



House of Commons
Health Committee

New Developments in HIV/AIDS and Sexual Health Policy

Third Report of Session 2004–05

Volume II

Oral and written evidence

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SW1. (Tel 020 7219 3074) hours of inspection are from 9:30am to 5:00pm on Mondays to Fridays.

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Oral evidence

Taken before the Health Committee

on Thursday 27 January 2005

Members present:

Mr David Hinchliffe, in the Chair

Mr Keith Bradley
Mr Simon Burns

Dr Doug Naysmith
Dr Richard Taylor

Memorandum by Professor George Kinghorn (HA 13)

GENITOURINARY MEDICINE SERVICES IN SHEFFIELD

1. Sexual Health services in Sheffield have been served by a multidisciplinary Joint Planning Group (JPG) for several years. The JPG contains three members of the Sexual Health and HIV Independent Advisory Group. The local population, which exceeds 500,000, is culturally diverse with varying social need. It is boosted by a student population of 60,000, and is also a centre for asylum seekers especially for the relocation of families affected by HIV.

2. The Genitourinary Medicine (GUM) clinic, which is based in the acute Trust, is one of the busiest in the country and has achieved a high reputation for clinical care, teaching, and research. It is open on six days each week and there is a “24–7” on-call team for inpatients and emergencies. Shared consultant posts with all surrounding clinics in District General Hospitals in South Yorkshire and North Trent have allowed the development of an effective clinical network.

3. Patient demand has rapidly increased during the past decade. Between 1996–2001, the annual numbers of new patients attending the clinic increased by 13%. Since 2001, there have been accelerated pressures on the clinic service. For the period 2001–03, the recorded increases for annual total caseload was 73%, for new patient episodes was 30%. The annual number of gonorrhoea cases has doubled and of new HIV patients has trebled. Moreover, syphilis, previously seen only sporadically, has re-emerged as an increasingly common infection.

4. The service has responded to this increasing demand by extensive modernisation of clinical practice by means of additional clinic sessions, developing nurse practitioner posts, reducing patient follow-up attendances, updating clinical management strategies, and revised triage systems, all designed to increase service capacity.

5. It has introduced several innovations. These include a new consultant post shared between GU Medicine and specialist Contraception Services, to coordinate the community-based chlamydia screening programme that began in 2004; all chlamydia tests from all clinical sites in the city are now tested using the most sensitive nucleic acid amplification (NAAT) methods. A new nurse consultant post in health advising has been established to develop partner notification for STIs in community settings, and a new specialist HIV social worker is employed to cater for the complex problems of HIV-affected black and ethnic minorities. We were also amongst the first GUM centres in the UK to streamline HIV testing and the annual numbers of patients accepting testing in our clinic doubled to 8,500 during 2001–03.

6. Despite all of these changes, there has been a serious deterioration in GUM access times. HPA data for May 2004 shows that the numbers of patients who were able to access the clinic within 48 hours of first contact was only 20%. The average time to a routine appointment has increased to around three weeks. The current waiting list now exceeds 600 individuals and continues to grow week by week. Despite our triage system, which aims to give priority to the symptomatic individuals and the young, gonorrhoea and chlamydia rates continue to increase, as do new cases of HIV, not least in pregnant women, and the re-emergence of syphilis cases in the city is very worrying.

7. GUM clinics were notified by the Department of Health of non-recurrent allocations of additional funding beginning in 2003 to promote additional capacity. Only half of the initial £140,000 allocation designated for GUM was received.¹ The remainder was retained by the PCT for other purposes not related to sexual health. This failure to receive the total funding, which was justified by the PCT on the basis that GUM services were not a national or local priority, significantly impaired confidence and our ability to expand service capacity in a timely fashion.

¹ Kinghorn GR, Abbott M, Ahmed-Jushuf I, Robinson AJ “BASHH survey of additional Genitourinary Medicine targeted allocations in 2003 and 2004”. *International Journal of STIs&AIDS* 2004; 15; 650–62.

8. Fortunately, since the additional targeted GUM funding has been made recurrent, the PCT has agreed to transfer the full amount of the additional allocation for GUM during the current year. As the clinic is now located within a Foundation Trust (FT), we attract full tariff for overperformance against the baselines agreed in the service level agreement. This contrasts with the non-FT GUM clinics, which only receive marginal costs for additional workload that do not cover the step costs of delivering more patient service.

9. Any further expansion of workload is severely impaired by serious space constraints. Our dedicated clinic premises were designed 25 years ago for less than half the current workload. In order to increase patient throughput, we have a very urgent need for additional consulting rooms and appropriate accommodation for personnel. The department was selected as the Strategic Health Authority choice for a share of the designated £15 million capital funding for GUM infrastructure. This funding was inadequate and was eventually allocated only to those services currently in temporary accommodation eg portacabins. Whilst this is understandable, this leaves significant accommodation/capacity issues that are pressing in Sheffield and elsewhere, which require a substantial increase in targeted capital allocations.

10. Up until 2004, there has been relatively little STI care delivered within community settings. The vast majority of patients with suspected or diagnosed STIs that initially present at other settings are referred to the specialist service for further patient and partner management and follow-up.

11. We have long been involved in undergraduate teaching and providing full-time and flexible specialist training. We are also committed to assisting the development of plurality of service provision within the city, and to actively support new community-based services for STI care. To achieve this end, we have already successfully introduced STI Foundation courses aimed at primary care doctors and nurses. But this theoretical training needs to be supplemented by increased opportunities for practical training and competency assessment within the clinic. Unless there are more staff and more space, it will not be possible to increase this to meet local requirements.

12. We are very pleased that many of the recommendations contained within the Health Select Committee report have now been adopted by the government in “*Choosing Health- making healthy choices easier*”, not least the additional priority at both national and local level that has been given to Sexual Health, and the strong performance management advocated to make progress to the 48-hour maximum wait goal for 2008. However, even in Sheffield where there is a strong tradition of innovation, of co-operative working between different sexual health services, and of extensive sexual health education, the situation is rapidly deteriorating. There is real concern that a new national education campaign will be undertaken before there has been satisfactory planning of the service consequences of this further stimulus to patient demand.

13. We strongly recommend that services for sexually transmitted infections and HIV receive immediate support. We need to plan for a 30–50% increase in GUM patient throughput before 2008, and to provide practical training of dozens of primary care practitioners to provide a similar or greater increase in capacity at community settings. To achieve the latter objective, we recommend that a sexual health-training budget be established.

