be profoundly undermined by poverty, the immigration system, failures and delays in benefits assessment and the provision of benefit, and by poor, and untreated, mental health. In all these areas NAT has undertaken detailed work.²¹ The stresses of such social and health factors undermine adherence and more broadly affect how well people respond to treatment and care. **With a high proportion of people with HIV within the immigration system, significant levels of severe poverty (between 2006 and 2009 one in six of all people with HIV had to access the charitable support of the Hardship Fund for emergency assistance), and disproportionately poor mental health, the planned national strategy must involve key relevant government departments. In particular for HIV treatment and care to be effective we need:**

¹⁹ Go to <http://www.nat.org.uk/News-and-Media/Consultation-Responses.aspx> and the response to 'Transparency in outcomes - a framework for adult social care', February 2011

²⁰ See 'Psychological support for people living with HIV', NAT July 2010

²¹ See 'Poverty and HIV 2006-2009', NAT/THT 2010; 'Unseen disability, unmet needs', NAT 2010; 'Psychological support for people living with HIV', NAT 2010

- **An immigration system which consciously and proactively supports access to treatment and adherence (including during dispersal, detention and removal)**
- **A benefits system which assesses people with HIV fairly and accurately, which supports those who can work back into employment, and which makes decisions on, and provides, benefits promptly and efficiently**
- **A healthcare system which acknowledges the elevated mental health needs of people with HIV, funds appropriate services and introduces joined-up commissioning and referral.**

G. Cost

70. The HIV interventions outlined above are all immensely cost-effective compared with the alternative of neglecting them. Work by the HPA has estimated that preventing a single HIV transmission in the UK would save between £280,000 and £340,000 in direct lifetime healthcare costs alone. On that basis, were we to have prevented all the UK-acquired infections diagnosed in 2008 we would have saved the taxpayer over time £1.1 billion.²² Of course we need to do more to demonstrate, as discussed above, the extent to which our prevention work currently does prevent new infections. It is also important to show that we are acting cost-effectively in our prevention work.
71. Similarly, early testing and diagnosis, timely commencement of treatment and good adherence all avoid the high cost of severe HIV-related illness and death, and the costs arising from further transmission of HIV by people who are unaware of their status or who are infectious because not adhering to treatment. Again, whilst the cost-effectiveness of timely testing and treatment is not disputed, we must, as discussed above, look critically at structures developed when HIV was a less common and an untreatable condition, and consider whether there are not more economical ways of providing the same quality of care.

H. Stigma and discrimination

72. HIV remains a stigmatised condition and those with HIV often experience discrimination. Stigma has significant impacts on, for example, disclosure (and thus on safer sex), on social inclusion, on mental health and prospects of employment. Reducing stigma both promotes the health, well-being and rights of people living with HIV, but also has an immense public health benefit, encouraging HIV testing and willingness to discuss HIV status and safer sex.
73. Discrimination against people with HIV is unlawful - everyone diagnosed with HIV is considered in law to have a disability. This protection extends to employment, the provision of goods and services, education, trade union membership and housing. NAT were delighted to see the Equality Act 2010 consolidate and extend discrimination legislation - there are now further protections against 'dual discrimination' (where someone is discriminated against because of a combination of two characteristics - quite possible for someone with HIV); against harassment of disabled people in the provision of

²² 'HIV in the United Kingdom: 2009 Report', HPA 2009

goods and services; and, importantly, it is now unlawful in most circumstances to ask about a job applicant's health and disability in advance of a provisional job offer (this last provision, which NAT were instrumental in securing, removes a significant barrier to people with HIV entering employment).

74. For all these legal protections, discrimination still occurs. One very robust study was that in East London HIV clinics undertaken by Professor Jonathan Elford, City University, and colleagues. 30% of the sample of HIV positive patients reported having experienced discrimination. Of this number a half had experienced discrimination from healthcare workers (most commonly from dentists and GPs); 42% from family or friends; 27% from a sexual partner; and 22% from work colleagues.²³ NAT conducted research amongst gay men in employment. 20% of HIV positive gay men had experienced discrimination in employment relating to their HIV status, with an additional 8% uncertain as to whether poor treatment was HIV discrimination or not.²⁴ The most common forms of discrimination were losing one's job, being treated differently or excluded, and breaches of confidentiality. The recently published Stigma Index and surveys undertaken by Sigma Research such as 'What do you need?' also provide important evidence of the continuing prevalence of stigma and discrimination in people's lives.
75. NAT has since 2000 conducted surveys of public attitudes to, and understanding of, HIV - in 2000, 2005, 2007 and 2010. Many of the questions have remained constant through a number of surveys allowing us to track attitudes over time. Looking at the 2010 survey,²⁵ it is clear more needs to be done to tackle HIV stigma. Whilst a majority of people think more needs to be done to tackle prejudice against people living with HIV (68%) and it is right that there are laws to protect people with HIV from discrimination (69%), significant minorities think that if a family member told them they were HIV positive their relationship would be damaged as a result (19%), or if a neighbour told them (23%). Nearly a third of people (30%) said they did not have much sympathy for people with HIV who were infected through unprotected sex. The overall picture reveals an association between knowledge of how HIV is transmitted and supportive attitudes to people with HIV. It also reveals a persistent minority of people over a number of issues holding ill-informed and/or stigmatising attitudes. There has in more recent years been little change in such attitudes - a more concerted and strategic approach is clearly needed.

