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House of Commons

Health Committee

**SEXUAL HEALTH**

Minutes of Evidence

Tuesday 23 July 2002

Communicable Disease Surveillance Centre,  
Public Health Laboratory Service  
Dr Barry Evans

Terence Higgins Trust  
Mr Nick Partridge

National Aids Trust  
Mr Joseph O'Reilly

Sigma Research  
Dr Peter Weatherburn

Brunel University  
Dr Alec Miners

Royal Free and University College Medical School  
Mr John Imrie

HC 990-iv, Session 2001-02

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# House of Commons

## Health Committee

### SEXUAL HEALTH

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TUESDAY 23 JULY 2002

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## Members present:

Mr David Hinchliffe  
John Austin  
Andy Burnham  
Jim Dowd

Julia Drown  
Sandra Gidley  
Dr Doug Naysmith

(In the absence of the Chairman, John Austin was called to the Chair)

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**Memorandum by the National AIDS Trust (SH 41)****SUMMARY**

Rapid escalation of HIV and STI rates indicate that England faces a public health crisis in sexual health. The National Strategy needs to be backed by significantly more resources and greater political commitment to avert further public health harm. The Strategy needs to radically increase its breadth beyond health services issues in order to represent a whole of Government response to this deepening crisis. The Strategy's implementation should be driven forward by a National Service Framework on Sexual Health and HIV so as to ensure that sexual health and HIV services receive adequate priority at local levels.

**NAT**

1. National AIDS Trust (NAT) is a registered charity and the UK's leading HIV/AIDS policy and advocacy organisation. We work in partnership with voluntary and statutory sector agencies across the UK to promote policies which are responsive to the needs of people living with HIV and communities most affected by the epidemic. Our work is informed by a human rights framework and we address both domestic and global policy aspects of the epidemic. Our priorities are to address complacency, combat stigma, promote innovative prevention approaches and support greater access to HIV treatments.

**CONTEXT—ESCALATING HIV AND STI RATES**

2. New HIV diagnoses are at record levels. The Public Health Laboratory Service (PHLS) report that the number of people are living with diagnosed HIV has been increasing by 10–15 per cent per annum since 1996, over 33,500 people living with HIV in the UK, and over 4,160 new HIV cases were diagnosed in the UK last year alone. Although treatments prolong life for many, there is growing evidence of drug resistance. HIV drug regimens are complex and difficult, and there is still no cure or vaccine for HIV or AIDS.

3. Since 1995, the rates of new episodes of genital chlamydia diagnosed at GUM clinics in England and Wales increased by 105 per cent in females and 98 per cent in males. In 2000, the highest rate of diagnosis was found in the 20- to 24-year age group in males and the 16- to 19-year age group in females. Almost 1 per cent of the 16- to 19-year old female population were diagnosed with chlamydia in GUM clinic in 2000. Similarly, the number of diagnoses of gonorrhoea rose by 102 per cent, from 10,204 to 20,663 between 1995 and 2000, with the steepest increases amongst older teenagers (PHLS).

4. In this context, NAT welcomed the publication of the National Strategy but we are disappointed with delays in its implementation and the failure to accord adequate resources to support implementation.

**STRONG LEADERSHIP IS CRUCIAL**

5. There has been increasing complacency about sexual health issues throughout the community and this has been reflected at the political level. STIs; and HIV are stigmatised conditions and unpopular causes. Those whose sexual health needs are greatest are often members of communities which experience social exclusion, such as gay men and African and Caribbean communities. Sexual health and HIV were accorded "key priority" status by previous Governments' policies (eg *The Health of the Nation* 1992) alongside heart disease, cancer, accidents and mental illness. This "key priority" status is no longer enjoyed, and there is no National Service Framework (NSF) planned for HIV and sexual health services.

6. Without NSF status, sexual health has poor prospects of achieving recognition as a priority at the local level by newly established Primary Care Trusts which will be required to give priority to meeting NHS targets for NSF conditions such as cancer, mental health and heart disease. NAT recommends that the Strategy's



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implementation be driven forward by a National Service Framework on Sexual Health and HIV, based on the framework provided by the Commissioning toolkit currently being drafted by the Department of Health and the service standards being developed by the Medical Foundation for AIDS and Sexual Health.

7. Implementation needs to be supported by mechanisms which ensure sustained political leadership for the Strategy, including Ministerial involvement in driving implementation forward, national ownership of the Strategy at the highest political levels, and periodic reporting to Parliament on Strategy achievements.

8. England's HIV epidemic is rapidly changing due to epidemiological shifts and treatment advances. An approach developed to address today's HIV needs is very unlikely to remain wholly applicable 10 years from now. Therefore regular Strategy evaluation and reviews, for example every three years, are required at national level.

#### FUNDING SHOULD MATCH GROWTH IN NEED

9. More central funding tied to the Strategy is required, particularly given that the mainstreaming of HIV budget allocations is expected to lead to a reduction of investment in local HIV and GUM services. GUM services have historically relied heavily on HV ringfenced/earmarked funds for their sustainability, GUM services are in crisis as funding increases have been unable to match the rapid rise in demand for STI and HIV diagnosis and treatment services.

10. Within hospitals HIV treatment providers will be increasingly competing for limited funding with other treatment services. HIV treatment costs are escalating as demand increases and treatment regimes become more complex. The London HIV Strategy (Modernising HIV Services in London, NHS November 2001) identified a projected £20 million shortfall in funding for London's HIV treatment services in 2003-04 given current projections in treatment demand.

11. Robust performance management measures need to be in place lest HIV services risk being sidelined. Where HIV-specific services are commissioned, preference is likely to be accorded to meeting escalating treatment costs rather than prevention needs. PCTs will need clear directives on the importance of sustaining prevention investments, and Strategic Health Authorities should be tasked with ensuring that targeted HIV prevention work is accorded a priority. The voluntary sector has played a leading role in providing HIV prevention and social care services. Pressures placed on budgets are likely to result in dis-investment in the voluntary sector, which will undermine the capacity to deliver the community-based HIV prevention interventions which have proved so successful to date.

12. NAT welcomes the AIDS Support Grant review but is concerned that robust quality protections are in place so that care services are maintained. Allocation of funds to address HIV social care needs should reflect HIV prevalence rather than prevalence of AIDS, to reflect the full range of psycho-social support and care needs which are experienced from the time of initial HIV diagnosis. HIV social care needs of groups such as asylum seekers are increasingly diverse and require the development of services that can respond to cases of complex and multiple needs. We are concerned that the funding environment is such that there will be insufficient HIV-specific social care and support services left to realistically meet the growth in demand. Plans to develop service standards will not necessarily resolve this problem.

#### PREVENTION SERVICES ARE AT RISK

13. Gay men continue to be the group amongst whom the majority of new HIV transmissions occur in England. Support for local targeted interventions with gay men is essential if the Strategy is to succeed in reducing HIV incidence. Further work is also required to implement a coherent national programme of work targeting African communities, as it is within African communities that new diagnoses are increasing most rapidly. The Strategy's implementation plan should provide a robust performance management mechanism whereby Strategic Health Authorities hold PCTs to account for the commissioning of targeted HIV prevention work with gay men, Africans, people with HIV and other priority populations.

14. The premise of the Strategy is that most prevention work will be commissioned locally. There are risks of adopting a localised approach to HIV prevention in relation to groups to be targeted such as Africans and gay men. These target populations may be small in number, dispersed unevenly across regions, and mobile. The implementation plan should provide clear guidance on the joint commissioning arrangements required for ensuring delivery of effective HIV health promotion for target populations in Strategic Health Authority areas. It is NAT's experience that there are very few PCTs planning to commission prevention services through consortia, and in high prevalence regions such as London there is a real risk that commissioning will be characterised by fragmentation of approaches due to the adoption of inconsistent prevention priorities and lack of co-ordination between PCTs. This would result in resources being wasted.



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15. A gap in the Strategy relates to the need for a national response to the potential for growth in the HIV epidemic amongst other ethnic minority populations living in England, particularly Caribbean, Latin American, East European and Asian communities. A national study of service capacity against current and projected needs would be a useful initiative.

16. NAT welcomes the Strategy's commitment to a national safer sex public education campaign. Within such a campaign, HIV should be referred to amongst the range of sexually transmitted infections from which people are at risk. However, the overall risk of HIV in the UK should not be exaggerated. Any such campaign should emphasise the relatively greater likelihood for most people of contracting other infections such as chlamydia, gonorrhoea or herpes, and the lifelong implications of these if undiagnosed and untreated.

17. Vaccines for HIV and microbicides for HIV and STIs are undergoing human trials and it is anticipated that by the end of the decade partially effective products are likely to be on the market in the UK. As the Strategy purports to provide a 10 year framework it is disappointing that it does not provide any guidance regarding the need to consider the implications of the development of these new prevention options. At a minimum a commitment to resource social research into the implications of technological changes to prevention priorities would be welcomed.

#### HIV DIAGNOSIS AND TREATMENT

18. The Strategy does not fully address HIV treatment and testing access issues. We know from data on late presentations for testing, resulting in unnecessarily high mortality levels, that this is a problem for particular populations. For example, in London one in four Africans and one in six gay men are diagnosed very late in terms of the progression of HIV illness, ie having a CD4 count of less than 100 and thereby being at a stage where they already have very poor immune functioning and will be unlikely to obtain the full benefits of HIV treatments (Modernising HIV Services in London, London HIV Strategy Group Nov 2001). A range of marginalised communities experience barriers to treatment access including asylum seekers, drug users and prisoners. Barriers to treatment access include fear of stigma; discriminatory practices of health professionals; lack of access to treatment information and regulatory impediments (eg such as NHS rules restricting access to HIV treatments for visitors to the UK).

19. The Strategy makes reference to adherence to drug regimes but does not refer to the implications of emergence of drug resistant HIV. It is estimated that over a quarter of new HIV infections in the UK have resistance mutations. The Strategy implementation plan should highlight the significance of drug resistance which threatens to undermine treatment advance, and commit to supporting development of expertise in resistance testing, treatment information and adherence support services to respond to this problem.

20. The commitment to reduce levels of undiagnosed HIV is a welcome element of the Strategy. However, the emphasis on testing needs to be complemented by measures supporting HIV positive people to maintain safer sex practices. The Strategy needs to provide stronger recognition of the crucial role that targeted prevention work with HIV positive people should play if reduction of HIV incidence by 25 per cent is to be achieved. This should include peer support interventions as well as professional advice. Testing in and of itself will not reduce new infections unless placed within the context of a continuum of support for positive people from those who are untested through to those who have been living with a diagnosis for many years.

#### STIGMA, DISCRIMINATION AND HUMAN RIGHTS

21. NAT welcome the Strategy's recognition of sexual health as a human rights issue. However, the Strategy fails to outline an agenda for action on human rights. The Strategy flags up the relevance of some areas of Government action outside the NHS such as prisons and education, but does not define the mechanisms for ensuring that there is a coherent approach across Government departments. To effectively address these areas in a strategic way over the life of the Strategy, will require ongoing liaison between the Department of Health, the Home Office, Department for Education and Skills, and the Department for Work and Pensions. The Department of Health should work with the Social Exclusion Unit to examine the broader social impacts of HIV and develop a model for cross-departmental co-ordination. We commend the All Party Parliamentary Group on AIDS' recommendations arising from their Human Rights hearings that the Social Exclusion Unit undertake an investigation into all aspects of HIV in the UK (APPG AIDS Hearing Report 2001).

22. The Strategy acknowledges that many people with HIV "still suffer prejudice and discrimination" (1.10). Stigma makes prevention work more difficult, acts as a disincentive to testing and treatment, and affects the quality of life of people with HIV. NAT is working with the Department of Health in implementing a national awareness campaign to combat HIV stigma, the "Are You HIV Prejudiced?" campaign. To support this campaign, national policy initiatives should be promoted through the Strategy. Most significantly, the Disability Discrimination Act requires reform to ensure that people with asymptomatic HIV



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are protected; and there is a need to incorporate HIV within the educational and standards setting work of the Disability Rights Commission. Discrimination is also experienced by carers and associates of people with HIV, but there are no legal protections in place for these groups.

23. HIV related discrimination complicates the process of working or re-entering the workforce for many people with HIV. The Strategy implementation plan should require the Department for Work and Pensions to incorporate HIV within broader policy on disability inclusion. Implementation of the Strategy could also link with the Disability Rights Commission's programme of activities addressing workplace disability policy.

24. Research conducted by Sigma Research in 2001 found that the most common area in which people with HIV experience discrimination is in the provision of health care services. The Strategy should respond to this through ensuring education and adoption of non-discriminatory professional standards for dentists, nurses, surgeons and GPs.

25. Section 28 Local Government Act remains in force and has a negative public health impact by deterring investment in health promotion targeted at gay men which carries positive or supportive messages about sex and sexuality. Litigation in 2000 based on the Scottish equivalent of the clause resulted in suspension of funding to HIV services in Glasgow, thereby demonstrating that Section 28 continues to constitute a threat to HIV health promotion. Liaison with the Department for Transport, Local Government and the Regions is required to ensure that Section 28 is repealed without further delay.

#### PRISONS

26. The National AIDS and Prisons Forum reports that access to condoms, clean syringes, syringe cleansing agents and treatments information is poor within prisons. Condom availability varies between prisons. Prisoners with HIV face particular difficulties in adhering to complex HIV treatment regimes, for example due to lock up restrictions, and lack of availability of food at necessary times. The Strategy only mentions (at 3.14) that there is work in progress by the Prisons Service to address communicable diseases. Priorities which could be established by the Strategy include that:

- HIV treatment, treatment information and adherence support services be provided to the same standards as apply in the general community;
- condoms and needle and syringe cleansing agents be made freely available according to a national best practice standard;
- the feasibility of a pilot prison syringe exchange programme be investigated, based on lessons learnt from Spain, Germany, and Switzerland where exchanges have already been successfully implemented in 17 prisons.

#### SCHOOL SEX EDUCATION

27. The Department of Health should work with the Department for Education and Skills to strengthen the Sex and Relationships Education Guidance. Sex and Relationships Education should be a mainstream entitlement for all children and young people rather than an option. The Ofsted report *Sex and Relationships* issued in April 2002 reports that schools have cut time spent on HIV in sex education, one in four lessons on preventing sexual infections were poorly delivered and 50 per cent of under 16s who were sexually active did not use a condom the first time they had sex. The Schools Health Education Unit concluded in a report issued in 2001 that four out of 10 teenage boys have not heard of a disease called AIDS or HIV. The Unit found only 10 per cent of teachers had talked to pupils in the final year of primary school about it.

#### IMMIGRATION AND ASYLUM

28. The detrimental impact of asylum seeker dispersal and voucher policies is continuing despite the announcement of an end to voucher welfare from Autumn 2002 and the phased introduction of changes to the dispersal system. Since the dispersal system was introduced in April 2001 there have been mounting concerns that health and social services outside London are inadequately equipped to meet the needs of dispersed asylum seekers affected by HIV. Of particular concern is the lack of culturally competent family support services and specialist HIV paediatric care services outside London. In addition, the Home Office voucher system for asylum seekers prohibits many from purchasing infant formula and condoms. The Department of Health should act urgently to address these issues in conjunction with the Home Office and community groups.