14. Expansion of the numbers of clinical personnel and of clinic space to accommodate training needs should begin immediately if we are to achieve the 2008 goal. In our view, the longer the delay before the new resources filter down to clinic level, the greater the risk of deepening the current sexual health crisis and of more preventable damage to the nation’s Public Health.

December 2004

Memorandum by fpa (HA 08)

SUMMARY OF SUBMISSION

- **fpa** (Family Planning Association) is the UK’s leading sexual health charity working to improve the sexual health and reproductive rights of all people throughout the UK.
- *The consequences of the new and proposed changes in charges for overseas patients with regard to access to HIV/AIDS services:*
 - We are concerned that the proposed changes will act as a disincentive for testing, which will have serious implications for public health.
 - There could also be a knock-on effect on Accident and Emergency services if treatment is denied in primary care.
- *Progress to date in implementing the recommendations of the Committee’s inquiry into Sexual Health (the Committee’s Third Report of Session 2002–03):*
 - **fpa** welcomes the Public Health White Paper proposals on sexual health and the additional funding of £300 million announced to implement these proposals.

- We believe that there needs to be much greater integration of sexual health services, in particular an increase in the number of services which offer both contraceptive and STI services, and greater integration between contraceptive and abortion services at the funding and commissioning level.
- We are very concerned that payment by results will act as a disincentive for integrated and effective sexual health services.
- It is vital that contraceptive services are improved, and that general practice provision of contraception is included in the forthcoming audit.
- There is a real need for improvements in general practice provision of sexual health services, with additional quality points and clarification of services covered in the GMS contract.
- All professionals working in sexual health must have access to good quality training which includes communications skills.
- There must be further prioritisation of sexual health at a local as well as a national level.
- Despite the omission of abortion services from the Public Health White Paper, there must be continued improvement in and access to these services for all women.

SUBMISSION

About fpa

1. **fpa** welcomes the opportunity to contribute to the Health Select Committee's inquiry into *New Developments in HIV/AIDS and Sexual Health Policy*. We are also willing to give oral evidence at the evidence session on 27 January 2005.

2. **fpa** (Family Planning Association) is the UK's leading sexual health charity working to improve the sexual health and reproductive rights of all people throughout the UK. **fpa** wants to see a society with positive and open attitudes to sex, in which everybody enjoys sexual health and where sexual and reproductive rights are respected. **fpa**'s purpose is to enable people in the UK to make informed choices about sex and to enjoy sexual health free from exploitation, oppression and harm.

3. **fpa** runs a comprehensive information service, including a national telephone helpline, which responds to over 100,000 queries each year on a wide range of sexual health issues. We also produce a variety of publications to support professionals and the public, and provide resources including training courses for those involved in delivering sexual health services and sex and relationships education (SRE). We also contribute to SRE through our series of publications aimed at young people which schools can use as part of their SRE programme.

The consequences of the new and proposed changes in charges for overseas patients with regard to access to HIV/AIDS services

4. This is not a specific area of expertise for **fpa**, but we do make the following general points:

5. As we understand it, in relation to access to HIV/AIDS services, only diagnostic testing and associated counselling will be exempt from charges. We are concerned that this will act as a disincentive for overseas patients to come forward for testing, as they will have to pay for treatment following a positive result. Given the nature and transmission of HIV, it is vital that people are tested and treated as quickly as possible. The public health consequences of undiagnosed HIV are significant. If people are denied access to HIV testing and treatment they are likely to pass infections on to future sexual partners, thereby increasing infection rates in the population as a whole.

6. Furthermore, diagnoses must be made quickly in order to limit complications which can in turn impact on acute services. If overseas patients are denied treatment in primary medical services, they are more likely to present to Accident and Emergency services where emergency treatment is free.

Progress to date in implementing the recommendations of the Committee's inquiry into Sexual Health (the Committee's Third Report of Session 2002–03)

7. **fpa** welcomes the inclusion of sexual health as a central theme in the Public Health White Paper and the injection of £300 million for sexual health services over the next three years. This is an excellent step forward in improving people's sexual health and should help to accelerate the achievement of the recommendations laid out in the Health Select Committee Report. However, the real test will be in how quickly and effectively implementation of these comprehensive proposals can take place at a local level.

8. *Integration of sexual health services*—We believe that better sexual health choices could be made available to users through the integration and joining-up of services, so that, for example, people can access STI screening at a family planning clinic and contraceptive services at a GUM clinic. There needs to be an increase in the number of services which offer both contraceptive and STI services, so that there is a more

holistic approach to people's sexual health. It would not be necessary to have a combined service in every setting, but GUM and family planning services should be linked together and seen as part of one sexual health service.

9. There also needs to be greater integration between contraceptive and abortion services at the funding and commissioning level. It is self-evident that where there are high quality and easily accessible contraceptive services there will be fewer unintended pregnancies and therefore fewer abortions. There are currently very few PCTs which integrate either funding or commissioning of these services, which means that there is no financial incentive to get the best out of both services. We believe it is an urgent priority for PCTs to recognise the links between contraceptive and abortion services and to integrate their approach accordingly.

10. *Payment by results*—We are concerned that payment by results will act as a disincentive for integrated sexual health services if services are paid for separate family planning or GUM consultations. This will result in service users being pushed to a number of different services rather than having a holistic service that can offer both GUM and family planning advice and treatment. There is a concern that if service users are referred to a separate service, they will not attend another appointment so may not access the services they need.

11. In addition, if services are organised so that payment is by visit rather than by treatment, this does not take into account provision of longer-term courses of treatment. For example, in contraceptive services, this could militate against provision of longer-acting contraceptives which last for a number of years (eg IUDs, implants, etc), and could instead incentivise repeat prescriptions of oral contraceptives at more frequent intervals.

12. *Quality of contraceptive services*—fpa welcomes the announcement in the Public Health White Paper that there will be an audit of contraceptive service provision to be carried out in 2005, followed by central investment to meet gaps in local services (following recommendations 29 and 31 in the Select Committee Report). We believe that it is vital that general practice contraceptive provision is included in the audit as well as family planning clinics.

13. Wherever users access contraceptive services, they must have access to all contraceptive methods. Anecdotal evidence suggests that not all services currently offer all methods, in particular in general practice where the majority of contraceptive advice is given. It is particularly important to prioritise contraceptive services overall—contraception is a positive health service, is the ultimate preventive tool in sexual health, and currently saves the NHS around £2.5 billion per year.