Access to legal redress:

76. Legal redress is possible for those who experience discrimination in healthcare and in employment. To access such redress knowledge of rights is of course important. In NAT's survey of gay men in employment one third of HIV positive respondents were unaware of their rights to protection against HIV-related discrimination, a much higher level of ignorance than for protection in relation to sexual orientation (where only 16% were unaware). Amongst those with HIV who were aware of protection from discrimination, a

²³ 'HIV-Related Discrimination Reported by People Living with HIV in London, UK', *AIDS and Behavior* 2008;12:255-64 Elford, Ibrahim, Bukutu and Anderson

²⁴ 'Working with HIV', NAT August 2009

²⁵ 'HIV: Public Knowledge and Attitudes, 2010', NAT January 2011

third were not, however, aware of their right to reasonable adjustments in the workplace.

The need for Government action to address HIV stigma and discrimination:

77. The other health condition most commonly compared with HIV in terms of the continuing existence of stigma is that of mental health problems. It has been encouraging to see the importance the Government accords to tackling mental health stigma in the newly published mental health strategy²⁶ which has as one of its six objectives that 'Fewer people will experience stigma and discrimination' and that 'Public understanding of mental health will improve and, as a result, negative attitudes and behaviours to people with mental health problems will decrease'.
78. Stigma and discrimination were addressed to a limited degree in the 2000-2010 national strategy for sexual health and HIV, and there was also a separately published 'Implementation Plan' from the Department of Health detailing some of the anti-stigma work undertaken by the voluntary sector it was funding and supporting, but both these plans have come to an end. Taking its work on mental health stigma as its example, **the Government should as part of a national strategy for HIV develop a clear multi-sectoral approach to tackling HIV stigma and discrimination. This should include:**
- **commitment to anti-stigma training across all of the NHS, with a particular emphasis on primary care**
 - **the inclusion of education on HIV and the unacceptability of stigma and discrimination in all schools' curricula**
 - **support for people with HIV in knowledge of their rights and of protections against discrimination, in personally dealing with stigma as well as in disclosure of HIV status**
 - **innovative work to improve public awareness, including -**
 - **better use of World AIDS Day to promote awareness and understanding,**
 - **identifying high profile 'champions'**
 - **supporting and empowering people with HIV to share their stories and experiences,**
 - **engagement with the media, and**
 - **regular surveys of public attitudes and understanding.**

Continuing discrimination in law and policy:

79. There are some areas of law and policy where HIV discrimination is preserved and sanctioned. Such provisions reinforce stigma and discrimination in society and need to be addressed as a priority.

HIV treatment charges

80. One is the continued charging of certain categories of migrant for HIV treatment and care. HIV is the only serious communicable disease or STI so

²⁶ 'No health without mental health', DH 2011

charged, although the public health argument for treating a serious infectious disease applies as, if not more, forcibly to HIV as to other infections. This is in our view *prima facie* an instance of discrimination at the policy level. Arguments around possible 'pull factors' to migration from HIV treatment provision for irregular migrants have been shown to be unsubstantiated in NAT's report 'The Myth of HIV Health Tourism' (October 2008). What charges do is dissuade people from certain communities from testing for HIV - the policy reinforces high levels of undiagnosed HIV and late diagnosis in African communities in England. It thus increases treatment costs for those diagnosed late (who may need emergency admission and intensive care) and furthers the spread of HIV. The policy is a classic example of discrimination, in which infectious disease is seen as the fault of outsiders who in some way need to be controlled or repelled. Such a position invariably means failing to tackle infectious disease effectively.

81. **NAT recommends that the Committee support the exemption of people with HIV from NHS treatment charges irrespective of residency status.**

Occupational exclusions for HIV positive healthcare workers

82. In employment there remain occupational restrictions for people with HIV working in certain healthcare professions. In particular those engaged in invasive procedures such as surgeons, dentists and certain midwives are prohibited from working if HIV positive. This is a particular problem for dentists who cannot readily re-train for other healthcare roles. In other countries, for example France, developments in understanding of HIV and infectiousness have resulted in changes to such rules, allowing HIV positive healthcare workers to work in areas previously prohibited. We believe that given what we now know of the impact of treatment on infectiousness it would be hard to defend these exclusions were a discrimination case to be brought. We also consider that such exclusions reinforce stigmatising and discriminatory attitudes within the healthcare system, and so contribute to the negative experiences of people with HIV cited above. There is currently a working group looking at these occupational exclusions in healthcare.
83. **NAT recommends that as part of a wider and concerted effort to remove HIV stigma and discrimination from the NHS, that the current 'blanket' occupational exclusions are ended on HIV positive healthcare workers engaging in any invasive procedure.**

Discrimination in the armed services

84. A further area where employment discrimination law does not apply is the armed services where we understand there still to be restrictions on the employment of people with HIV. The International Labour Organisation (ILO) last year agreed its Recommendation on 'HIV and AIDS and the World of Work',²⁷ a part of the body of international law, which applies to 'armed forces and uniformed services' and which prohibits HIV status being a ground for discrimination in 'recruitment or continued employment' of any individual. The policy of the armed services needs to be reviewed in the light of what we now know of the manageability of HIV and a recommendation from the Committee to this effect would be very useful.

²⁷ ILO Recommendation concerning HIV and AIDS and the World of Work, 2010 (No.200)

85. **NAT believes that current occupational restrictions around the employment of people with HIV in the armed services are discriminatory and should end.**

NAT
February 2011