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## DRUGS POLICY

29. Transmission of HIV through injecting drug use is given little attention in the Strategy. The Strategy needs to build on the successes of the last decade whereby the early adoption of harm reduction measures ensured that rates of HIV remain low amongst injectors. There is an opportunity to address issues such as equity in access to needle exchanges; investment in health promotion efforts which address issues of HIV and hepatitis C co-infection, decriminalisation of possession of injecting paraphernalia; and development of quality standards in provision of HIV and hepatitis C prevention and needle exchange services for injectors. Needle use and needle exchange issues are currently falling through the gaps in national public health policy, as are the needs of HIV positive drug users. NAT recommends this be remedied by the Strategy setting an agenda for harm reduction priorities and defining more explicit linkages between the Sexual Health and HIV Strategy, national policy on hepatitis C and the National Drugs Strategy.

June 2002

## Memorandum by Sigma Research (SH 101)

## BACKGROUND

1. Sigma Research is one of the US only social research groups specialising in the policy and practice aspects of HIV and sexual health. Sigma Research is affiliated to the University of Portsmouth and based in South London. During the last seven years, Sigma has undertaken more than 50 research and development projects concerned with the impact of HIV on the sexual and social lives of a variety of populations. Our research includes needs assessments, audits, evaluations and service reviews funded from a range of sources. We have published more than 75 research-into-practice reports, journal articles and book chapters.

2. Sigma Research is the main research partner in CHAPS, the Community HIV and AIDS Prevention Strategy co-ordinated by the Terrence Higgins Trust and funded by the Department of Health. The CHAPS partnership undertakes targeted HIV prevention work with gay men and other homosexually-active men. As part of CHAPS, Sigma has been instrumental in producing and disseminating the *Making it Count* model for local commissioning of gay men's HIV prevention. *Making it Count* is endorsed in *The national strategy for sexual health and HIV* as a best practice model for national and local HIV prevention with gay men.

3. Since 1997, as part of CHAPS, Sigma Research has undertaken the National Gay Men's Sex Survey (GMSS). Undertaken annually, GMSS is the World's largest on-going HIV prevention needs assessment of gay and other homosexually active men, recruiting over 15,000 men in the latest survey in 2001. Sigma also undertakes the largest on-going national survey of the needs of people with HIV and undertakes survey work with African people with HIV.

4. Peter Weatherburn is the Director of Sigma Research and a Senior Research Fellow at the University of Portsmouth. He has worked in HIV and sexual health policy research (continuously) since 1989.

## 1. HIV EPIDEMIOLOGY AND HOMOSEXUALLY ACTIVE MEN

1.1 Homosexually-active men (HAM) are the group at greatest risk of acquiring HIV infection in the UK. They constitute about 1.6 per cent of the population of England but bear an estimated 56 per cent of the burden of new HIV infections. Approximately 1,400 new HIV infections are reported to the Public Health Laboratory Service (PHLS) per year, giving an HIV incidence on par with gay men in San Francisco and New York. Gay men are 50 times more likely to acquire HIV infection than the rest of the population.

1.2 Some of the factors contributing to HIV incidence are becoming more common thanks to successful interventions in other areas. The number of men acting on their homosexual desire appears to be increasing, as does the prevalence of HIV due to reduced mortality in people with HIV because of anti-HIV therapy. Men with HIV infection are sexually active for longer and an increase in well-being will be accompanied by an increase in sexual activity.

1.3 Awareness of the on-going national CHAPS mass media campaigns is remarkably high (averaging about 50 per cent of all gay men in England). Awareness of small media (leaflets) and other HIV-related educational resources is less consistent and more dependent of voluntary sector infra-structure. The geographic availability of other HIV prevention interventions resemble the infamous "postcode lottery"—arising from a lack of voluntary sector infra-structure and from historic and continuing inconsistencies in Health Authority (now Primary Care Trust, PCT) commissioning. Overall, there are more opportunities in the gay population for sexual HIV exposure than ever before. This means that change in incidence is a poor indicator of the worth of current HIV prevention programmes.



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## 2. SEXUAL HEALTH—WHAT IS IT?

2.1 One of the original stated aims of the strategy was to develop a broader public health understanding of sexual health. However, it was ultimately structured to limit the meaning of sexual health to those aspects addressed by NHS clinical services. Although paragraphs 1.1 and 1.2 suggest the strategy will adopt a broad and inclusive definition of sexual health, this is quickly reduced to concern about infections and unwanted conceptions. In addition, while the proposed approaches to meeting people's HIV and unwanted pregnancy needs are chiefly educational and community-based, the strategy concentrates on describing the funding and infrastructure of clinical diagnostic and treatment interventions.

2.2 This limiting of sexual health to the absence of infection/conception and the limiting of interventions to clinical NHS providers runs throughout the strategy and causes "blind-spots" and gaps which seriously limit its likely effectiveness. Below, we outline how this might be addressed during the implementation phase, especially in the Health Promotion and Commissioning toolkits that are promised in the strategy's *Implementation plan*. If the strategy's ambitious targets are to be achieved these toolkits must provide future PCT commissioners and health promoters with a template against which to assess and prioritise local need and deliver services.

## 3. HIV HEALTH PROMOTION (HIV PREVENTION)

3.1 Health promotion (HIV prevention) is neither art nor a science. It is both far less exact than medical services, and far less mature a discipline. The strategy assumes that "prevention" = "information giving" and "services" = "clinical interventions". These assumptions lead to a belief that any provider of a clinical service is qualified to deliver any non-clinical prevention service. This is not the case and most prevention interventions require specific expertise. These skills and expertise must be acknowledged, valued and fostered if we are to collectively increase our impact on sexual health.

### *Defining HIV prevention as a discrete and highly specialised activity*

3.2 By adopting an inclusive approach to sexual health, the strategy fails to state unequivocally what constitutes HIV prevention and who should be concerned with it as a specific endeavour. Throughout the strategy, HIV prevention is confused with information provision. In turn, information-provision is confused with the methods used to achieve it (most notably outreach). Greater uptake of HIV testing is also championed as a panacea for preventing HIV infections on the basis of very little evidence and without ever articulating the process whereby it might serve to reduce the number of new infections.

3.3 The health promotion toolkit needs to define HIV prevention and its purpose, scope and rationale. It also needs to specify key target populations and outline acceptable methods to increasing access to, and the quality, of HIV prevention and other sexual health interventions. That the specialism of non-clinical HIV/STI prevention be recognised, valued, and included in the levels of interventions, rather than described separately.

### *Financing and prioritising HIV prevention in wider sexual health provision*

3.4 It is widely recognised that the long-established ring-fence around HIV prevention funds has not prevented their misuse. When these funds have been used to address HIV prevention needs, they have often failed to address those populations most likely to acquire HIV infection in the future: namely gay men and Africans.

3.5 The strategy eliminates the ring-fenced HIV prevention allocation and trusts that current changes in the NHS will improve HIV prevention services. In addition HIV prevention is "mainstreamed" with other sexual health services administered by PCTs out of their main financial allocations. It is our view that this can only exacerbate historic inefficiency and under-investment in HIV prevention, as well as existing inequalities in HIV infection, by:

- removing the very limited financial accountability that exists;
- substantially reducing the likely national spend on HIV prevention; and
- increasing already substantial competition for funds by placing HIV prevention in direct competition with other, less stigmatised, concerns such as unwanted pregnancy.

3.6 There is a real and pressing danger that HIV prevention will be lost within broader moral and financial imperatives of PCTs.



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*Targeting groups at substantial HIV prevention need*

3.7 The strategy provides an opportunity for historically mis-allocated HIV funds to be further diverted away from those who will become HIV infected. Hence, it is feasible that the strategy will foster HIV incidence, not reduce it.

3.8 The cessation of ring-fenced funding and the transfer of commissioning responsibility to PCTs has the potential to affect adversely the targeting and effectiveness of HIV prevention. The strategy conflates the causes of morbidity (sexually transmitted infections including HIV and "unwanted" conceptions) in one section, the conflated groups experiencing them in another, and finally puts all these needs in competition with each other and all other health needs for very finite funds. Because of the lack of expertise and/or prejudice amongst PCTs, "young people" will come to mean "heterosexual young women" who may become pregnant rather than "young gay men" who may get HIV.

**4. USING RESEARCH TO SUPPORT CHANGE**

4.1 It was not helpful in this complex strategy, which will be implemented over very many years, to state specific research priorities or areas. These will inevitably change as the epidemic develops, as research is undertaken and published and as interventions become more focussed in areas of practice. The listing of potential research priorities was also at odds with the very welcome statement that the research agenda should be "identified by consultation".

**5. THE WAY FORWARD (PROPOSED ACTIONS)**

5.1 The Health Promotion and Commissioning toolkits announced in the *Implementation action plan* are urgently needed. They need to address fundamental flaws in the strategy that mean the current target of reducing new HIV infections by 25 per cent seems unlikely to be met.

They should:

- Stress that while HIV prevention activity is probably best provided by specialists with health promotion experience, it is also a function of all sexual health services including primary care and specialist out-patient services (such as HIV and GUM clinics). Specialist training needs arise from this recommendation and will need to be addressed.
- Stress unequivocally that targeted HIV prevention activity is a necessary and vital part of every local sexual health strategy.
- Stress that HIV prevention is very cost effective even where it is only partially successful, given the costs associated with the treatment and care of people with HIV.
- Separate the targets of the strategy (rates of unwanted pregnancy, and the incidence of HIV, chlamydia, HPV, NSU, HPV, gonorrhoea and syphilis) from the priority groups that they affect. This involves stating specific priority target groups for each of the targets.
- State unequivocally that local HIV prevention activity should be guided by national patterns of HIV incidence and what is known of the existence of priority groups in local communities. Thus, as a general rule, interventions targeting gay men and African communities should take precedence over interventions targeting groups who are easier to access but at little risk of HIV such as "the general public".

5.2 Finally, recognising that research priorities will change constantly, the Department of Health should set-up a forum where researchers, key policy and intervention practitioners, Departmental officials and key research funders meet on an on-going basis to develop and refine research priorities.

July 2002

**Memorandum by the Terrence Higgins Trust (SH 82)****1. INTRODUCTION**

1.1 Thank you for the opportunity to give evidence to this review of the effectiveness of the national strategy for sexual health and HIV.

1.2 The Terrence Higgins Trust (THT) is the largest HIV charity in the UK. We provide HIV care and sexual health promotion services to people with HIV and HIV prevention programmes for those communities most at risk—gay men and African people in the UK. Through our care services, research and client involvement work, we are in a unique position to comment on the effectiveness of and challenges facing national plans that aim to affect the sexual health and HIV status of people throughout the UK.



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## 2. FACT AND FIGURES

2.1 The UK currently has the highest rate of sexually transmitted infections (STIs) since the NHS began, and they continue to rise dramatically. Between 1995 and 2000:

- Gonorrhoea, chlamydia and syphilis rates all rose by more than 100 per cent<sup>1</sup>
- In 2001, approximately 4,100 new HIV infections were diagnosed; more than in any year since records began<sup>2</sup>;

2.2 Meanwhile, GU services and the HIV voluntary sector are struggling to meet client need:

- THT has found that over 40 per cent of people needing sexual health appointments have to wait more than a week to be seen, and 1 in 10 have to wait more than a fortnight<sup>3</sup>;
- Clinic workload has increased by 34 per cent in 5 years<sup>4</sup>;
- Uptake of THT services has increased between 10 per cent and 500 per cent in the last two years<sup>5</sup>.

2.3 A survey by THT and PatientView found that GPs are reporting problems

- Collaborating with specialist HIV services;
- Understanding complex issues of confidentiality and HIV<sup>6</sup>.

2.4 In the same period, the government has:

- Removed sexual health and HIV as a core priority for action;
- Removed ring fencing from HIV prevention funding;
- Devolved commissioning power to local, non-specialist PCTs;
- Issued the draft national strategy for sexual health and HIV but not provided, or indicated an intention to provide a corresponding National Service Framework that could transform principle into practice.

## 3. ANALYSIS

3.1 The recent dramatic rise in the number of STIs, combined with unprecedented levels of HIV diagnoses make it clear that sexual health and HIV are health issues that require urgent, prioritised action from central government. It is sadly ironic that, as prevalence has increased, the government has undertaken a range of reforms within the NHS that have actively de-prioritised sexual health and HIV. These have had the effect of undermining the national strategy before it has had time to take effect.

3.2 The government has provided all PCTs with a wide range of targets and priorities for general healthcare provision as well as four specific clinical priorities (cancer, CHD, mental health and older people). Given this government emphasis on performance within the NHS, it is clear that anything outside this framework is unlikely to be a priority for PCTs as they struggle to establish themselves. The voluntary sector, whose services have never been in such high demand, are at particular risk in this new climate.

3.3 THT welcomes the aims laid out in the draft strategy but recognises that without active guidance, most usefully through a National Service Framework (NSF), they will be difficult, if not impossible to achieve. A NSF would ground the aims of the strategy in practical guidance and give teeth to the upcoming commissioners' toolkit, by

- Setting national standards and providing practitioners with service models for a defined service;
- Putting in place strategies to support implementation;
- Establishing performance milestones against which progress within an agreed time-scale will be measured.

3.6 Intentions spelt out within the draft strategy to encourage greater involvement in sexual health and HIV testing and treatment by generic healthcare providers, particularly GPs, add to the concern around PCT capacity. The difficulties even HIV friendly GPs continue to face require training and guidance that springs from an in-depth understanding of a complex medical and social issue. Given the already high demands

<sup>1</sup> *Sexually Transmitted Infections in the UK: New Episodes seen at Genitourinary Medicine Clinics, 1995–2000*, Public Health Laboratory Service, 2001.

<sup>2</sup> Source: Public Health Laboratory Service.

<sup>3</sup> THT/PatientView/BHIVA survey of GU consultants, 2001.

<sup>4</sup> *Sexually Transmitted Infections in the UK: New Episodes seen at Genitourinary Medicine Clinics, 1995–2000*, Public Health Laboratory Service, 2001.

<sup>5</sup> *Terrence Higgins Trust Annual Report 2000–01*.

<sup>6</sup> *Managing HIV: a new role for GPs*, PatientView in collaboration with Terrence Higgins Trust, 2001.



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placed on PCTs, there is an urgent need for the government to issue clear guidance for training for all primary care staff and agreed good practice guidelines for GPs and dentists. These would be best developed in consultation with HIV organisations.

3.6 GU clinics are already under immense strain and there is nothing to suggest that demands on their services will not increase. Increased prevalence of HIV and other STIs; spiralling drug costs; increased client numbers as a result of the national awareness campaigns proposed in the draft strategy; and confusion around PCT commissioning arrangements mean that this situation urgently requires an unambiguous lead from central government; something that is unlikely to happen without sexual health and HIV being re-prioritised at the highest level.

#### 4. RECOMMENDATIONS

4.1 To most effectively underpin and support the draft strategy, the government should:

- Reprioritise sexual health and HIV.
- Develop a National Service Framework for sexual health and HIV.
- Issue HIV training and good practice guidelines for generic healthcare providers.
- Review levels of investments in GU services against projected trends in STI and HIV prevalence.

June 2002

#### Memorandum by Alec Miners, Brunel University (SH 100)

This is an "edited" and "updated" version of the discussion that accompanied an economic evaluation comparing treatment with highly active antiretroviral therapy with two nucleoside analogues (NA) [1].

Since 1997, the mainstay of antiretroviral therapy for individuals in the UK infected with the human immunodeficiency virus (HIV) has been treatment with highly active antiretroviral therapy (HAART) which includes the addition of at least one protease inhibitor (PI), a non-nucleoside reverse transcriptase inhibitor (NNRTI) or a third nucleoside analogue (NA) in combination with two NAs. This is based on evidence that HAART is more efficacious in reducing disease progression and mortality compared with two NAs alone [2-6]. However, ever increasing pressures on health care budgets has made it important for health care technologies not only to demonstrate their safety and efficacy but also to show that they are cost-effective.