14. *Impact of the GMS contract on sexual health services provided in General Practice*—We are very concerned that out of the 1,050 quality points in the National Quality and Outcomes Framework in the new General Medical Services (GMS) contract, only two relate to contraception—one on a written policy for emergency contraception, and the second on a written policy for providing pre-conceptual advice to women who want to become pregnant. We believe that this lack of quality points for the provision of contraceptive advice seriously undermines this aspect of the contract, and does not incentivise general practice to provide a comprehensive contraceptive service. These concerns about primary care provision of sexual health services were highlighted in recommendations 28 and 30 in the Select Committee Report, and still remain to be adequately addressed.

15. We believe that the Department of Health must also work with the British Medical Association to provide clearer guidance on the impact of the GMS Contract on the provision of STI services in general practice. As we understand it, provision of information, advice, testing and referral for STIs is included within the management of patients required in essential services, but we hear anecdotally that some general practices are declining to offer these services in the mistaken belief that they are not covered in essential services. This situation must be clarified as soon as possible.

16. As the GMS Contract is developed, we urge the introduction of additional quality points for contraceptive services, for the diagnosis and treatment of STIs in general practice, and for sexual health promotion.

17. *Training/support for professionals*—In order to create better choices in sexual health we believe that professionals working in primary care need to receive improved information and training. In particular, we believe that greater attention needs to be paid to the role of general practice in providing sexual health services, and to the needs of those who work in general practice for adequate education, training and support on all areas of sexual health.

18. It is encouraging that the Public Health White Paper sets out that sexual health services will increasingly be delivered by a flexible, multidisciplinary workforce, including nurses, youth workers, community workers and pharmacists. However, it is vital that all those involved in the delivery of these services are appropriately trained. Sexual health is a sensitive area, and communication skills of professionals working in sexual health services are vital to reduce the “embarrassment factor” during user appointments. Sexual health training should cover attitudes and values, and must include communication skills to ensure a sensitive and non-judgemental approach to service users.

19. Similarly, the proposed NHS-accredited health trainers must have adequate training in sexual health as well as other aspects of public health, in order to be able deliver effective support and advice to all groups in communities.

20. We are also concerned about the lack of sexual health training required as part of the GMS Contract. In particular, while we welcome the fact that general practices which offer contraceptive services will now be required to offer information and advice about the full range of contraceptive methods, we are disappointed that there is no training requirement attached to this.

21. *Prioritisation at local level*—Despite the National Strategy for Sexual Health and HIV, there has been a failure by local NHS organisations to recognise and deal with sexual health as a major public health issue. Currently, sexual health is given low priority amongst NHS planners and commissioners at both SHA and PCT level. To enable sexual health services to meet the increasing demands placed on them and expand their services accordingly, sexual health and HIV must be a national and local priority for the NHS.

22. The Public Health White Paper has made a step forward in ensuring local prioritisation of sexual health: *National Standards, Local Action: Health and Social Care Standards and Planning Framework* (2005–06—2007–08) will now include improving sexual health within the national targets for the NHS, and sexual health will be included in the forthcoming round of Local Delivery Plans. In this context, it is crucial that future sexual health targets include contraceptive services as well as GUM services.

23. **fpa** is keen to see further measures to ensure that sexual health is embedded and mainstreamed as an ongoing priority for PCTs and SHAs, which is fully accounted for in core budgets at a local level beyond the 3-year timeframe of the recently announced additional Department of Health funding.

24. *Abortion services*—Despite the Health Select Committee’s recommendations on abortion services (7, 32 and 33), **fpa** was disappointed that the recent Public Health White Paper did not include any initiatives on abortion services. **fpa** believes that, having taken the decision to end a pregnancy, all women should be able to access abortion services promptly and without delay. We recommend that there should be a target waiting time of 72 hours for abortion, with one week as a minimum standard. In the meantime, it is crucial that the Government retains the National Strategy for Sexual Health and HIV’s target that from 2005, commissioners should ensure that women have access to abortion within three weeks of the first appointment with the GP or other referring doctor. It is also important that the Healthcare Commission retains its PCT performance indicator of the percentage of NHS-funded abortions performed under 10 weeks.

25. Many women face long and unacceptable waits for an abortion to be carried out in a hospital. We believe that early medical and surgical abortions could be carried out in community settings such as family planning clinics and general practices, thereby making use of existing settings and enabling greater access and choice for women. At the same time, we believe that nurses should be allowed to play an expanded role in abortion procedures. This would not only increase the number of professionals working in abortion services and thereby improve access and waiting times, but would also fit in with the broader NHS strategy of developing nurses’ skills and specialisms.² These recommendations would require a legislative change.

26. We are also concerned that women are not currently able to access the abortion services to which they are legally entitled. Anecdotal evidence suggests that women presenting at later gestations find it difficult to access NHS abortion services. We are aware that, in some PCTs, this can be from as early as 13 weeks’ gestation, and certainly in many parts of the country difficulties in access are more common from 16-18 weeks’ gestation onwards.

27. Despite the omission of such specific recommendations in the Public Health White Paper, we believe it is vital for the Government to take additional steps to improve abortion services.

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² For further information about these recommendations please see **fpa**’s report *Early abortions: promoting real choice for women*, December 2003.

Witnesses: **Professor George Kinghorn**, Consultant in Genito-urinary Medicine and Clinical Director for Communicable Diseases, Sheffield Teaching Hospitals NHS Foundation Trust, **Ms Anne Weyman**, Chief Executive, Family Planning Association and **Dr William Ford-Young**, general practitioner, were examined.

Q1 Chairman: Good morning, and may I welcome our witnesses. We are pleased to see at least two of you before the Committee once again. As you know, this part of this morning's session particularly is, in a sense, an update on developments since the publication of our report on sexual health two years ago. Obviously we are aware of a number of developments. I think you appreciate that we are taking evidence later this morning on one aspect of an area that we looked at during our inquiry. I wonder if we could start by particularly asking you, Professor Kinghorn, for your views on developments since 2002, trends on STIs, on HIV, since we reported and what has been happening, in your view, with regard to how quickly people can be seen at genito-urinary clinics. As you know, we expressed a very serious concern over the delays in people accessing treatment in various parts of the country.