In this economic evaluation of HAART, cost-effectiveness was assessed using modelling techniques to combine information on treatment costs and disease progression for adults from observational data from English treatment centres. Assuming that the clinical effect of HAART lasts for five years, produced ICERs of £14,602 per life-year saved and £17,698 per QALY saved. Moreover, although the sensitivity analysis showed that the baseline ICER was particularly sensitive to variables such as the discount rate, by assuming continuous costs of HAART for the whole 20-year period despite but on average five-year treatment effects, a conservative estimate of the cost-effectiveness of HAART was produced. Using the Wessex Institute of Public Health Decision Matrix [7] which takes into account the size of the ICER and the quality of the information used in its construction to interpret these results, the use of HAART for adults compared with dual NA therapy is "recommended" on economic grounds.

The ICER of £14,602 per life-year saved is higher than the ICERs produced by Cook *et al.* [8] of US\$13,229 (approximately £8,500) per life-year saved and Reisbrough *et al.* [9] CAN\$13,900 (approximately £8,200). Apart from the fact that these studies are set in different health care systems, in our study the costs of HAART were assumed to be continuous and independent of clinical effect. The study by Risebrough *et al.* also included estimates of the costs of salvage therapy and the indirect costs associated with HIV infection. If indirect costs were included in our analysis, cost-effectiveness is likely to increase because many individuals infected with HIV are likely to be of working age and treatment may help to reduce these indirect costs. Sendi *et al.* [10] estimated the incremental cost-effectiveness of HAART with at least one PI from a Swiss health services perspective to be 33,000 CHF (approximately £10,000) per life-year saved. However, for this Swiss study, the comparative treatment programme was "no treatment" which is unrealistic in an English setting. A more recent US economic evaluation by Freedberg *et al.* [11] reported the cost-effectiveness of HAART to be US\$23,000 (approximately £15,000) per QALY gained. However, this study also compared the use of HAART with "no treatment".

In conclusion, the results from this analysis suggest that HAART is, at the very least, a moderately cost-effective method of treating individuals infected with HIV compared with two NAs alone. However, reductions in the cost of HAART would dramatically increase cost-effectiveness and longer-term data on the relative effectiveness of HAART are required to fully substantiate these findings. Finally, whether treatment with an NNRTI as a third drug is more cost-effective than treatment with a PI and when treatment should be started, remains to be determined.



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[Continued]

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## Memorandum by John Imrie, Royal Free and University College Medical School (SH 102)

## 1. BEHAVIOURAL SURVEILLANCE AND HIV EPIDEMIOLOGY

## 1.1 Background:

- Sexual behaviour, specifically the rate of partner change and the types of sexual active that people engage in, are essential factors in determining the transmission of STI and HIV.
- Behavioural surveillance involves monitoring and measuring patterns of sexual behaviour in populations in order to understand changes in STI and HIV incidence and prevalence.
- Behavioural surveillance is important in relation to prevention as it provides essential information to determine what types of interventions are needed and the follow-up data to gauge their effectiveness.

## 1.2 Main sources of behavioural surveillance data:

1. Routine reporting from health services settings to the CDSC (eg KC-60).
2. Repeat cross-sectional and longitudinal studies (eg NATSAL)
3. Ad hoc and one-off studies of sample populations from the most affected groups (e.g. HIV positive gay men, African ethnic minorities) (eg Mayisha Study of African Communities in Camden and Islington).



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Routine surveillance data collected by CDSC is largely limited to demographic characteristics, likely route of STI transmission/sexual orientation and HIV status. Limited sexual behaviour, HIV status and HIV testing history data are collected in some programmes.

Repeat cross-sectional studies—The frequency with which these studies are repeated in part indicates the degree to which changes in study populations' sexual behaviour is likely to impact on trends in STI and HIV epidemiology.

Ad-hoc studies are used to study specific populations provide detailed information but are usually of limited longer term value because they only measure at one point in time and have limited ability to detect change over time.

### 1.3 *Current sources of behavioural surveillance data according to population group:*

#### 1.3.1 *General Population*

- Routine data from CDSC (eg KC-60, Survey of Prevalent HIV Disease Seen in Clinics (SOPHID), Unlinked Anonymous Prevalence Monitoring Programme)
- Cross-sectional studies—National Survey of Sexual Attitudes and Lifestyles (NATSAL).

#### 1.3.2 *Homosexually Active Men*

- Routine data from CDSC (eg KC-60, Survey of Prevalent HIV Disease Seen in Clinics (SOPHID), UA Prevalence Monitoring Programme)
- Three ongoing behavioural surveys (2 exclusively London focused, 1 nationally focused (ie England and Wales) that includes London).
- One London surveys includes anonymous saliva testing for HIV linked to self-completed questionnaires
- Several smaller studies examining limited populations (eg men with diagnosed HIV infection attending clinical services).

#### 1.3.3 *Sub-Saharan African Communities*

- Routine data from CDSC (eg KC-60, Survey of Prevalent HIV Disease Seen in Clinics (SOPHID), UA Prevalence Monitoring Programme)
- Collection of ethnicity data in relation to HIV testing and STI diagnosis has been reported since 1996.
- Included in wider cross-sectional population surveys (ie NATSAL) however numbers recruited were too small to make generalisable comments.
- No ongoing behavioural surveillance studies in place.

#### 1.3.4 *Injecting drug users:*

- UA Prevalence Monitoring Programme routinely collects basic behavioural data specifically regarding injecting practices and sharing of needles.
- Some qualitative studies have considered the sexual behaviour of IDU in relation to HIV transmission
- No ongoing behavioural surveillance studies in place, unlikely that they are needed.

## 2. *TRENDS IN RECENT BEHAVIOURAL SURVEILLANCE STUDIES*

### 2.1 *Homosexually Active Men*

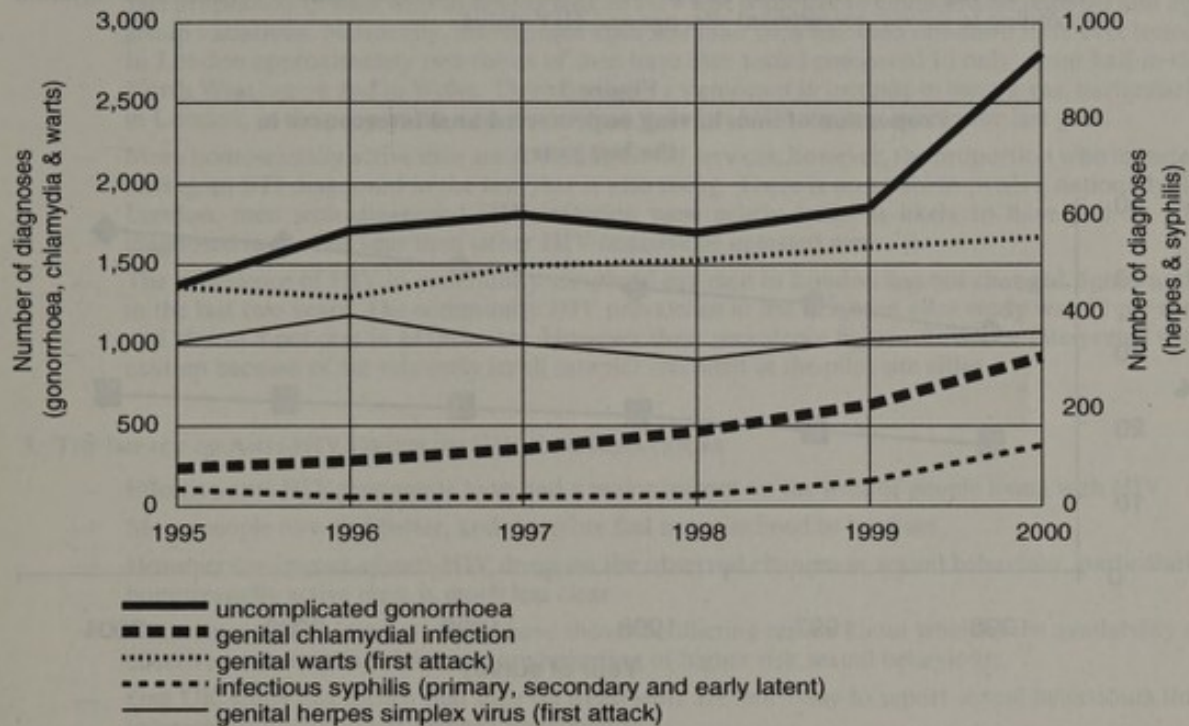
There is increasing prevalence of HIV in this group, partly due to better survival, but also due to continued transmission. Over the passed six years researchers have observed :

- Increases in new diagnoses of STI in homosexually active men, and particularly in men with diagnosed HIV infection and those of unknown serological status (see figure 1 and figure 2).

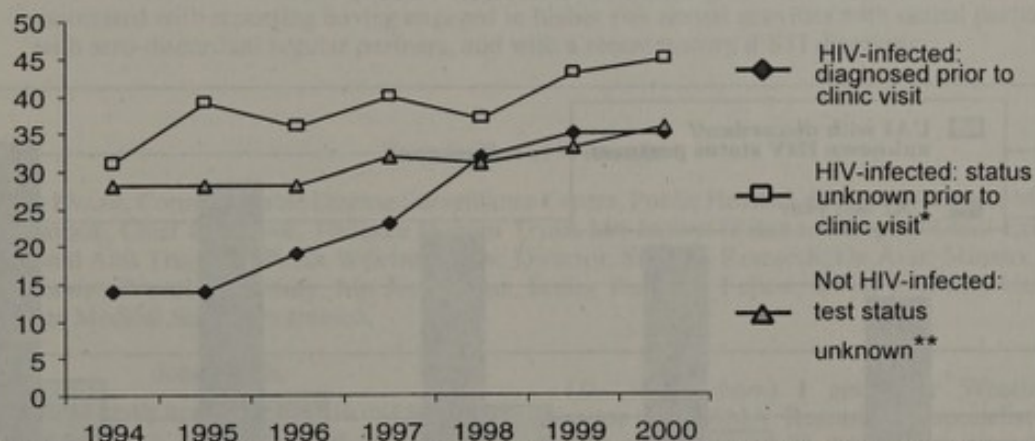
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**Figure 1:**  
New diagnoses of selected STIs in men who have sex with men.  
England and Wales 1996-2000



**Figure 2:**  
UA Surveys: Percentage of homo/bisexual men with an acute STI by HIV status  
England & Wales and N Ireland



\* Will include those HIV infected men who had their HIV infection diagnosed during this clinic attendance

\*\* Data is not collected on the voluntary confidential HIV test history of those who are not infected with HIV as from unlinked anonymous testing

- No overall increase in the numbers of sexual partnerships either regular or casual.
- Nationally, a reduction in the proportion of men who report having engaged in anal intercourse (AI) in the last year, but this is not the case in London.
- Among men who report engaging in AI, an increase in the proportions who report routinely using condoms.

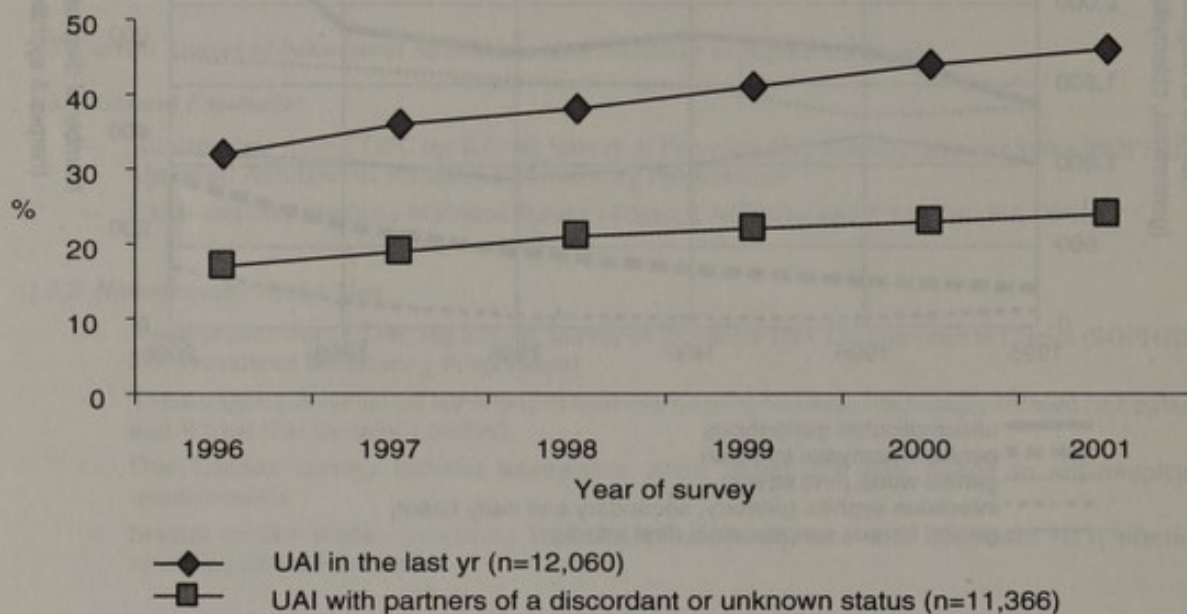


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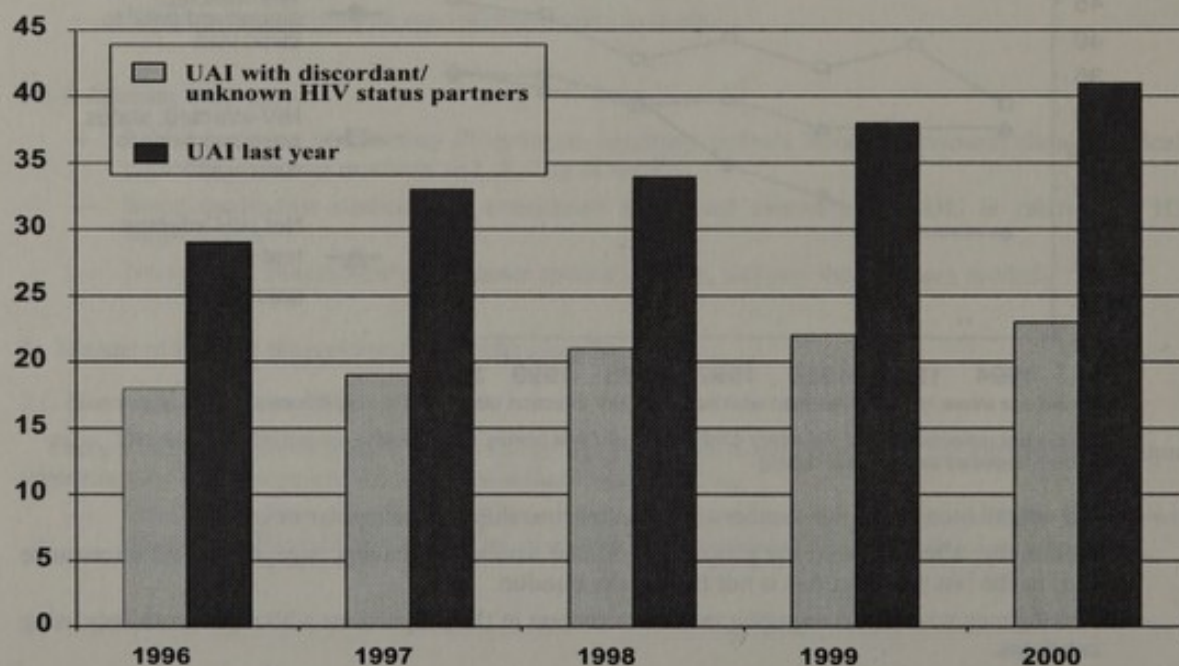
- Equally, among men who report engaging in AI, an increase in the proportions reporting having had unprotected anal intercourse (UAI), with both regular and casual partners. The proportion who report any AI in the last year ranges from about 70–82 per cent, while the proportion who report having had UAI exceeds 50 per cent in all of the surveys. There is considerable variation according to survey, recruitment site, age and HIV status.

**Figure 3:**  
Proportion of men having unprotected anal intercourse in the last year



- An increase in the proportion of men who report that they only engaged in sero-concordant (i.e. both partners of same HIV status) unprotected anal sex (UAI).

**Figure 4: Trends in unprotected anal intercourse in serial community samples of gay men. London 1996-2000 (n = 2000)**





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[Continued

- The greatest changes in the behaviours carrying the greatest risk for transmission have been observed among the youngest men, usually the under 25's and among men with diagnosed HIV infection.
- The proportion of men who have ever had an HIV test is subject to considerable regional and age group variations. Nationally, among men aged less than 20 is less than one-third have ever tested. In London approximately two-thirds of men have ever tested compared to only about half in the North West region and in Wales. There has been a significant increase in most areas, particularly in London, in the proportion who report that their last HIV test was within the last year.
- More homosexually active men are attending GUM services, however, the proportion who reported having an STI diagnosed in the last year is also rising. There is no uniform pattern nationally. In London, men with diagnosed HIV infection were nearly twice as likely to have had an STI diagnosed in the last year than either HIV negative or untested men.
- The prevalence of HIV in community sample of gay men in London has not changed significantly in the last two years. The community HIV prevalence in the Brighton pilot study was 12 per cent and almost 8 per cent in Manchester. However these prevalence figures should be interpreted with caution because of the relatively small samples recruited in the pilot site cities.

### 3. THE IMPACT OF ANTI-HIV DRUGS ON HIV RISK BEHAVIOURS

- Effective anti-HIV treatments have had a major impact on the lives of people living with HIV.
- Many people now feel better, and therefore feel more inclined to have sex.
- However the impact of anti-HIV drugs on the observed changes in sexual behaviour, particularly homosexually active men, is much less clear.
- Numerous studies internationally have shown conflicting results about whether the availability of effective treatments has led to more reporting of higher risk sexual behaviours.
- One UK study has shown that men on treatments are less likely to report sexual behaviours that increase the likelihood of onward transmission.
- Among all homosexually active men other factors also seem to be involved, including: alcohol and recreational drug use, psycho-social factors including depression and low self-efficacy (ie belief in one's ability to perform a specific behaviour (use a condom) in a given situation) and prevention fatigue (ie tired of the same messages).
- In the case of men with diagnosed HIV difficulties around disclosure and assumptions about HIV status to sexual partners, previous negative sexual and lifetime experiences (including early initiation of homosexual sex, having ever been raped, or forced to non-consensual sex), ever having been involved in commercial sex and experience of sexual and erectile dysfunction appear to be associated with reporting having engaged in higher risk sexual activities with casual partners and with sero-discordant regular partners, and with a recent history of STI diagnosis.

### Examination of Witnesses

DR BARRY EVANS, Communicable Disease Surveillance Centre, Public Health Laboratory Service; MR NICK PARTRIDGE, Chief Executive, Terrence Higgins Trust; MR JOSEPH O'REILLY, Deputy Chief Executive, National Aids Trust; DR PETER WEATHERBURN, Director, SIGMA Research; DR ALEC MINERS, Health Economist, Brunel University; MR JOHN IMRIE, Senior Research Fellow, Royal Free and University College Medical School, examined.

#### John Austin

341. Could I firstly apologise both to our witnesses and to members of the public for the delay in commencement of the proceedings and also for the absence of the Chair, David Hinchliffe. Most of you are aware that the Secretary of State has been making a statement in the House on services for older people which is extremely relevant to a report which the Health Committee is publishing tomorrow on delayed discharges and hence it was felt appropriate that as many members as possible should be in the chamber for that statement. Mr Hinchliffe is trying to speak this very minute. Could I ask the witnesses to briefly introduce themselves by stating their name and their position and relevant expertise?

(Dr Weatherburn) I am Peter Weatherburn, director of SIGMA Research, a specialist sexual health and HIV health promotion research unit affiliated to the University of Portsmouth. I am based in London.

(Mr Partridge) I am Nick Partridge. I am chief executive of the Terence Higgins Trust and Lighthouse, the largest AIDS service provider covering prevention, social care, advice and support.

(Mr O'Reilly) My name is Joseph O'Reilly. I am the deputy chief executive of the National AIDS Trust which works both across the UK and internationally on HIV policy and advocacy.



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DR PETER WEATHERBURN, DR ALEC MINERS AND MR JOHN IMRIE

[Continued]

[John Austin Cont]

(Dr Evans) My name is Barry Evans. I am a consultant epidemiologist at the Public Health Laboratory's Communicable Disease Surveillance Centre based at Colindale.

(Dr Miners) I am Alec Miners. I am a health economist. I am a visiting research fellow from Brunel University but also a health technology analyst at the National Institute for Clinical Excellence.

(Mr Imrie) My name is John Imrie. I am a senior research fellow in the Department of STDs at the Royal Free and University College Medical School.

342. Dr Evans, could I ask you what the main countries are, outside of the African continent, whose epidemics may be affecting the UK?

(Dr Evans) At this point in time, there is no country other than the African countries making a big impact on the UK new diagnoses, but there are small numbers from countries such as the Caribbean, small but slightly increasing numbers from India and about between 50 and 100 cases a year where people have acquired their infection in Thailand and south east Asia. There are small numbers from those three parts of the world, but parts of the world which historically the UK has had links with. We need to maintain a watchful brief in terms of their impact in the UK. We also need to maintain a watchful brief—historically, we have not had big links but the situation in eastern Europe is fairly dire at the moment with regard to HIV transmission, especially amongst injecting drug users, their sexual partners and it is further spread heterosexually. That has had minimal, if any, impact on the UK as yet, but potentially it is another area where we need to maintain a watchful eye on its potential impact for the UK. Africa has had a major impact. The Caribbean, India, south east Asia and eastern Europe, in terms of the potential, but this is a global epidemic. We must maintain a watching brief in terms of the worldwide pandemic, rather than just viewing ourselves as isolated in some way from the rest of the world.

343. Some of the specialist service providers who have given evidence to us argue that to cope with the rise in infections from abroad which manifest themselves in the UK we need to provide acceptable, appropriate and culturally competent services. Are there specific difficulties in monitoring HIV from abroad?

(Dr Evans) Sometimes our main sources of data come from laboratories undertaking HIV testing or from clinicians undertaking appropriate HIV care of patients. The facts that we would like to collect from a public health viewpoint are sometimes not the facts which are necessarily obtained in terms of the history from the patient. Sometimes we do not have all the information which we would like and need to generalise from perhaps having partial data available, data such as when the person arrived in the UK if they were born abroad. It may not be available to the clinician reporting to us.

Jim Dowd

344. Can I first of all apologise to the Committee and to the witnesses because I have a constituency engagement at six o'clock. Can I look at the information about the communicable nature of the infection? What do we know about the proportion of those with HIV and AIDS who are infected within the UK and those infected abroad, either with partners normally resident in the UK but infected abroad or those infected by partners not normally resident in the UK?

(Dr Evans) Our best estimate of this—and it is based on partial data to a certain extent—is that of the new diagnoses made in 2001 about 60 per cent were acquired outside the UK and about 40 per cent within the UK. If you look at people born within the UK and infected abroad, we think about seven per cent of the total are in that category.

345. Do we know what proportion of those are going abroad?

(The Chairman took to the Chair)

(Dr Evans) There would be potentially a higher figure. These are the new diagnoses occurring in 2001. Of people born abroad, infected abroad, it is about 53 per cent. Those constitute the 60 per cent acquired abroad and, of people born in the UK and infected in the UK, about 30 per cent; born abroad and infected in the UK, about ten per cent. Historically, it has not been like that. If you look at the cumulative number of people living with HIV that has been diagnosed currently, it is more a 60/40 breakdown the other way round, so 60 per cent of those currently living with HIV diagnosed in the UK at the moment have acquired it in the UK and 40 per cent outside the UK. The figures are different for recent diagnosis because of the increasing impact of the African epidemic but cumulatively the people living with HIV currently that have been diagnosed, about 60 per cent acquired in the UK and 40 per cent abroad.

346. Is that comparable with the historic trend, going back to the early 1980s?

(Dr Evans) If you look way back to the very early 1980s, many of the infections acquired in men who have sex with men were acquired in America or had links with America. This is one of the problems with looking at the pandemic and blaming other countries. It was fairly soon that an epidemic took place in gay men in the UK. The very first cases we had reported to us at CDSC had links with the US. The US epidemic was two to three years in advance of our epidemic so some of the transmission patterns were of people who had acquired it in the US. Then it became endemic. People acquired it in the UK but that pattern is changing now, since the mid-1990s, where we have seen an increasing impact of the worldwide epidemic.

347. When you say the pattern is changing, do you mean in terms of the origins of the infection or that the problem is generated from within the UK rather than abroad?

(Dr Evans) Two things. There is an ongoing epidemic within the UK in men who have sex with men. There is a limited amount but small in terms of heterosexual transmission within the UK and the



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[Continued]

**[Jim Dowd Cont]**

main heterosexual component are people who have acquired their infection within an African context and have migrated to the UK.

(Mr Partridge) Over the past 15 years, we have been in a position to be able to make considerable public health interventions, particularly for men who have sex with men, for gay men, so there has been a consistency of targeted HIV prevention work for gay men. That is not evident and has been much more difficult to create in the recent past for African communities living in the UK, partly because we have been well aware that most of those infections have happened outside of the UK. Secondly, because it is new and difficult work for us and for other African community organisations that we need to build up experiencing HIV prevention work for African people living here. Thirdly, because there has been a lack of resourcing and a nervousness about doing that work. In a way it should not be surprising that we have seen an ability to contain new infections amongst gay men in a way which was unexpected for many of us in 1985. It is still not good enough for many to say that there is a continuing level of new infections amongst gay men, but at least there are targeted, resourced programmes for gay men. What we need to be able to do is to build up work for and with African communities as the epidemic is changing. Finally, an aspect that ought to be highlighted is that we do see a difference in terms of a time of presentation for testing. If you look at late diagnoses in this country, if you look at people being diagnosed both with AIDS and HIV through accident and emergency or in a hospital setting, well over half of those are people from African communities presenting very late with a very poor clinical outcome. That is another part of the picture that I think we need to paint.

348. Do you mean recent arrivals in the UK from African communities or from established African communities in the UK?

(Mr Partridge) It is quite mixed. It can be from people who have been living here for 10 years or more. Otherwise, it is people who have arrived over the past two to five years. The data is not complete because it is difficult to collect that data but all of these people have arrived in the UK for good, practical reasons.

349. Would it be too simplistic to say that the attitude, the approaches, the policies we have taken towards HIV and AIDS within the UK are robust but that we are part of a wider world?

(Mr Partridge) That is very fair. We have had a very robust, strong response. Certainly talking to colleagues in the United States of America or Australia much of the work done in this country for and by gay men is seen as a world leader. It is seen as something which has continued to contain the epidemic and it is also seen as being vitally important to sustain. What is much more complex is how we deal with the global impact being seen in this country. What we can do in this country is limited. Once people are infected, you are looking at service provision, support and creation of good networks of care. How we interact and work with DfID to ensure that we play our role in stemming new infections in sub-Saharan African countries is a key question. The record that is beginning to grow of the UK's

investment in those prevention exercises is something that we need to build up. Secondly, how we forewarn ourselves and forearm ourselves to deal with any changes that we know will happen in the years to come, particularly with the expansion of the European Union, is something that we are very conscious of at the Terence Higgins Trust and I know that other prevention agencies are also conscious of that.

350. That was an oblique reference to eastern Europe?

(Mr Partridge) Yes.

Chairman: Could I apologise for the inconvenience of the meeting being called late and for my own late arrival?

**Dr Naysmith**

351. I apologise as well. I have to leave in a few minutes to chair a meeting in another room. I wanted to follow up what it means for sex education and public health and a number of things that have been said in answer to the opening round of questions. What things do we have to take into account to take account of the prevalence of HIV infections and the nationality of those infected? What does that mean for health education and sex education and public health in terms of policies to be adopted?

(Mr Partridge) Firstly, we need to remind ourselves where we can be effective and we can be most effective in containing and preventing as many new infections within the United Kingdom. That needs to be our key task, so ensuring that we maintain good harm reduction policies in needle exchange schemes and injecting drug use; to ensure that the targeted work for gay men is properly linked to any proposed, more general public safe sex campaigns, so that those messages do not cut across. Thirdly, that we continue to build on sex education in schools so that we have a well educated group of young people as they start their emotional and sexual lives. Then we need to look at how we ensure that the materials for people coming to this country potentially with HIV are appropriate both linguistically and culturally. That is new, ground breaking work, the kind of work that we need to be doing, particularly with African communities at the moment. There are no clear, immediate answers to that, but there is a lot of good work being done by the African HIV policy network in order to be able to address that.

352. Will that involve targeting particular groups?

(Mr Partridge) Absolutely. What we have learned amongst gay men is transferable in terms of how we work with what are quite small community groups and often they are fragmented and under resourced, so using different venues, be that where people meet in faith communities, in barbers, clubs and so on. That is work that we are learning about all the time. If you think about what we can do on a general public level, that is particularly based on how we improve, enhance and use the evidence we now have around sex education in schools and colleges, how we then take that forward in the communities most at risk, and sustain that work and make sure it is linked in to a general public understanding so that those not



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DR PETER WEATHERBURN, DR ALEC MINERS AND MR JOHN IMRIE

[Continued]

**[Dr Naysmith Cont]**

directly affected by HIV and AIDS can support their children, their brothers, their sisters, others in the community to be able to keep themselves safe from infection both from HIV and other STIs, right through to unwanted pregnancy.

**Chairman**

353. How do you feel that current sex education in schools could be better related to men who have sex with men?

(Mr Partridge) I believe that we have the tools available to us. We know what we can do and in the best schools that is well done and well delivered. We know that there is a correlation between homophobia in schools, homophobic bullying in schools, self-esteem and the risk of HIV infection. The difficulty which covers sex education—I am sure that you have been through this in previous sessions—is how we lift the whole of the school system up to what the best schools are doing. It is now quite clear to me that we have a good evidence base of what works in sex education in schools. It is how we apply that and fund that across the system as a whole.

(Dr Weatherburn) I would agree entirely. My sense from my research among gay men is that very many of them are in early adulthood and are hopelessly ill equipped to deal with the hazards that they face. It is no coincidence that most of the public health laboratory services' surveillance shows that young gay men are most affected by new infections and this is as a direct consequence of them entering a culture where hazards and risks that are beyond their understanding are encountered in a very immediate way. Sex education in schools does not serve boys very well generally. Boys who enter into a gay culture or heterosexual career are terribly served by it since they have in many cases no reference made to the feelings that they have. In other more shocking cases, they have had the feelings they have directly undermined by the homophobia and prejudice of their teachers or their peers.

354. What do you feel our Committee might recommend on that issue? We have had many debates in this place about section 28 and the impact that it still continues to have. Is it a factor that teachers are very fearful of entering this whole area for the reasons that we all understand? What are your views on the kind of areas where we might make recommendations that could be of direct relevance?

(Dr Weatherburn) The review undertaken by the Institute of Education in London last year suggested that section 28 had a huge inhibiting effect on teachers because it was so poorly understood. Very many teachers in private schools understood well that it did not disallow them doing anything and managed to provide adequate sex education for boys, but most do not and are too fearful of going there. A clear reading of the Act does not impede you from doing anything, but that is not widely understood within the teaching service.