Professor Kinghorn: We are delighted that the public health importance of STIs has been recognised, that they have been given additional priority and that there are new resources to support service expansion and meet patient demand for services. We are especially pleased that the recommendations of this Committee have been acknowledged in this way. We are very grateful for your influence and support. In talking about the changes that have occurred over the last two or three years, generally there have been accelerated pressures on clinic services. In my own city of Sheffield, our new patient episodes of care have increased by 30%. We have had a doubling of diseases such as gonorrhoea and syphilis and our number of new cases of HIV on an annual basis has trebled.

Q2 Chairman: Before you go further, could I ask you for your thinking on the reasons why more people are coming forward. You say that there is more incidence, or is it that people are more aware of the means of accessing help? Are there other factors that may have a bearing on the increased presentation of people at your clinic?

Professor Kinghorn: I think there is very definitely a worsening, an increase, in the incidence of sexually transmitted diseases, as evidenced by the cases of gonorrhoea and syphilis that we are seeing. These are new problems. Although some additional resources have gone into clinics, the amount of resource that went in was less than that recommended when we met with you previously. There is a widening gap between the patient demand and our clinic capacity and, sadly, I think that is going to get worse. It is true that there is increased knowledge about the risk of sexually transmitted diseases, and I am glad to see that more people are attending for check-ups to assure themselves that they are healthy before they change partners, but all of that just tends to increase the pressures on services. Unless we do something to increase capacity, both in the clinics and in other community settings, then I think that gap is going to stay wide.

Q3 Chairman: You recall that one of the issues we raised was this question of a 48-hour access target, which is picked up, of course, with the White Paper. In listening to what you have just described are the problems now, what is going to need to be done to increase capacity to meet the target that the Government has set?

Professor Kinghorn: I think the target is welcome but it is very challenging for us to achieve by 2008. Despite extensive modernisation of our clinical practice to increase the throughput of new patients, as I have indicated, there is still this very wide gap between capacity and demand. In order to achieve the 48-hour target, there is a need for resource to increase the clinic capacity not only to meet the current gap but also the additional workload that will inevitably result from an education campaign. We also need to increase capacity in community settings. There needs to be additional provision of services within community contraception clinics, also in primary care, and it is essential that there should be increased training opportunities for practitioners in those settings. I think that this will require a separate training budget to be established. In the specialist services, we do have an additional problem of space. I could employ the people but I need to provide additional services, but I would have great difficulty in providing the space for them to work in the most effective way. So I hope that the current national review of GUM services will help us to show where those resources need to be put so that we can increase space to maximise service capacity.

Q4 Chairman: Your comments obviously relate to your experience in Sheffield. Do you feel that the picture you have given us applies across the country as well as just in your part of the world?

Professor Kinghorn: Yes, I think the evidence is that there is a problem throughout England, but we do know that when we look at trends in sexually transmitted infections, there are worse problems in north and eastern England than perhaps there are in London, but it does tend to appear that the worst problem, in terms of increased incidence of disease, occurs in those locations where clinic access is worse. So poor access tends to lead to more problems.

Q5 Chairman: Is this anecdotal or can you give hard circumstances?

Professor Kinghorn: There is evidence.

Q6 Chairman: Can you point us in that direction?

Professor Kinghorn: There is published evidence from the Health Protection Agency both in terms of their GUM waiting times survey report and also in their annual reports of STI incident that cover 2001–03.

Q7 Chairman: What you are saying is that if there are more awareness campaigns in terms of prevention that will result in more people presenting themselves to GUM clinics? I recall when we were in Manchester one or two of us making suggestions

27 January 2005 Professor George Kinghorn, Ms Anne Weyman and Dr William Ford-Young

about preventative campaigns and the people in the GUM clinic there put their hands up and said, "No, we could not cope with the additional demand that would arise from what you are proposing". That is a picture that applies across the country presumably, a concern that the more the awareness, the more the demand and the more difficulty in meeting the capacity?

Professor Kinghorn: Yes. We are in a bit of a dilemma. I wish to encourage people to take responsibility. I wish to encourage people to take that personal responsibility for their health and for the health of their partners, but, unless capacity increases go hand-in-hand with the education campaign, then there is a risk that services which are under severe pressure would be in a state of collapse. The concern we have at this present time is that new resources for capacity may not become available until 2006–07, which will be after the education campaign has been proposed. That, in our view, would lead to a great dissatisfaction amongst the public because we could not cater for the obvious increase in demand.

Q8 Mr Burns: Do you have collective statistics or do you have any evidence that when someone goes to a clinic and they find that they have to wait possibly four, five, six, 10 or 12 days before actually seeing someone then they fail ever to turn up again?

Professor Kinghorn: Yes, there is a proportion of patients who will not come. This is particularly the case with the young. There is a window of opportunity and it is important that when individuals present they should be seen at that time, otherwise there is a risk that they will not turn up and they will continue to ignore symptoms.

Q9 Mr Burns: Do you think it is more that they will continue to ignore symptoms rather than that they will try and get help elsewhere, like going to their GP or whatever, or to another clinic, depending on where they live?

Professor Kinghorn: Some will try to go to other settings, but I think many will fail to turn up.

Q10 Dr Taylor: May I go back to the 48-hour targets for the moment? We gained the impression with the GP 48-hour target that some practices actually suspended the list at 48 hours so that nobody was over it. Is there any evidence that you are doing the same sort of thing, or have you managed to avoid that?

Professor Kinghorn: This is an issue about which I feel particularly strongly. The 48-hour access should be from the time that the person first makes contact with that service. It is not acceptable to me that they should be required to ring up on succeeding days.

Q11 Dr Taylor: They should ring up every morning at 8.30?

Professor Kinghorn: I think that is quite an iniquitous system and should be strongly discouraged. I think what we are saying is that we

wish to have access, if not immediately, at most within 48-hours from the time that the person first makes contact.

Q12 Dr Taylor: Going on to funding, you have already said you welcome the new money but that the resource is rather less than recommended. What we want to explore is whether it is actually getting through to you. In the brief, the British Association said that 90% of the £5 million that was allocated directly to GUM clinics got through, but not all of the rest that went to PCTs, and in fact it is so bad that approximately 50% of the money only reached its intended destination. What is the answer to this?