(Mr O'Reilly) Section 28 is a big factor. The fact that it is not understood means that it is read in a very conservative way. If the Committee could see its way to recommending its repeal once again, that would be a very positive move. What you need to do is create

an enabling environment in which HIV can be tackled effectively. That will take a variety of forms, one of which is a positive, constructive legislative environment and one of the impediments to that sort of environment now is the existence of section 28. Another key factor is leadership. I think Nick provided a very eloquent list and a compelling testimony of the sorts of things that are required in respect of sex education and the targeting of educational efforts with a view to preventing HIV towards at risk communities. Just like we have seen in respect of Peter's point about the resistance in schools to dealing with sensitive sexual matters, such as homosexuality and sexual practices and behaviours of ethnic minority communities and the reasons why they are more at risk than others, those same impediments and sensitivities exist out in the wider community where decisions in respect to investments in HIV prevention effort are being made. In respect to an enabling environment under the new sexual health strategy, one of the things we have to do is provide good guidance and a good sense of what is required from primary care trusts who by and large will be responsible for making the investment and commissioning prevention effort at a local level. What we do in not providing that leadership is run the very same risk that we have seen occur in our schools and that is provide inadequate leadership and inadequate guidance in respect to what primary care trusts should be doing in resourcing and investing in the very prevention efforts that Nick alluded to earlier.

**John Austin**

355. In terms of those presenting with HIV or being diagnosed, has there been any significant change in the age profile?

(Dr Evans) There has been very little change in the age profile over the years. There has been a slight aging in injecting drug users but the number of new diagnoses in IDUs is small and there has been an aging cohort effect. The median age in gay men has remained remarkably constant over the last 15 years and that in heterosexuals has been, if anything, creeping up a little bit but not very much, so very little change. We know from new diagnoses in people under 25 and other sexually transmitted infections rates that the amount of unsafe sex, especially at a younger age, is increasing, but we do see new infections across the age spectrum.

**Andy Burnham**

356. On the issue of section 28, to my mind a false impression is given of the real issues in the media, particularly the Terence Higgins Trust and the National AIDS Trust. To what extent have you tried to engage with the media to encourage a more calm, sensible coverage? Clearly, that stalls progress on this issue because people are fearful of the outcry that any progressive move might receive. Have you actively tried to engage with them?

(Mr Partridge) For almost 20 years. It is a bruising experience at times. I remember bringing together agony aunts from all the newspapers and to her credit Deirdre in *The Sun* has done some excellent work.



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[Andy Burnham Cont]

Lumping the media together as though it is all awful does a disservice to the media. We should not underestimate the positive impacts of that. The long, ongoing story line with Mark Fowler in *Eastenders* is something the Terrence Higgins Trust have been consulted on and sadly that is going to come to an end soon but that has had an educative impact reaching an audience that we at the Terrence Higgins Trust would otherwise find very difficult to do. Where it gets very difficult is in knee jerk reactions to particularly sex education in school stories. We do see very mixed, very confused messages being sent out by the media. It is tragically easy journalism to be able to polarise between the views of, say, the FPA and one of the family values groups. It is very simple to get a rent a quote response. Developing a better debate has been far more difficult but we will consistently try to ensure that we get a good, honest airing of the issues so that there is better public understanding of sex education, sex and relationships and what people of any age can do to ensure that their sex lives are rewarding and healthy.

(Mr O'Reilly) From a health promotion and HIV prevention point of view, the media provides one of those characteristics of a good environment if it is treating the issue properly. It creates a popular culture in which people are aware of HIV and in which we can respond to it very well, but the point that Nick makes underscores the fact that we cannot rely on the media for the HIV prevention message. What we have to do is invest in efforts to make sure that communities most at risk from HIV get an accurate message that is not distorted by the media's interest in portraying the issue in a particular way. Whilst we need to look at the media for open and honest reportage and encourage it to lift its standards in respect of its reportage of HIV, in respect of health promotion and HIV prevention, the message has to be targeted and that targeted message has to be supported by investment which is underscored by real engagement with the communities most at risk, because they are not going to get the message or the honesty that is required from the media.

Sandra Gidley

357. There has been a lot of work outlined with gay men. Recently, we have had the increase in the Afro-Caribbean population. Could that have been predicted in any way or are we always going to be having to react to an emerging group?

(Mr Partridge) There has been an awareness in the Terrence Higgins Trust in south London, given the population in south London and what we knew of increasing rates of STIs and of unwanted teenage pregnancies, that there was a clear area of work for us to address. In that sense, yes, it could be predicted. Being able to fund and create interventions we are still not as good at doing in a timely fashion as we should be, because there are always going to be very real sensitivities. These affect the most vulnerable groups in a very vulnerable part of London and it is terribly difficult to ensure that your interventions are not going to be misunderstood, misused and seen as a potential for raising issues of racism, similar kinds of issues that we had right at the beginning of this epidemic, of how it may well raise homophobia

which thankfully we have been by and large able to overcome. We have regularly been reigned in by our own timidity matched with a lack of imaginative funding and forward thinking. There are ways forward as we get better working relationships, particularly in south east and east London, and a recognition that we can make interventions. As we get a better tie in between statutory health services and voluntary services we should be able to take those risks. The difficulty is if we get it wrong and some of the more malicious media find out about that and choose to target it. Then it can damage that work for a number of years.

(Mr O'Reilly) What we know now provides us with an opportunity to look back and see how in the future we might be able to better predict where emerging infections might occur. It also provides us with an opportunity to do more now because what we know at the moment in respect to the emerging epidemic in the African community and the Afro-Caribbean community is that we do not know enough about it. One of the real challenges is to invest in research to better understand the nature of the epidemic in those communities. One of the things that we have in respect to the epidemic amongst gay men in this country is a large amount of social research whereby we understand sexual practices of gay men, how they live their lives, how HIV impacts upon them. As a result, we are better able to understand all of those factors with a view to creating new prevention efforts. There are deficits in respect to what we know about them and we need to make investments to ensure that that information is kept up to date and we know the plethora of concerns. We have much more information in respect to gay men than we do African communities. One of the things that we desperately need in order to make sure that our future interventions, HIV prevention efforts, treatment and care efforts in respect of the African communities, are effective is more information about HIV in those communities and how it is affecting them. That is a very significant challenge because without that information our efforts will not be effective and useful.

(Dr Evans) In terms of research, in terms of sexual behaviour, that is very necessary, but also we need to maintain sensitive, confidential surveillance systems so that, at the very first signs of an increase, we are able to flag that up as a warning with people doing HIV prevention with communities. I have no doubt that other parts of the globe will impact on the UK. We will see certain communities within the UK more affected by HIV than they have been previously. We need to maintain sensitive surveillance within the UK to flag that up as an issue.

(Dr Weatherburn) My sense is that research funding and funding to do with HIV prevention follows quite slowly after emerging epidemics. It is still quite a substantial challenge to fund research into gay men's sexual health. It is still almost impossible to fund research into the needs of African communities with HIV or affected with HIV. To try and trace what might happen as a priority for research or for interventions seems somewhat naive in the current climate of funding, both the prevention activity and the research to support it.

358. What would make it easier?



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(Dr Weatherburn) We need a far more responsive system that allows the expertise around the table to say what might happen and to invest and risk being wrong in looking at how we might stop it happening or at least intervene early enough to minimise the harmful effects. It is still very much the case that HIV follows the fault lines of society. Marginalised groups are affected by HIV. We mainstream the way we provide services around HIV and HIV prevention but it is still an infection that fundamentally occurs amongst groups that are marginalised from society or otherwise socially excluded. We could conjecture now about who else might be infected in the long term but that conjecture would be unlikely to bring you money in the current funding climate.

359. Dr Evans, you have given us pretty much a broad overview of the origins of the affected groups. What about geographical distribution in the UK?

(Dr Evans) London has been more affected than other parts of the UK. About two-thirds of the people with HIV are resident in London in terms of having been diagnosed. We have seen over the last couple of years a bigger increase in certain regions outside London, especially in the ring around London, the eastern region, the south east region, Trent in particular, and the north west has been one of the more affected regions in terms of Manchester in particular with its MSM epidemic. We are seeing changing patterns and part of that is as people migrate from London or one can speculate it might be to do with the dispersal of asylum seekers. We do not know that for sure. We do not collect that information but we have seen larger increases out of London in terms of African people being diagnosed.

360. Is that something that more work needs to be done on?

(Dr Evans) More liaison with policy colleagues in terms of the major implications, in terms of if we do have dispersal of asylum seekers the implications of that for local HIV services are considerable, in terms of potentially a large increase in a clinic that has only seen a small number of HIV infected individuals, both in the quality of care, in the language or other ethnically appropriate services for those individuals being diagnosed and the appropriateness of antenatal care as well. We need to make sure that we liaise with colleagues and not be surprised when, if you have a policy of dispersal of asylum seekers from high prevalence parts of the world, you then say that is going to have a big effect on local HIV services.

(Mr Partridge) It seems to me this is not solely about dispersal of asylum seekers but, in terms of the national strategy and how that sees an enhanced role for primary care, as the number of people living with HIV continues to grow in this country and will naturally disperse out from the centres that we have seen so far, that does create real challenges for the training of primary care staff in issues as simple as confidentiality, access to treatment and so on. There are issues that we know from surveys that we have carried out about concerns that many people with HIV have about discrimination that they face within the health service and within GPs' surgeries, so how that is going to be dealt with. There is something about how that more diffuse nature of the epidemic, what that means in terms of the strategy for resourcing and for minimum, poor standards for

services and how those can be built on the BMA foundation of evidence that you have already heard. Finally, a key issue of how we encourage PCTs to form consortia in order to be able to meet the demands that are going to be placed on them and that is going to be really key. How do we encourage what are new health bodies to work together in order to be able to meet the prevention challenges which need to be done over a larger population basis than the average primary care trust would cover. It has to be done with a consortium arrangement. One of the things that I would certainly urge the Committee to look at very carefully is the encouragement of the Department of Health that you could give to ensure that appropriate, robust funding happens at an appropriate level, because this is not going to be able to be done by individual PCTs, whether in developing clinical networks for clinical care or consortium arrangements for social care, advice, peer support and so on.

## Andy Burnham

361. You mentioned dispersal of asylum seekers. Is there any attempt made at the moment to screen people when they arrive in the UK?

(Mr Partridge) No, there is not.

362. There is no attempt to find out if they are HIV positive?

(Mr Partridge) There is no attempt made to find out whether people have tuberculosis or a range of health conditions.

363. We are in very controversial territory. Obviously it would make the lives of the public health laboratory services easier but it is controversial in terms of human rights. What would you say to this?

(Mr Partridge) Having any kind of testing process at borders has not worked. If you look at, say, the experience in the United States of America, which has an exclusion around its borders of people living with HIV, it has failed in all senses to prevent a far more substantial epidemic than we have in this country. It would be damaging in human rights terms and damaging to our own sense of ourselves as a nation. I do not think it has any place. It is just not going to work, it would be hugely expensive to implement and it would help no one.

(Mr O'Reilly) HIV testing is obviously a very topical issue. Only yesterday there were front page articles in both of the major dailies in respect of doctors and nurses joining the NHS, but the principle still is that any testing for HIV cannot ever be mandatory. Wherever coercive attempts to test people for HIV have been instituted, they have failed for a variety of reasons and they have caused huge other problems in respect to getting people to be open about their status. They have worsened stigma and discrimination associated with HIV and they have undermined the prevention effort and surveillance effort. Whether at the border or in respect of someone seeking employment in the NHS or anywhere else, mandatory HIV testing has to be dismissed at the outset.



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**Sandra Gidley**

364. As you have mentioned the subject that was highlighted in yesterday's *Times*, Dr Evans, as far as I am aware, no health worker has caused a transmission of infection, but I wondered what your view of the *Times* article was yesterday. Is there a risk? Can we say it is safe? Are you in a position to say at all? Do you have any predictions as to the future shape of the epidemic in the UK?

(Dr Evans) In terms of the worldwide literature around transmission of HIV from a health care worker occupationally to a patient, there have only been two cases, one in France and one in the US, one a dentist and one an orthopaedic surgeon. The issue of performing what are called exposure prone procedures, where effectively you cannot see the tips of your fingers because they are in the patient's body and you are sewing or whatever, they are not giving injections. The picture in the *Times* yesterday was very misleading because that is not an exposure prone procedure. You do not jab yourself or if you do, you do not use it to inject the patient. Theoretically, there is a risk in terms of an HIV infected health care worker performing exposure prone procedures, operative surgery and so on. That risk is extremely small, we know from the world literature, but a person who is diagnosed with HIV in this country is not allowed to perform exposure prone procedures. Most nurses do very little in the way of exposure prone procedures. They may act as a scrub theatre assistant and may assist operatively and in intensive care units they may do exposure prone procedures but most ordinary nurses on the wards do not perform exposure prone procedures. It is only with exposure prone procedures that any risk occurs at all. We know that risk is extremely small because of only two instances in the world literature. Anyway, nurses perform very few exposure prone procedures. All of that makes us say that the risk is extremely small under these circumstances. If someone has been diagnosed with HIV, they are not allowed to perform exposure prone procedures whether they are from Africa, whether they are a gay man, whatever their exposure category. The same rules apply.

365. There would be plenty of useful jobs they could do in the health service with no patient risk?

(Dr Evans) Yes.

(Mr Partridge) The other contextualisation is that this should be seen as being blood borne viruses as a whole and what applies to hepatitis C and HIV. There is no reason why people who do test positive should not be able to retrain and use their skills within the NHS or elsewhere very effectively.

366. Anything about future trainers?

(Dr Evans) It is very difficult to see, when we are talking about the sensitivity of research and surveillance, in terms of what other parts of the world are going to impact on the UK and what the policy of migration in terms of the African impact in the UK is. We have an ongoing epidemic and transmission in men who have sex with men. I think it is still tragic that 1,500 new infections are diagnosed each year in men who have sex with men. Our best guess is that roughly the same number of new infections are occurring each year because we are not seeing any

aging of that epidemic. We are going to see an increasing but gradually increasing number of heterosexuals infected within the UK. I do not think we are going to see an exponential rise but we are going to see more transmission within the UK heterosexually. We have already mentioned the impact of other parts of the globe, so an increasingly complex epidemic, increasing numbers as people live longer, taking newer treatments, and increasing complexity around their care as more develop resistance and therefore second line therapies. There is a lot going on and that on top of a big increase in other sexually transmitted infections. So our GUM colleagues are faced with chlamydia screening, with a big increase in other STIs, complexity of HIV and HIV numbers going up pretty sharply. Our initial look at our annual prevalence survey suggests a 16 per cent rise in 2001 compared with 2000. That is a lot of extra people.

(Mr Partridge) We are also seeing people being diagnosed who are poorer, less well educated and who have a greater number of more complex needs, so not only are we facing an increase in number year-on-year of the 16 per cent that Barry just alluded to, but we are also seeing people, a sub-set of whom have multiple and complex needs both in a clinical setting and in more social care setting provided by social services in this country, and we are seeing rapid increases in demand, and it is going to be harder and harder for us to provide a broader range of services to more diverse people than we have in the past.

**Julia Drown**

367. You said a bit about the social services that government needs to be sure are there for people with HIV, in particular the PCTs who work together to get a preventative service together. Particularly given there is such a differing incidence across the country of two-thirds of HIV diagnosis in London, what is the priority in terms of getting government to ensure that HIV services do meet the right quality and standards? Can that be delivered in each and every area or does it lead to concentration of services?

(Mr Partridge) Certainly money alone is not going to be the answer of how we help. How we choose the structures is a huge challenge for both colleagues in GUM services and how we create networks of clinical care in which someone who is receiving their clinical care in a very low prevalence area can also be guaranteed that they will be receiving high quality, up-to-the-minute care, because HIV medicine thankfully develops really very rapidly, so the consistency with which new minimum standards of care and best practice guidelines are updated needs to have a conduit, from the centres of excellence held in the major metropolitan cities through to the networks of clinicians.

368. How much of that is happening at the moment?

(Mr Partridge) I think it happens patchily. It is not well-structured and I think it depends as much on past friendships as on current robust training. It is not structured and that means, for a person with HIV, it results on luck. No person with HIV should be placed in that position, and it still does mean many people with HIV travel considerable distances to



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access their specialist HIV care. It creates other difficulties in the more social environment, and I think there are substantial risks that we need to be able to overcome for funding for, say, voluntary sector organisations. We had an experience recently when Avon County Council was disaggregated into three unitary councils, and the impact on the Aled Richards Trust, which we merged with and became Terrence Higgins Trust West, was in that disaggregation one of the new unitary councils deciding it did not wish to fund. That meant the Aled Richards Trust was faced with an immediate 25 per cent cut in its funding which destabilised the whole of that unit. I fear there are potentials for that to happen as health authorities, if you like, are being structured down into PCTs, so it is how we ensure a consistency of funding that is appropriately used, meets local needs and gains all of the benefits that primary care trusts have for local populations, but does not mean that organisations find parts of their funding being sheared off. This recommendation that the Department of Health just monitors the impact of this really is not enough for a voluntary sector in this country which is mainly financially vulnerable, mainly working on the margins, does not have substantial financial reserves, and—one of the key issues for many organisations—is managing cash flow. So I think how we see ourselves through this period of rapid structural change within the NHS and how we constructively engage with that, certainly the Terrence Higgins Trust and Lighthouse is looking at new models of care so we can look at innovative, integrated care services, for example. If you want to come and visit our new integrated care service with King's College in Denmark Hill, that is a really fascinating way of bringing together charitable fund raising, local social services and the hospital in providing an integrated service for people with HIV so they do not need to be assessed two or three times. Those are the kinds of things we need to be looking at.

369. You are saying that national monitoring is not enough. Does the Avon experience suggest that you do not think local politicians can be trusted for supporting local voluntary groups in their way?

(Mr Partridge) I am not sure if it is local politicians. It is down to PCTs and commissioning, and because HIV and sexual health—this is not solely about HIV. Broadly there are issues for Brook, FPA, for all of the voluntary services allied with HIV and sexual development, focusing on HIV and sexual development—is not a priority for PCTs, it is not on the 20 “must dos” in the SAF round, it has not got a national service framework. Now diabetes, for example, is not on that top 20 list either but it does have a national service framework. What concerns me is that at the moment HIV and sexual health has neither, so it has very little to encourage chief executives of primary care trusts to ensure that sexual health and HIV need is met and that good competent people are placed to work collaboratively—and we know that working consortia is difficult. It is often slow; it only takes one person to say “No” and the whole thing can collapse—

370. So it is about keeping it high enough on the agenda.

(Mr Partridge) Yes, whether it is done through SAF, through the NSF, but it needs to find greater clarity because we also know that HIV and sexual health can get health authorities into trouble. It can be at local media level—“Why is this money being spent on African people or on gay men?” It is very easy to knock and, if you have major deficits elsewhere I fear that some may say, “Well, actually it is not on the top 20, not in the NSFs, I think I can get away by drawing some money out of this”, and if that happens we risk unpicking very rapidly the major advances in steps being made both in GUM services, in social services and in voluntary services.

**John Austin**

371. I do not expect you to answer this now necessarily but you point to the fact that there is no national service framework in this area. Does your organisation have a ready-made NSF which you would like to see the government adopt?

(Mr Partridge) Oddly enough we have got the framework for it and I think it would not be difficult with colleagues in the BMA Foundation—or MEDFASH as it now is—with colleagues on the clinical side and from our perspective, I do not think it would be difficult for us to pull together an NSF very quickly indeed.

(Mr O'Reilly) Just to follow up, I would reiterate everything Nick says in respect to the need for central government to put in place some sort of method other than a monitoring mechanism to ensure that, at a local level, with the devolution of responsibility for prevention, treatment and care in respect of HIV to those levels, it occurs. One thing Nick did not mention in terms of those changes was also the removal of the HIV ring-fence which had previously existed. We had a pot of money which was spent at a local level but which was monitored and targeted to particular communities who were most at risk from HIV. The reality is that monitoring, targeting and provision of money which was linked to particular things failed by and large because in many areas it was not spent on those areas, but it provided at least a mechanism by which guidance could be provided. So in the absence of nothing at all, apart from retrospective monitoring, our concern is that in low incidence areas—and even in high incidence areas—people will not get adequate care for all of the reasons that Nick outlined: that HIV is sensitive and a difficult issue, something that primary care trusts in the main might not like to deal with. At the moment the real risk with the HIV Strategy is there is nothing in place to ensure they do that work, and there is a real risk that HIV and people living with it and the communities most affected by it and vulnerable to it will fall through the gap, and what will then happen is we will have compounding problems and increasing incidence, difficulties in respect of people presenting late for treatment, and the costs will be greater than the costs in investing in the provision of a mechanism which makes sure that HIV is a priority at a local level.



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**Chairman**

372. Have any of you got any experiences of where the health action zone has addressed this area and looked specifically at HIV, AIDS and sexual health strategies in a way you would feel is commendable that we might look at and perhaps learn from in the process of our inquiry? You may want to come back to us on that.

(Mr Partridge) Can I come back to you on that?

(Mr O'Reilly) I do not have a health action zone as an example but I might say that the teenage pregnancy strategy provides another framework which we could look to in terms of guidance and central government leadership. I think we are learning from some of those lessons and in discussions with the Department we are looking at the establishment of some sort of mechanisms which parallel that, but I think it would be fair to say there is a quantifiable difference in political prioritisation of the teenage pregnancy strategy as against the sexual health and HIV strategy.

(Mr Partridge) Adding to that, the teenage pregnancy strategy was created and implemented pre the shifting of the balance of power, and I am not convinced that the same strategy could be implemented in the same way in the new environment in which we now work. Finally, we need to remember that, within all of this, we have seen a 70 per cent rise in the number of people living with HIV and seeking care since 1995 but only a 30 per cent rise in resources made available to meet that, so we are also dealing with PCTs that start often with a funding gap, so we have to be very careful about how we are going to see this pan out in years to come.

**Julia Drown**

373. Moving to a slightly different issue, I am interested in where people with HIV first present themselves? What proportion go to GUM clinics and what proportion go to GP surgeries and other centres? Is that different from other STIs?

(Dr Evans) We do not have good information on that. The majority of people get diagnosed within the GU setting. There are some diagnosed within primary care but currently not very many. Often, even if they present to general practice, they will be referred to GU in terms of the initial counselling and then testing. Some are diagnosed within ante-natal context and some within family planning but the bulk of new diagnoses occur within GU. A distressingly high proportion still are diagnosed late, especially from the African community, and as we were saying earlier, this often takes place within an inpatient setting, having gone into hospital with PCP or tuberculosis.

374. So in terms of that, it is similar to STIs, where the bulk would be GUM?

(Dr Evans) The majority of STIs do get diagnosed within GU, but chlamydia in particular has an increasing diagnosis within a primary care context, and other STIs may be treated within general practice but not have the diagnostic specimens to make the diagnosis. They may get a course of antibiotics for a vaginal infection or what may be

thought to be a urinary tract infection, but the diagnosis for an STI is not necessarily made within the primary care context.

375. Would it get recorded or not?

(Dr Evans) No. That would not be recorded as such.

(Mr Partridge) What should be added is the number of people with undiagnosed HIV infection and the questions that still remain about how all of us and the GUM service and the NHS as a whole are going to meet the targets laid out in the national strategy for reducing undiagnosed HIV infection, and for speeding up access to GUM services and to clinic services. What we have seen sadly over the past three years is the delay, the wait, growing rather than reducing. There are significant challenges for the service as a whole in order to meet those targets.

(Dr Weatherburn) In the absence of any more robust data, in our recent experience it is relatively rare to encounter a gay man with diagnosed HIV who did not learn of his diagnosis in the GUM or HIV outpatient sector, but we are moving towards the end of a relatively large peer-led survey of people, African people with HIV in London, and having conducted the first 350 interviews we found that less than half were diagnosed with HIV in outpatients, with a full third being diagnosed as an inpatient in hospital after emergency admission, and another 10-15 per cent being diagnosed through ante-natal testing or standard GP tests that they had been persuaded to have. So there seems to be a huge disparity between the two main groups—the African people and the gay men with HIV, who we barely ask where they are diagnosed because the answer is so obvious.

**Chairman**

376. When will that conclude?

(Dr Weatherburn) The fieldwork is about to conclude at the end of the month so it should be published in September or October.

377. So it will be within the timescale of our inquiry?

(Dr Weatherburn) Absolutely.

**John Austin**

378. Dr Evans has said there is clearly evidence to show on-going HIV transmission in men who have sex with men through the 1990s and on-going. We have also received in evidence some of the information of the behavioural surveillance work that has been carried out. I wonder if Mr Imrie could summarise that work?

(Mr Imrie) I presume that you are speaking to the behavioural surveillance with respect to gay men?

379. Yes.

(Mr Imrie) And I would just like to confirm that all of the members of the Committee did receive the memorandum because I think, rather than discussing in any detail the nature of the various surveillance mechanisms that are in place, I would address the headlines and then talk perhaps a little bit about the interpretation. Among those with diagnosed HIV infection and also those with undiagnosed HIV



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infection. Among men nationally, of the men who report having engaged in anal intercourse more men are reporting using condoms. I think this is a point that perhaps sometimes gets lost in a lot of the surveillance data. However, at the same time, and it may seem apparently contradictory, the proportion of men who report having engaged in unprotected sex is also increasing. This may appear at once contradictory but I think what it shows is that we are moving away from a kind of dichotomised group, where people are either non-condom users or 100 per cent condom users. I think it also indicates that we are seeing that people are developing over the years of the epidemic more sophisticated strategies that may involve them making decisions in particular situations about when they feel there is a greater risk or there may be less risk, or they may be influenced by other factors—alcohol, drug use, that sort of thing. I think it is important to understand that in a sense what we are seeing is a breakdown of this dichotomisation, and what we also see is that the proportion of men who report never using condoms has remained very small. The proportion of men who say they routinely use condoms continues to be high, but also those who have lapses or inconsistencies or do not use condoms every time is the area where we are seeing the greatest increase.

**Julia Drown**

380. On the one hand you are talking about lapses where people do not use condoms but, on the other hand, you are talking about people making more sophisticated judgments. Is it more sophisticated not to use a condom?

(Mr Imrie) No. When I say that, I think to be clear what I am saying is that people are developing their own strategies, so the rigid adherence to the early condom messages of "a condom every time" or "one hundred per cent condom use", are falling more by the wayside. One of the important things, and I believe it is figure 4 in the submission, shows that although we are seeing a trend of an increase in the proportion of men who report having had any unprotected anal sex, we also see a significant increase in the proportion of men who report only having sero-concordant, and by that I mean having established or believing their partner is of the same sero status as they are, either positive/positive or negative/negative. We should emphasise that in public health terms this carries no risk of transmission so it can be an effective prevention strategy. Perhaps one of the areas for concern about this is that, in one of the studies that has been using anonymous saliva specimens to test for HIV that are linked to questionnaires, we found there is a fairly important proportion—it is a large proportion relatively but fairly small numbers—of men where their perception of their HIV status does not tally with what the saliva specimen said, and if these men are choosing to engage in the different approaches or perhaps not using condoms consistently there are perhaps important prevention and possible onward transmission issues. I should add that those who incorrectly perceived their HIV status, men in both groups, so men who perceive themselves to be

positive, or believe they are, who are in fact negative and the reverse. It is not an even split but there are men who fall into both groups.

(Dr Weatherburn) I would just reiterate that we are using the language of unprotected sex as though it was a strategy to some extent. Unprotected sex is only risky if it occurs between men of different HIV status—something we often overlook, especially in the Health Service. Most gay men do not have HIV, and anal intercourse between two men who do not have HIV is of no consequence to HIV transmission.

381. You do not know, do you? Even if you have just had your test and been cleared, you do not know your antibodies about to build up, and is there not also an issue for people who are both positive about resistance?

(Dr Weatherburn) There is but that is a different issue because most men are not positive. My sense is it is a very absolute position and I can see why you take it. I am fairly confident that I do not have rabies but I have never been tested for it. I just have not been bitten by a dog in 20 years. Many men apply that kind of criteria. They have been safe and have only taken very specific risk; they have been tested negative; and in that context it is a risk worth taking. You have to bear in mind that using a condom every time for the rest of your life is a very difficult thing to do. The other thing to bear in mind is that HIV risk occurs in a social and cultural context. Few men engage in HIV risk without thinking of the consequences and most men apply some form of risk or harm reduction strategy. It is not that they do not care or that they do not know what might happen as a consequence of the act they are about to engage in; it is about the risk worth taking. It is important in that context and it is worthwhile. They are very sophisticated strategies and they are not epidemiologically perfect. Errors will occur and that is the nature of risk. There is no such thing as safe sex and there never was.

**John Austin**

382. And that risk will be compounded by drug influence or alcohol influence?

(Dr Weatherburn) I would agree absolutely with John's point about lack of self esteem, lack of self efficacy, depression, anxiety, alcohol or drug use. Also, social and cultural factors have a fairly large part to play. If you are poor and badly housed and black and young and unhappy with your life, the chance of getting HIV and dying at some point in the next two or three decades might not seem that relevant to your everyday life, so there are interpersonal psychosocial issues that are important but that is not everything.

John Austin: I am a little bit cross with Nick Partridge for having blown the storyline in *EastEnders*. As someone who does not read the tabloids or the media and relies on a video of the omnibus edition on a Sunday, it has all been blown! But I think the Mark Fowler point may be of interest. You were saying you have been very much involved in consultancy on the Mark Fowler character and that it has been very positive, but I wonder if any of our witnesses think that the availability of the effective anti HIV drugs has in any way contributed



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to more risk-taking behaviour. At one stage AIDS and HIV was an instantaneous sentence to death, and now the Mark Fowlers of this world have shown us that he is still alive and has been for quite some time.

**Chairman**

383. The Chairman still has not got a clue who Mark Fowler is!

(*Mr Partridge*) I ought to be clear he is not dying in the series; he is just going to leave it to live somewhere else, just to clear that point up. He is a character in a soap opera and he has been living with HIV since about 1987, and we have been consultants on that story line since then.

384. Thank you.

(*Dr Weatherburn*) Unfortunately Mark Fowler's means of transmission has never been very clear, and when it has been it has not been one of the ones that was most common, but I do approve of his presence in the programme. John will probably talk about this more productively than me but treatments optimism, which is what we have dubbed the notion that the awareness that HIV is possibly a long-term treatable condition, has in my view had less than no impact on the risk behaviours undertaken by gay men or any other target group. The research is not conclusive but I have seen reviews that cite 200 papers with conflicting evidence. John has been involved in some very robust work looking at the beliefs of positive gay men and the contribution that treatments make to their risk behaviour and I am sure he will tell you about that in a second. I would be really plain though and say that it is impossible to estimate, but my sense is the notion of treatment optimism has absorbed a third to a half of all research funding for the last 2-3 years, and it has been impossible, as it always is in research terms, to prove something is not the case but the frustration I feel to even talk about it is a consequence of its ability as a sponge to soak up everything that might occur. I should not go any further or I will get really bitter!