Professor Kinghorn: If I may give some further explanation to this, in 2003–04 there were two allocations. The first was £8 million of recurrent funding; the second was £5 million of non-recurring funding. Both of these allocations were made to PCTs rather than directly to clinics and only half of all of the clinics recorded receiving their full allocation, and one-third of the total funding in 2003–04 appears to have been used for other purposes. In my own city of Sheffield half of the recurrent amount in 2003–04 was withheld by the PCT, and their reason was that sexual health and GUM services were not seen as a priority. I think the answer is that we now have increased priority as a result of the White Paper. As ever the optimist, I hope that there will not be a repeat of this in the future. I think that the other answer which is very important is that there should be strong performance monitoring by strategic health authorities to make sure that this cannot happen again.

Q13 Dr Taylor: They should be monitoring that the money actually gets where it is intended to go?

Professor Kinghorn: Yes.

Q14 Dr Taylor: If you get all that is proposed, will that enable you to meet the 48-hour target, for example?

Professor Kinghorn: I can only say that I hope so. I think that with the potential capacity requirement, if we encourage everyone who changes their sexual partner to seek a check-up before they have a relationship with a new partner, we are talking about a demand for services which is hugely increased from that which is met by GUM services at the present time. We are talking here of potentially millions more patient episodes. I am optimistic that we can do more, but I think we will just have to see how things develop. I know that within my own setting we are planning for there to be a 50 increase in new patient episodes within the next three years. I know that we need to increase community capacity by two or three times if we are to meet the demands which are going to be placed upon us, but I am ever optimistic.

Q15 Chairman: Could I clarify that I understood you correctly to say that when people change their sexual partners they should have a medical check?

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Professor Kinghorn: Yes.

Q16 Chairman: And people who change their partners several times a night could cause some difficulties, presumably?

Professor Kinghorn: They will need to be seen more frequently!

Q17 Dr Taylor: I am wrestling with the recommendation we have to make because strategic health authorities have only one aim, and that is to balance their books. If the PCT does not have enough money even to meet its stated targets, we are going to have to wrestle with this one. I think we have the message.

Professor Kinghorn: I think we also see a role for the Healthcare Commission in making sure that they are supporting sexual health and that they do have an increased role in the future in ensuring that the services are appropriate to meet local need.

Dr Taylor: That is a very good point and it is something we can stress to the Healthcare Commission.

Q18 Mr Bradley: The White Paper also announced the introduction of chlamydia screening throughout England by 2007, with particular emphasis on women under 25. First do you have any general comments about that aspiration? Secondly, could you update us on the availability of the NAATS screening testing in England?

Professor Kinghorn: We are very glad that the availability of the most sensitive tests will occur throughout England by 2007. Currently, about 25 of the country has access to the most sensitive test. I am concerned to ensure that the most sensitive tests are used for all people, irrespective of their age, and not just reserved for those women under the age of 25. Of course, a screening programme based on opportunistic screening of young women alone has its drawbacks when the prevalence of infection is about one in 10 of those sexually active women under the age of 25. The prevalence in young men under the age of 25 is also about one in ten, or more. It is important that we should be encouraging young men, as well as young women, to be screened.

Q19 Mr Bradley: So I am clear, you are saying there is 25% access to the NAATS test now?

Professor Kinghorn: Yes.

Q20 Mr Bradley: By 2007 what percentage do you think will be available for that?

Professor Kinghorn: I am assured that the programme intends that all areas of the country will have access to the most sensitive tests, but the availability of such tests in all areas may not necessarily be the same thing as access of all patients to the most sensitive tests. It is important that diagnostic services should be equally available for all who need them.

Q21 Mr Bradley: But you do not believe that will happen by 2007 for all categories?

Professor Kinghorn: I hope that it is going to be available by 2007, but I think there may well be difficulties in achieving that date.

Q22 Dr Naysmith: Could I bring in Dr Ford-Young now and talk a little bit about primary care services as they have been mentioned. In 2001, the Sexual Health and HIV Strategy envisaged a crucial role for primary care in this area. As we understand it, the new GMS contract does not offer much in the way of incentives to do that, so do you think there has been a missed opportunity? Perhaps you could help us understand the issues surrounding that and why there are not incentives?

Dr Ford-Young: I think there has been a great missed opportunity in our new GMS contract. GPs who have an interest in sexual health, like myself and my colleagues, very much welcomed your report in June 2003, and you recognised the potential that general practice and other parts of primary care have in delivering good quality sexual health services. We see a lot of patients through our doors. We provide up to 80% of contraception services in England and, in a way, we are the sleeping giant of sexual health services. Your Committee and we ourselves were optimistic that our new contract would help improve the provision of quality of care for sexual health but, unfortunately, it does not. It appears to have ignored the National Strategy for Sexual Health and HIV.

Q23 Dr Naysmith: Why do you think that is?

Dr Ford-Young: I think it has ignored the levels of care that exist within the National Strategy for Sexual Health. Basically, we have a three tier contract. The most basic level is what is termed essential services. That is for us to react to patients who walk through our doors who are ill, or believe themselves to be ill; to provide management for chronic disease; and to provide terminal care. Within that, I think I, as a general practitioner with an interest in sexual health, would include sexual health as part of general medical services because sexual health is part of our health and wellbeing as human beings. I think, however, the negotiators who negotiated the contract felt that sexual health was not part of essential services. Whilst the national strategy provided holistic levels of care for all the various parts of sexual health from contraception to STIs and cervical cytology, *et cetera*, our contract decided to place these various elements of sexual health into various additional add-on bits of our contract over and above essential services. The only part of our contract that really encompasses sexually-transmitted infections is what is called the National Enhanced Service, which is very much a high level, add-on bit of the contract. There would be very few practitioners in the country who would have all the skills and competencies to provide that service. In my experience, there are very few PCTs that are commissioning that kind of service.

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Q24 Dr Naysmith: Would it enable some practices to specialise in this sort of area of medicine for a particular part of a city or something? The system is there but you are saying you think it is unlikely to happen?

Dr Ford-Young: That is possible. It is happening in some areas but there is a reluctance, I think, by many PCTs because of what they see as financial constraints and where they see the importance of sexual health on their agenda to decide to commission such services. We lack any formal national training programme to upskill general practitioners and their nurses, and so on, to provide these services. We need to include general practice as a good site for chlamydia screening, but screening is not seen as an essential service, so again that needs to be supported and resourced. I am aware that the Department of Health is looking at a model whereby it could be formed as an enhanced service into general practice, but that does need the commitment from the Secretary of State to provide the resource to do that. We need to look at the competencies involved for that, and so it is not going to happen overnight.