(*Mr Imrie*) I would support much of what Peter says. Something that was drawn to my attention today is that this idea of treatment optimism was developed by a psychiatrist and is effectively a highly medicalised concept, and I think that is important to take on board. I think the bottom line answer to your question in terms of what impact and to what extent has the availability of antiretroviral therapy influenced sexual behaviour is not terribly satisfying. It is not entirely clear, and if we look at the main most affected groups in the United Kingdom, the African communities and homosexually active men, the first thing to say is there is only very limited data to look at the impact of antiretrovirals in African communities. However, if we draw inferences from the one large behavioural surveillance study done in African communities, this suggested that 70 per cent of the respondents who came from five mainly affected African communities in central London believed that they were not at risk of acquiring HIV but this certainly did not tally with their previous history of STI diagnoses or their condom use at the last intercourse. I think the important thing here is that it may emphasise an underlying lack of

awareness of HIV and of treatments. Internationally when we look at studies of gay men, the results are very conflicting—even opposing. For example, one very large study in the United States showed that, among positive men who were treatment optimistic and prevention fatigued, these men were more likely to engage in high risk behaviours. Perhaps most alarmingly it was the men with the highest viral load, the most likely to transmit, who were likely to engage in this behaviour. In contrast, in a study in Amsterdam, they found it was the men who had achieved the greatest level of viral suppression that were most likely to report having engaged in high risk sexual behaviours. A third possibility was that, in our findings here in the United Kingdom, a large study of HIV positive gay men attending a central London clinic, what we found was that on the whole being on antiretroviral therapy meant men were less likely to report engaging in high risk behaviours for onward transmission and, even when we controlled for things like age, disease stage and other potential founding factors, this continued. So I think the picture within the positive men is still a bit murky. When we look at negative and untested men I think it is not a dissimilar picture. We have studies from the US that show that young men who believe in some of the treatment optimism ideas are more likely to engage in unsafe sex, but I think it is important that we consider the other factors and what other factors have come out of these studies as being involved. I think particularly with HIV positive gay men they tell us a lot about where we should be going with prevention. Specifically we identified other factors as being more important than the availability of treatments—issues around disclosure, and assumptions about sexual partners HIV status, previous negative life experiences and negative sexual experiences—so ever having been raped or having had non consensual sex—ever having been involved in commercial sex, and, quite controversially, experience of sexual dysfunction or erectile dysfunction were also predictive of more high risk sexual behaviours. We found there were strong associations with all of these and having engaged in high risk behaviours, but also important for transmission is recent STI diagnosis. So treatment optimism I think we should probably put to bed and start looking at other factors.

**John Austin**

385. Can I go back to one of the points made earlier about safe sex and risk behaviour? You referred to two men who may be HIV negative or positive, and therefore in a public health sense there is no risk in transmission. That only relates to HIV, of course, and people are at risk of other sexually transmitted infections so there is still a risk or an increased risk by non use of a condom, even with seroconcordant partners.

(*Mr Imrie*) Absolutely, but I think when we are thinking of the social implications it is more the long term care of HIV that is a much more critical issue than dealing with gonorrhoea or what ever other STIs may be acquired, but this is also a factor that has to be included. I think that particularly within partnerships the kinds of negotiated arrangements



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that individuals will have is key to making sure that those strategies remain safe for reducing the likelihood of STI acquisition as well as HIV.

**Julia Drown**

386. Could any of you help us with issues on HIV mums and babies? Recent figures show a high awareness of HIV amongst mothers before they give birth yet the number of HIV babies has gone up. Why?

(Dr Evans) There is somewhat of a gap between the interventions that one can put in place and those having an effective outcome. We have seen increasing new diagnoses: we are achieving the targets in inner London but we are not achieving those targets in outer London nor in the rest of England and Wales, and that is an issue in terms both of monitoring and encouraging lower prevalence areas to get on with the job of more routine testing, and a recommendation of testing during pregnancy. So we have a way to go there before we can achieve those targets. We do have those specific targets and we need to monitor in terms of offering the tests as well as the outcome of those tests, and I do not think there is any doubt we will begin to see a decrease in the number of children newly diagnosed.

387. So is it that the testing is not taking place outside London?

(Dr Evans) We have not achieved the targets outside inner London.

388. Why?

(Dr Evans) I think there is a whole variety of reasons. I do not think HIV has been normalised in terms of ante natal testing in lower prevalence areas when people say, "We have such a low prevalence it is not worth our while doing it", and there may be currently a fairly low prevalence but unless we normalise HIV testing with the other tests in pregnancy people can say "No" to the test if they do not want it but if it is a recommended test with the other tests in pregnancy, then we are not going to achieve those targets outside inner London.

389. So is it that some areas are seeing this as an opt-in test, whereas others see it as an opt-out test?

(Dr Evans) That has been traditionally the issue that has prevented us from historically achieving the kind of targets we are now seeing we can achieve in London. It needs to be normalised so that it is not an opt-in; it is a normal test in pregnancy that the woman is given brief counselling and saying, "This is part of our testing", and if they want to opt out they can be counselled and opted out but the norm is that the testing is done.

390. There were some nods across the panel. Would there be general agreement on that?

(Mr Partridge) Yes. I think it is quite clear that one area of public health failure in this country has been the unconscionably long time it has taken us to gain proper benefit from the dramatic reduction we have seen in mother-to-child transmission, and the quicker we are able to roll out the ante natal programme that has worked well in inner London to the rest of the country is clearly vitally important. What that should mean is we get virtually close to no newly born, infected infants in this country but I

would like to comment on some of the additional factors away from delivery and into care. Firstly, there is an issue that is raised with us very regularly which is the supply of free baby milk formula, and I would like to re-emphasise what that means for some of the most vulnerable mothers in this country, those seeking asylum or of uncertain immigration status. It is vitally important that is changed as quickly as possible. Also, given that the strategy covers a 10-year period, we should look at what changes in services are going to be required which manage both those of a declining number of children living with HIV as they grow older but also manages to care for the HIV negative children of positive parents and what implications they have for the provision of creche services and children services in what will become an increasingly invisible infection, if you like, but which will still have all of those really dramatic impacts on family life where parents are dealing with their own severe ill health. So I think there needs to be a focus on how we ensure that those children's issues, which will change thankfully over time, are met and that both health services and social services and voluntary sector services do not lose sight of the uninfected children of infected mothers and continue to care for infected young people.

**John Austin**

391. Can I refer to the rates of acquired HIV acquired heterosexually? The evidence we have received suggests a number of areas where rates are going down, those who have a heterosexual partner who is an intravenous drug user or a partner who is bisexual, but we are told that the number acquiring HIV heterosexually from a partner who acquired their infection heterosexually is increasing, albeit these are small numbers and a slow increase. Do you have any views on the reason for this?

(Dr Evans) We have had a small IDU epidemic which in countries in southern Europe, for instance, have driven a heterosexual epidemic so within the European context and within a North American context the IDU epidemic has determined a lot of the on-going heterosexual transmission. There have been transmissions from bisexual men but it has not driven a large increase, an on-going increase, so it has been the IDU epidemic, which in this country has been pretty small. Can I just say that we must not ignore the potential for spread of HIV through shared needle use. We are seeing significant amounts of hepatitis C and some hepatitis B transmission as well, and we must not let go of our goal in terms of continuance of needle exchange programmes, and let our eye go off the ball in terms of IDU. Canada has shown us when there are fluctuations in drug supply and new injecting habits and so on that you can get rapid transmission of HIV, even in situations where historically you have had very little HIV, so do not forget IDU transmission.

392. That is obviously clearly important, but the figures of people acquiring HIV from a partner who is IDU have gone down, so that is good news.

(Dr Evans) It is.

393. And yet the rate of heterosexual HIV is rising slowly.



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(Dr Evans) It is. What I was saying previously was in terms of this slow but gradual rise in people acquiring HIV heterosexually within the United Kingdom from partners who had themselves acquired it heterosexually, so it is not primarily from injecting drug users and bisexual men, but now from people who do not realise themselves to have been at risk and therefore do not get tested until late, therefore have high viral loads, and therefore their transmissibility in terms of their sexual partners is increased.

Chairman: Dr Miners, one of the more sensitive members of the Committee has passed me a note saying she is feeling sorry for you because we have not come on your to area, but we will!

## Sandra Gidley

394. The strategy contains some proposals to deal with stigma and discrimination around HIV and AIDS. To what extent do you think the strategy has it right and that what is proposed will work, and is there anything else that should be done?

(Mr O'Reilly) Thank you for the question. The strategy I was going to say is light on detail in respect of how we approach HIV related stigma and discrimination. I might go as far to say it is almost completely absent, and I point out that I think this is a deficiency in respect of the development of the strategy which is not just manifest in respect of the absence of a strategy to tackle HIV discrimination. That deficiency exists because the strategy was led by and exclusively the domain of the Department of Health, and the Department of Health does not have responsibility, for instance, for antidiscrimination legislation, or for the plethora of other law frames required to create the enabling environment in which HIV is best tackled that I alluded to earlier in our session today. So before going on to point out that the stigma issue has been inadequately dealt with in the strategy, we need to recognise that in developing the next HIV and sexual health strategy that has to be about a cross-government and joined-up approach, and it has to include departments and government officers who would otherwise have something to say on this issue but who would be excluded purely by health driven strategy such as the Home Office in respect of asylum and antidiscrimination legislation and all of the other areas—prisons and corrective services more generally. So I think that is a real priority area and an absence in the strategy across a variety of domains. I think, however, that we have acknowledged in the form of the strategy that HIV discrimination is an issue and one of our recommendations is that Parliament has to address the deficiency in the Disability Discrimination Act that HIV to all intents and purposes is not covered; that AIDS, once one becomes symptomatic, is but that the vast majority of people who remain well with HIV could legally in some cases be discriminated against on the basis of their HIV status, and that has to be addressed and that uncertainty with respect to our antidiscrimination law has to be tackled. More broadly, though, discrimination occurs in a variety of

other ways and settings and that is why we need a cross-departmental working group on this issue at a very high level operating with a view to developing a strategy to tackle discrimination in its manifest forms and in the variety of settings I am alluding to. So I think the strategy says that it is an issue and we have been talking to the Department of Health about that, but I think it would be very helpful if this Committee acknowledged that HIV discrimination exists and it is a priority, but it has to be dealt with by a variety of parties across government and not just the Department of Health. Also, in respect of HIV discrimination, it is directly linked to people's prejudicial attitudes about sexuality and race and this is the confluence of discriminatory factors which I think come together most compellingly in respect of HIV. One of the gravest deficiencies in tackling HIV discrimination is the absence of sexuality discrimination legislation. Not only does it remain lawful for people to discriminate against people on their HIV status, but one of the groups that is most adversely affected and shares the greatest burden in respect of HIV—gay men—can be discriminated against too. And so in a sense at a leadership level, a legislative level, a political level, the community at large does not see you, our legislators, our Parliamentarians and our political leaders, sending a clear message that discrimination on the basis of sexuality and HIV status and those things alone is acceptable. I think we all have work to do in making the Race Discrimination Act work better too and protecting people from it, but people with HIV and the two at-risk communities from which they come, the gay community and the black Afro Caribbean community, are incredibly adversely affected by the inadequacy of our antidiscrimination legislation and our antidiscrimination effort.

(Mr Partridge) Adding something slightly more specific to this, I think the main thrust of the strategy for sexual health and for HIV is a greater involvement at primary care level and the creation of primary care teams able to deal much better with sexual health and HIV issues, and clearly we know from research I alluded to earlier of the discrimination that can be felt and perceived as coming from within the NHS itself, so the way in which resourcing is made available for the training and support of staff to deal with issues which are difficult, and are personal and complex often to deal with, is part of the human resources strategy that needs to work alongside and is part of the HIV and sexual health strategy as a whole. I fear there is a lack of clarity about the scale of that task if we are really going to make primary care part of the leading force for improvements in sexual health and HIV in the future.

395. Is that more of a problem in areas with a lower prevalence?

(Mr Partridge) I do not think it is as clear cut as that and I do not have the evidence to be able to answer that. I certainly think there is a distinction between the experience of the major hospitals dealing with HIV, but I would not necessarily guarantee that a GP practice or a primary care trust just yards from a major teaching hospital would necessarily be any better than one located in Exeter, for example.



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**John Austin**

396. There has been a shift in policy with regard to where HIV fits into NHS planning, and I think at one stage even the Terrence Higgins Trust was arguing for HIV to be not seen as part of a sexual health agenda, whereas it very clearly now is being integrated and instead of having ring-fenced and identified funding it is fed through in the budgets. That may be good in mainstreaming but it may have its disadvantages in ensuring the money gets spent, and I think we touched on this in the BCC Commission, etc. What do you think needs to be done to ensure that that implementation happens?

(Mr Partridge) This is a crucial question but you are absolutely right: when the HIV strategy began to be developed four years ago, we were keen as an organisation to ensure that there was a coherent, cross-government, appropriate HIV strategy. We are, above anything else, realists and recognise that is not the world we currently inhabit and that we need to take advantages of the synergies that do exist between HIV work and broader sexual health work. However, how we ensure that resources are made available and properly used in the new environment of PCTs or arguments I rehearsed earlier this afternoon so will not go into in detail again, but I do believe there really is a need for either an NSF or for reprioritisation of HIV and sexual health to hit the top 20 SAF issues if PCTs are going to be encouraged, particularly in the next couple of years, adequately to fund GUM services, primary care services and voluntary sector services in sexual health and HIV. If we do not do that we need to remember how fast the clock is ticking. Even though this is a ten year strategy, we are already into year one of implementation, and when you begin to look at how soon some of the targets need to be met there really is very little time for this to be on the back burner of primary care trusts or of strategic health authorities. At the moment we are not convinced that the mechanisms are in place to ensure that much of the good work that we have done is sustained and much of the very important targets that are articulated within the strategy will be hit, be that from the voluntary sector side or from colleagues working in over-stretched GUM services and elsewhere in sexual health.

397. You mentioned the voluntary sector there as well. What do you think the Department of Health should be doing in relation to the voluntary sector to get the strategy working? What is the key role that the voluntary sector can play?

(Mr Partridge) We have produced a report which reflects on the impact of shifting the balance of power. It is a very constructive engagement for the voluntary sector with the new environment in the NHS, but it is going to be difficult and there are really substantial challenges. The key one for me is that we need better, more robust guidance and direction from the Department of Health in terms of the importance of consortia between PCTs and the importance in the short term of rolling contracts over. If in doubt, do not retrench at the moment because if we lose the activity that we currently have, it is going to be 50 or 100 times more difficult to re-create it in the future. Once it has gone, it has gone. So failing an immediate availability of a National

Service Framework or of an ability to reprioritise HIV and sexual health within "must dos" for PCTs, at the very least we need clear guidance to ensure the continuation of funding to see us through this period of great upheaval, not just for the voluntary second but for other parts of the NHS as well.