Q25 Dr Naysmith: In a kind of anecdotal way, how do your colleagues feel about this? Would they like to get more involved in it if there were more incentives? When we were doing this last time round, we all agreed that we, as Members of Parliament, hardly ever got any complaints about sexual health services. We get complaints from constituents about all sorts of other things but rarely about sexual health services. I wondered if the same kind of thing applies amongst professionals. Is it low down on the horizon?

Dr Ford-Young: I think people's perception covers a wide range and where they themselves as general practitioners would put sexual health on their agenda. Generally speaking, certainly anecdotally from my area where I have been involved in trying to roll out a chlamydia screening programme at a phase two site, of my colleagues who unlike myself do not champion health but feel that chlamydia is an important cause, over 50% in my area wish to be involved in the chlamydia screening but see the contract as getting in the way of being able to find the resource in time to provide that service.

Q26 Chairman: Could I ask you about an issue that obviously struck us all when we looked at sexual health two years ago and it was that as MPs I do not think any of us had received any representations from constituents about problems with GUM services or accessing services. At that point, I think all of us saw a dilemma. In the process of moving decision-making on health care more and more towards local people through PCTs and decision-making in the secondary sector as well to local people, that same problem of us being unaware of what was happening would be shunted to local decision-makers from national decision-makers. How do we get an awareness of the kinds of problems we are talking about here today across to those people who are making the decisions that

result in Professor Kinghorn only getting a small part of the money he ought to be getting? Do you understand the problem I am describing? Money is a difficulty which we felt, as a committee, was hard to challenge and how you got this awareness across that enabled you then to direct the resources where they were needed.

Dr Ford-Young: One of the things we probably need to look at and support, and again it does need support from the centre, is managed clinical networks. When we lost health authorities and moved to PCTs and we were shifting the balance of power, we actually lost a lot of expertise and competence around commissioning sexual health services, especially some of the more specialised sexual health services like HIV treatment and care. I feel a PCT is too small a body to be commissioning at that level because the more specialist services lie across several PCTs. In the implementation plan of the national strategy it suggests that we should be looking at more joined-up commissioning of primary care organisations working together. There is a good example, I think, of a managed clinical network in Greater Manchester, which covers the strategic health authority area whereby I think a lot of the problems we had with shifting the balance of power can be addressed, still at local level, without everything coming from the centre nationally. A managed clinical network like that helps to link the various service providers from a GUM clinic to an HIV provider to a general practice or a community family planning clinic or a voluntary organisation. It can help to have all those service providers providing a basic minimum standard of care, which would be a good standard of care to ensure patient care pathways exist. All too often we forget that the patients should be at the centre of our care in our pathways rather than developing our services to suit ourselves. I think they will be the drivers in the clinical governance issues to ensure good value for money in those areas and to ensure that patients actually get the choice and the service they need and deserve.

Q27 Dr Taylor: Can I go on and explore that a bit further because managed clinical networks are thrown up as the answer to so many of the specialities in difficulty. How does Manchester actually work? Could you give us some detail? Are there any other managed clinical networks that are co-terminus with strategic health authorities? For cancer, cancer networks are not co-terminus with strategic health authorities, and that always seems to me to be a bit odd.

Dr Ford-Young: I do not think necessarily a managed sexual health network needs to be co-terminus with an SHA but I think that is useful because of the SHA's hopefully increasing involvement in quality and performance management, perhaps with the extension of local delivery plans at PCT level. This is something else and I think a managed network can help co-ordinate PCTs to incorporate sexual health in their local delivery plans so that sexual health does get on the agenda at PCTs.

Q28 Dr Taylor: So a network should really be just a central unit with the consultant travelling out to outreach clinics and involving the GP specialists as well?

Dr Ford-Young: I do not think you necessarily need to have the consultants travelling out. I think the network allows people to stay where they are in their service providing their service, but the network helps to co-ordinate those different elements of care. I think the important thing is that it is a managed network and that resource is found actually to manage it, so that we do not rely on people's goodwill to come to a meeting at lunch time from their work to try to get round a table, but that there is a facilitated network.

Q29 Dr Taylor: Going back to the GP specialists, because again in geriatrics and in palliative care GP specialists are seen as the answer until there will not be any poor GPs left. How many GP specialists in sexual health are there? Have you any idea?

Dr Ford-Young: I do not actually know, and I am not certain that the Department of Health's Sexual Health team knows either.

Q30 Dr Taylor: It is probably very few?

Dr Ford-Young: I think there are very few who are actually employed as GPs with a specialist interest in sexual health. There are also GPs like myself who have an interest, but we are not actually classified as GPs with a specialist interest and contracted as such.

Q31 Dr Taylor: So there is a difference?

Dr Ford-Young: There is a difference, yes.

Q32 Dr Taylor: You have already hinted that there is not much training. What would be the ideal way of training and attracting more GPs to take on this?

Dr Ford-Young: I think we very much need to look at driving and funding a nationally-agreed training programme organised through professional bodies such as the Royal College of General Practitioners, the Royal College of Physicians and the Faculty of Family Planning, for example, because we need to be looking at sexual health holistically. A very good model was developed around the management of substance misuse in general practice because there was the will by Government to fund that and the will of the Royal College of GPs to take that on board and develop a course. I think a similar model would work well for sexual health in that managing sexual health, like managing substance misuse, is often seen by many as a not very nice thing to be dealing with, and a client group of people may have some problems in dealing with it, too. I think that has very much helped to normalise the care of people who have substance misuse. One of the most important things we need to do with our care is to normalise talking about sex and sexual health in all care settings, but particularly in general practice.

Q33 Chairman: What drove you to specialise in this area? If you were in Manchester or London or wherever I could understand, but Macclesfield? Sir

Nicholas Winterton is a very good friend of mine but I do not get the impression there is a great deal of sex going on in Macclesfield!

Dr Ford-Young: I can assure you there is a lot of sex going on in Macclesfield, regardless of whether Sir Nicholas is our MP or not! He is a good friend of mine as well. I have always had an interest in sexual health and I have always worked part-time in GUM clinics as well. In fact, I work in one in Withington, as well as the one in Macclesfield, as well as being a GP. I am fairly unusual in that. A lot of my GP colleagues, whilst they do not wish to work in a GUM clinic as well as in general practice, still have a firm desire to provide good quality sexual health care holistically to our patients because we are generalists and are finding it very difficult to be rewarded to do that. Also, PCTs do not have any sticks to beat us with if we do not come up with the goods, so we have no carrots or sticks basically in sexual health in general practice.

Q34 Mr Burns: Professor Weyman—

Ms Weyman: May I say that I am not a professor. I do not know how that crept in and I am very flattered.

Q35 Mr Burns: You obviously are not a politician because, if you were, you would not have admitted to that! As you are aware, the White Paper has announced an audit of contraceptive services during the course of this year. Would you like to share with the Committee your observations on that, and also the scope and the quality of the services currently provided across the board?

Ms Weyman: We greatly welcome the fact that there is going to be this audit of contraceptive services. We feel that contraception has been very much the neglected area of sexual health for a long time. Just as we have heard all the problems that there are around GUM clinics, the problems around contraceptive clinics are many: the lack of resources; problems of premises; problems about having insufficient staff to run them. There is a huge number of problems. We do very much welcome this audit but we think it must be something that really is quite comprehensive. As Dr Ford-Young has said, a great deal of contraceptive advice is provided in general practice in England, and so the audit must look at what is going on in general practice as well as looking at what is going on in community clinics and take that comprehensive view. As I say, we are aware of the variability in the quality of services, not only those from general practice but also within community clinics as well. There is a question about looking at how the full range of contraceptive methods is provided so that there is proper access to the full range, which is patchy in many areas. This is partly a question of the skills and capacity of professionals but also about the funding that they have access to in order to provide particularly the longer-acting methods, which in the short term are more expensive. So this is a really important review. We do very much welcome that it is happening.

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Q36 Mr Burns: Do you have high hopes for the outcome of it?

Ms Weyman: The review is the start, is it not, and it is really about what happens after that and how we go about improving the services that are available. I think there is a great deal of work to do there both in terms of the investment that is required—and we have a certain amount of money set aside for that but we do not know until we have done the review whether the amount of money is in any way going to match up to what is needed to be done—and also in terms of looking at who the professionals are who are going to provide the service, the doctors and nurses who would be involved, and how they are going to be trained. One of the problems at the moment about attracting people in to work in community clinics is the way they are paid compared with other areas of health care. There is a whole range of questions that needs to be looked at to ensure that we have the physical capacity in terms of places but also the people who can provide that services as well.

Q37 Mr Burns: If we can move on to the actual services, as you are aware, since the publication of the Sexual Health Strategy, there has been a number of initiatives set up to evaluate an integrated sexual health service bringing together GUMs and family planning services. How is that progressing, to your mind? Do you have any general comments on the initiatives so far?

Ms Weyman: I think this whole question of how you look at sexual health and sexual health services together is still a very big and an unresolved one. If you look at the way the White Paper is constructed and the way the funding is constructed, it is all constructed in terms of individual services rather than thinking about the experience of the person who is coming along to make use of those services. So I think there is a conceptual level which has not really been taken on. The managed network is already talking about the management of something, but you need a strategy that is going to take account of all these different aspects and be working out how they work together. Integration of specific services is one thing; but the integration of how you think about sexual health as a whole and how you plan it and how the budgets are structured is another thing, which in many areas is not on the agenda. Some of those divisions are quite interesting. If you look at it in most areas, for example the budgets and the commissioning of services for contraception and abortion are separate. They really ought to be brought more closely together. There should be more integration between those aspects of the services as well as discussions about the relationship between GUM and contraception. In terms of some of the things that Professor Kinghorn was talking about, such as testing for STIs in other settings, unless you get those services up to standard, those settings will not be there either. There are lots of different issues about making sure that you are thinking about it as a

whole so that the various elements are of a sufficient level and capacity for you to think about service delivery in a more related way as well.

Q38 Dr Naysmith: I wanted to ask Anne Weyman very quickly—and I know Simon Burns said she was not a politician but this is a slightly political question—what she thinks is the driver for the White Paper to announce the audit of contraceptive services? What is the background to it? Is it perceived as really something wrong that has to be put right or is it a reaction so that we remember that a few years back we were all talking about taking clinics out of the community and giving them to GPs? This may be an opportunity to switch over. Do you think at last that concern has got through or is it for some other reason, or have you just been beating the drum?

Ms Weyman: I hope it is because, first of all, in your own Committee's report you highlighted problems around contraception, the quality of services and the difficulties of assess. It is something we too have been talking about for a long time. Again, one hopes that the message has come through. In this area as well people do not come forward and complain about the quality of the contraceptive services that they are getting. Often I do not think that women have the knowledge that they are being denied methods of contraception; they do not know that all these methods exist because nobody is telling them about them. I do think that a lot of that has come from the pressure that we collectively have been putting on to have the services looked at and the needs that there are. I think there is also recognition of the problem. If you look at the relationship between conceptions and abortions in different parts of the country, there are very great variations, and in many ways that gives some indication, I would say, that contraceptive services are not always meeting the needs, because quite clearly they are not preventing as many unwanted pregnancies as they could be. If one is looking at the way the best compare with those with the worst records, you can always see considerable room for improvement.

Q39 Chairman: Anne Weyman mentioned a few moments ago the link between abortion and contraceptive services. You will recall that in our previous report we made some recommendations regarding abortion provision, none of which has progressed into the White Paper. I wonder what your thoughts are on this and the implications of the Government not perhaps picking up the concerns we expressed.

Ms Weyman: We were disappointed that abortion was not mentioned in the White Paper because there are many issues, as you highlighted in your report. There has been some progress in relationship to the provision and access of abortion services over the last few years with the under 10-week abortions being within the balanced scorecard for PCTs, and with some central investment going to PCTs to help them improve, but there is still a huge variation. If you look at questions around access, there are two measures that you can use: one is the difference

between those women who get their abortions before 10 weeks, and in the 2002 figures the variation was between 9% and 79% at the top and bottom of the range, and the numbers that are funded by the NHS, which is another measure of access, and the variation was between 46% and 97%. So we are still seeing huge variations in these measures of access. There is a great deal more to do. We do not have detailed PCT figures for 2003; they have not been published. We know that in many areas there are still long waiting times and that there is a lack of choice of method, lack of availability of the early methods for medical and early surgical abortions as well. There still is an enormous amount to do. Another particular area is access for abortions at later gestations where in some areas it is almost impossible for women to get their legal entitlement. We receive quite a lot of calls on our help line from women who have been told they are too late when they have come perhaps at 12, 13 or 14 weeks. There are still many areas to be addressed. We hope that in the implementation plan for the White Paper these will be picked up alongside the other issues that have already been mentioned in the White Paper.