(Dr Weatherburn) My sense is I have less faith in the commissioning practice, whether it be in PCTs or historically where it has been in the health authorities. My sense is that the Department of Health can do something very profound with the health promotion tool kit and also the commissioning tool kit that they promised in the Implementation Plan. Both of these need to give substantial guidance to PCTs and probably refine the targets of the Strategy. My sense is that the Strategy is hugely problematic because the Implementation Plan conflates the causes of morbidity, sexual infections and unwanted conceptions in one section, and then conflates the groups experiencing them in another, and then put these needs in competition with each other for very finite resources amongst the PCTs. Our experience would say that because of a lack of expertise, and ignorance and prejudice amongst elected commissioners at a local level, young people will come to mean women who might get pregnant rather than young men who might get HIV and black communities will come to mean whoever is not white that we might reach instead of black Africans who might get HIV. The fundamental problem and the very real danger is that historically mis-allocated HIV funds will be further siphoned away from where the real risk of HIV infection occurs. The chances of a 25 per cent reduction in incidence seem very slim. The Strategy or its Implementation Plan does not provide any of the detail necessary for us to see a reduction in incidence of anything like 25 per cent. It barely defines what HIV prevention is, it does not prioritise it on a local level, and it does not give any clear indication of why it should be a priority. The sense is a reduction in incidence is unlikely on the basis of the documentation that the Strategy has come forth with to the present day.

(Dr Evans) The voluntary sector to which you refer is also at various stages of development and preparedness with respect to dealing with HIV. For instance, we have grossly under-estimated the investment required in African community-based organisations to bring them up to speed and to give them the capacity to deal effectively with HIV. They face all of the same challenges that existing HIV community organisations face but they are doubly disadvantaged by the fact that they are often completely unfunded. Their governance, management and other structures are very nascent and we have to make a priority of engaging with them in a very constructive way centrally as well as locally so that they are equipped to deal with HIV.

**Sandra Gidley**

398. At the recent Symposium in Barcelona there were various announcements including an HIV vaccine available in five years—but we have probably been hearing that for the last five years—and also big news about microbicides. Do you think this will make any difference over the next five years?



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(Mr O'Reilly) The National AIDS Trust is a partner on the international AIDS vaccine initiative and the international microbicides initiative, so we are actively involved in trying to make sure that both of those prevention technology developments do have an effect. The announcement by VaxGen in Barcelona was a little optimistic and we cannot over-estimate the need to retain our focus on existing effort despite the fact that we need to invest in preparedness for both of those possible prevention technology investments. In the event that we had either of those developments ready in the next five years—and I think that is probably much more likely with respect to microbicides than it is vaccines—the question of getting them out to populations, to making them available, and to ensuring that they are affordable, and resolving the ethical and other dimensions that will arise in respect to all of those issues, are vast and we are nowhere near making either of those technologies readily available. So I think there is some hope but I do not think that we should engage in the sort of false hope announcements that might have come out of Barcelona. I acknowledge there is an imperative for the companies developing those products and for the researchers involved to retain interest in them and to generate political and community will to ensure that they are funded, but we also have to do that responsibly and at the moment we are not there yet. The National AIDS Trust here has some things to say to government about making sure that we are prepared when those technologies are available to make them available and to make sure that the issues associated with making them available are dealt with, but we are a long way from that at the moment.

## John Austin

399. Dr Miners—saving the best to last—could you give us some indication of the cost-effectiveness of the long-term use of antiretrovirals in HIV-positive patients? When you have answered that, if there is anything else you want to say please do.

(Dr Miners) I am grateful for that but economics is very much my field. Quite surprisingly, when we started looking into this question a couple of years ago there were very few studies that were out there looking at the cost-effectiveness of antiretroviral therapy. Most of the studies that were there were from the US, but a paper published last year in *HIV Medicine* would suggest that highly active antiretroviral therapy is extremely cost-effective and, in fact, the figures that were produced were in the region of 15,000 per life-year saved to 18,000 per QALY saved. To put that into some kind of perspective, because when you talk about cost-effectiveness it is always relative to something else, if you think about second-line mono-therapy taxanes for advanced breast cancer, they are certainly in that bracket in terms of being comparable in terms of cost-effectiveness and I would even suggest probably a bit better.

## Julia Drown

400. In the strategy it says the lifetime costs for an HIV-positive individual could be up to £180,000 and, prevention, if you are looking at also benefits as well as savings in health service costs it could be anything between half a million and a million pounds. Does your work suggest those figures are in the right sort of region? Would you have any other comments to make on those costs?

(Dr Miners) Absolutely. Particularly with relevance to cost, I would point to the paper to which I referred a moment ago. If you look at the costs and the costs of treating people with HAART they were in the £180,000 region. I am not sure where that particular £180,000 came from to which you were referring. The benefits of treatment depend a bit on what you mean by benefits and how they are calculated. One of the problems we had when actually trying to do these studies originally was that we had some figures on mortality, but in terms of morbidity there are very few studies there that we could try and synthesise into the models. In terms of the health benefits, if you want to talk about quality of life, I would say that we have under-estimated costs on those studies.

(Mr Partridge) It seems to me from my activist past, if you like, that we have in one sense scored an own goal in talking about the high cost of therapy because when you listen to what Dr Miners says, it is clear that in terms of benefit gained these are very reasonable costs attached and we are seeing a reduction in per year drug costs over time. The other point I wanted to raise was the half a million pound to one million pounds per infection stopped cost, because that obviously folds in with the other impact of economic benefits lost to the country, the loss of useful time, and so on. I just want to set that half million to one million pounds into context. If you look at the current Department of Health funding for the CHAPS programme, which is the Community HIV and AIDS Prevention Strategy, which is a partnership which Terrence Higgins Trust runs, that is currently running at about £1.1 million a year, so it is arguable that the only outcome from that is two stopped infections in year. You can also look at it another way that says we as a country get extraordinarily good value through that programme. You can look at it a third way which says there needs to be increased investment for targeted prevention works that can be shown to work. Fortunately, the independent researcher that we at the Terrence Higgins Trust commissioned to do all of the background research is Sigma here so we do have good, robust evidence that the CHAPS programme is working and that it is extraordinarily cost-effective.

## Chairman

401. Could I ask Dr Miners, from your perspective what do you think is the most cost-effective way of addressing the kind of issues we talked about today? You answer a specific question, can I broaden out the point, from the committee's point of view we need to look at what we recommend, perhaps you are in a



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more objective position to have an overview of the expenditure in these areas, what do you suggest are the target areas we should look at?

(Dr Miners) Do you mean in terms of prevention versus treatment?

402. Absolutely, yes.

(Dr Miners) I think the problem with making that comparison, from what I have understood today and what I understood before, talking about prevention itself does not seem to be sufficient, you have to talk about particular types of prevention, and also those particular types of prevention within particular sub-populations, the HIV community, if you like. In terms of broad-brushing I think it is very hard to make that comparator. The other thing I would say is, even where I have seen that preventive programmes do seem to have some kind of impact in terms of clinical end points at the end of the day there has been little information on the actual cost-effectiveness of those treatments. Another thing I would add is, I think intuitively prevention will always win through, but at the same time there is clearly over 30,000 people in Britain who are receiving HIV treatments or are eligible for HIV treatments—and that number seems to be stable, or perhaps even increasing—I am not too sure about that. It seems that there are still a sizable number of people who will continue for some time to require treatment, particularly as they are now living longer. Even though the intuitive is to think in a data free zone is to think about prevention I think for people who already have HIV should not be forgotten and the treatments should still be funded on that basis

403. Okay. We talked about the differing views on the role of PCTs, do you have any thoughts on where the resourcing decision should be made? It is a very difficult one, because it is an issue we touch on in every inquiry, how we determine who gets the money, at what time and how we come to the decision? Do you have any thoughts on the structures we now have that will have a bearing on those decisions? Would you concur with some of your colleagues concerns about the role of PCTs in this issue?

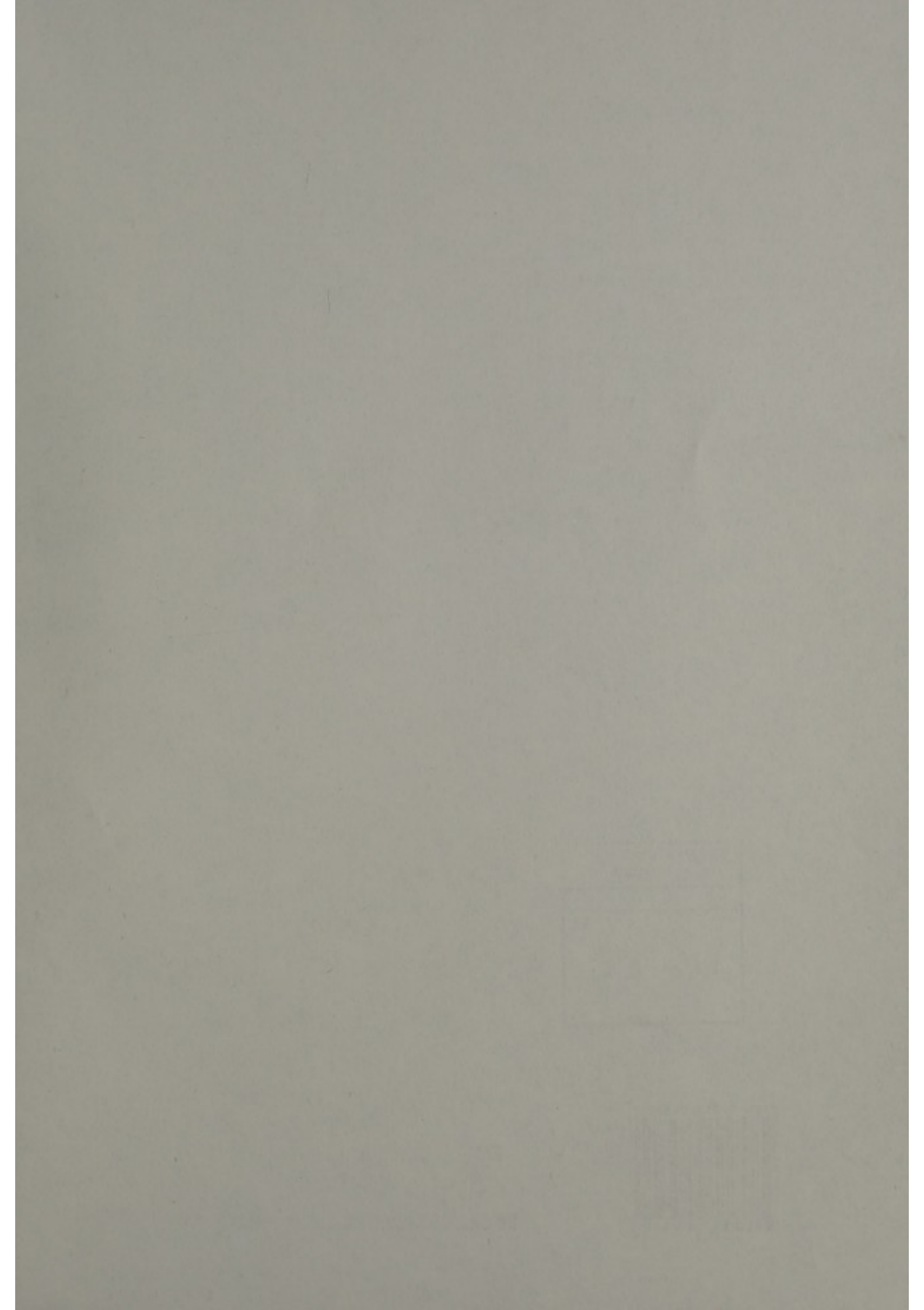
(Dr Miners) I am not sure if I am the best person to answer that question, if I am honest. I think the role, if you like, of technology appraisal is to provide information on clinical cost-effectiveness and that various PCTs will always face various decisions as to what they should fund. Going back a step further I think it is very difficult to make those decisions if that kind of information is not available I would almost go back a step further and say we need to generate more robust evidence before those decisions can be made.

Chairman: Okay. Excellent.

Julia Drown: I am aware of the time.

Chairman: We have kept you quite a long time tonight. I do apologise for the fact we had to delay starting. You are aware of the circumstances and what happened today was beyond the control of this committee. I do apologise to you. It has been a very interesting session, can I thank you for the contributions all of you made and for your evidence. We are very grateful for your help. Thank you very much.

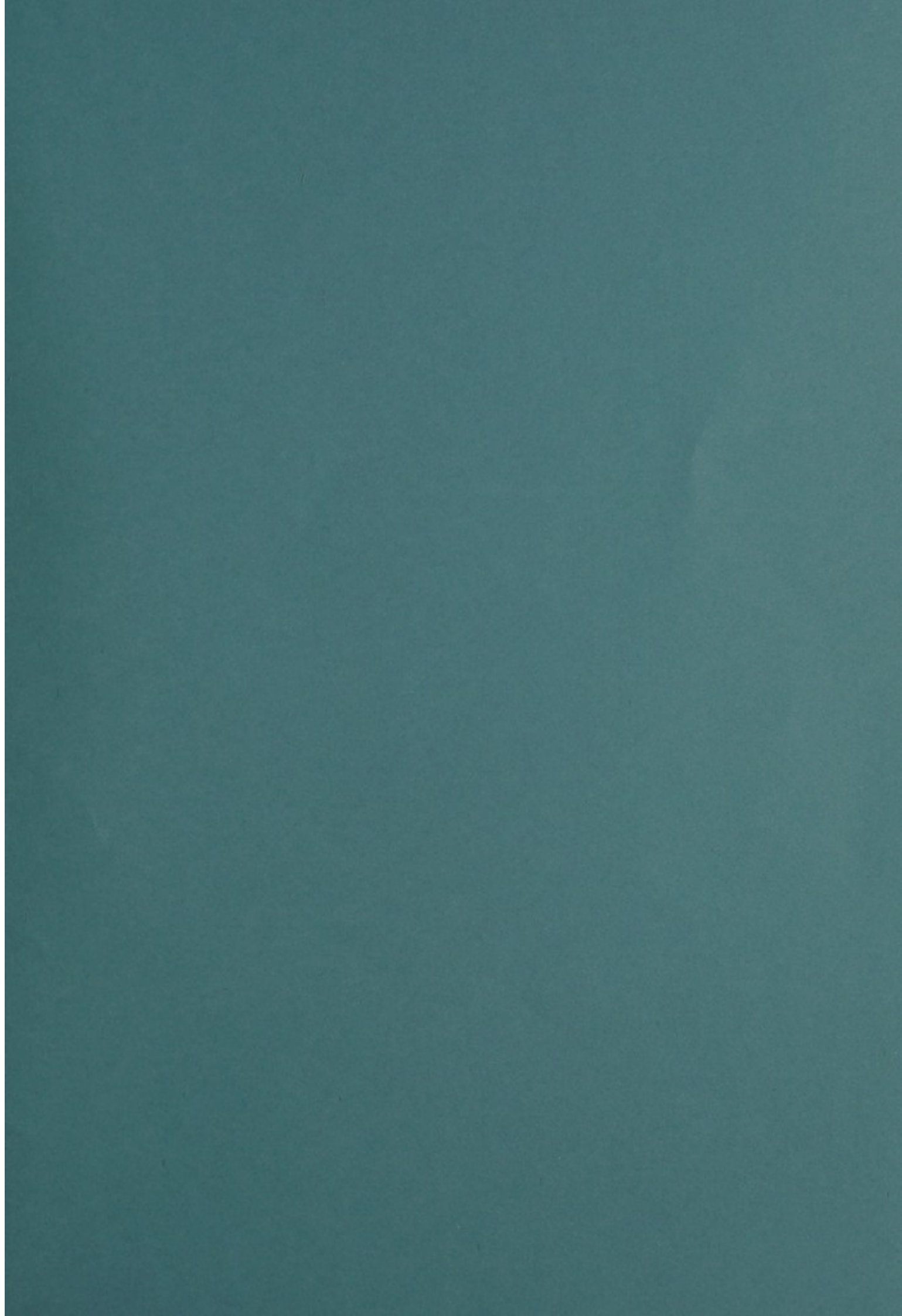
















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