Q40 Chairman: Would it be fair to say from this short session that the impression, particularly from Professor Kinghorn's evidence, is that we still have what we term a crisis in sexual health? If that is the case, what further steps can we take perhaps to press for what I think to us was the most obvious step forward, which was the issue of sex education? The message we got loud and clear, whatever our views as a committee, was that where there is good quality sex education, despite the views of some, that tended to delay the onset of sexual activity and people were more aware of the implications. We made recommendations about the National Curriculum and sex education at a younger age which, sadly, have not been picked up by the Government. What do you think we can do to press this issue further, bearing in mind the serious state of the services that you and Professor Kinghorn have described?

Professor Kinghorn: There is a continuing crisis and in some respects the situation is worse, as I was trying to indicate, than it was in 2001. We have an opportunity, and we are very grateful for that opportunity, to address the problem. Education is important at all levels, not just for young people. It needs to start with young people but it needs to be continued and it needs to be seen to be applicable to all of us, whatever our age. It also needs to be sustained. The danger has been in the past that education campaigns have come and they have gone. Unless it is sustained and there is seen to be a commitment for the future, then it will only have a temporary effect. It is important that education and service provision should go hand in hand, that we should not fail to meet the expectations of our public. If we have stimulated them to looking after their health in a better way, we have to be ready to provide the services that they require. We need to be able to extend services not only within secondary care but also in primary care. There is a huge need, as Dr Ford-Young was explaining, for training within

general practice and developing potential providers. It is important that it should be co-ordinated and we should not see it as either being one or the other. There has to be this combined attack on the problem.

Ms Weyman: If I may say something about sex education, this week we have had the report from the Chief Inspector of Schools about personal, social and health education and sex relationships education, which was damning about what is going on in schools. I do not think there has been very much progress since your report. Although the Department of Education says that it is committed and then there is guidance for schools, it is quite clearly not happening. I think we have to go on making the demands for sex and relationships education to become a broad programme, not the small amount of sex education that is currently compulsory but that we have this within the National Curriculum from an early age. I think it would be very valuable if your Committee continued to press for it, otherwise we are failing in providing young people with their entitlement to appropriate education and the capacity that that can provide for them to protect their sexual health and make responsible decisions about what they do to protect themselves and their partners. I think this is an area which needs constant pressure and that the Government's response has not been strong enough.

Q41 Dr Naysmith: Dr Ford-Young, you were nodding vigorously when education was mentioned. In our previous report we came across at least a couple of instances in this country, and two or three in other countries, of general practitioners, primary care professionals, going into schools in a kind of very informal way, a drop-in way, and students could drop in. I wondered, given the previous discussion about the lack of incentives and so on, how we could try to make that happen more widely in various communities around schools, as well as what the Chairman was asking for.

Dr Ford-Young: I would certainly echo what my two colleagues have said about the importance of relationships and education on sexual health taking place in education. As a general practitioner, I have an advantage in that when I see a patient I can provide some education, but that is all too often too late because they may be presenting me with a problem and we have missed the boat. That has to take place in education and not be left to health. I have mixed feelings about professionals like myself going into schools to deliver education. I do that for our local high school, and it goes down well with them. Apparently I can say things that the teachers or other people cannot say. I think it is a great shame that I can and they cannot say things. However, I am not trained as a teacher or an educator, and I think that needs to be looked at. I am here as a general practitioner and if I go into a school I am there as a GP not as a teacher or an educator.

Q42 Dr Taylor: Can I go back to raising the profile, which we have all agreed is absolutely essential, particularly with strategic health authorities and

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PCTs, because the alarming rate of increase alone has not been enough to do it? Who should be the champion at PCT level? Should it be the public health lead; should it be the specific PCT lead for sexual health, if there is one; or should it be consultants in infectious diseases or GUM? Where should the push come at PCT level to make them get it into their local delivery plan as a high priority?

Dr Ford-Young: Speaking from experience as a sexual health lead for our PCT and having met other ones around the country, I think the lead needs to come not actually at PCT level but probably at strategic health authority level to ensure that PCTs do incorporate sexual health messages and lines into their local delivery plans. I think one of the biggest drivers we have, and maybe in a way this is the thin end of a wedge around sexual health, is about chlamydia and chlamydia screening. I understand that LDPs are now going to have a line in on chlamydia screening. I think chlamydia screening is a good opportunity for us to improve our approach to sexual health because it is the commonest STI we have; it affects young people; and the screening can be delivered in a whole variety of health care and non-health care settings. For a PCT, that is a great line to have in their LDP. I would call it the thin end of the wedge because it can then help us to talk about sex in the generalist setting, which we have difficulty doing, and we have difficulty with our skills. That then means we should then be able to start talking about other STIs, other risk-taking behaviour, and we could start maybe to normalise talking about HIV and HIV testing in general practice, which we know we need to do but there is great reticence in the profession to do that. I think the way in and the way forward is through chlamydia screening with local delivery plans and PCTs actually being performance-managed on the uptake of chlamydia screening.

Ms Weyman: I want to make a comment about what has been happening in London. I think there have been very interesting developments in the strategic health authorities in London. The five chief

executives of the strategic health authorities decided that they would make sexual health an area that they wanted to look at in greater depth. They set up a steering group to develop a strategy for London, with certain levels of performance that they wanted to see. That has now been adopted across London. The strategic health authorities are discussing with their PCTs how that can be put into effect in the local development plans. Some of the objectives in the strategy are more rigorous than those which are within the White Paper commitments. What we have to see now is how that really does come down to PCT level and how that is delivered and monitored within London to make sure that that is happening.

Q43 Dr Taylor: In London, that is at chief executive level?

Ms Weyman: There is a cabinet of chief executives and they decided that they would look at this as one of the issues which they consider across the whole of London together. They chose this as one of their issues. They have been working on it now for I suppose about a year to lead into the local development plans for the coming period.

Q44 Dr Taylor: On the PCT lead, would you have a direct route to get in touch with the chief executive of your strategic health authority? How helpful would the public health specialists be in this field?

Dr Ford-Young: I think it would be very variable from PCT to PCT and PCT lead because we are very disparate people. I am a GP; a PCT lead could be a health promotion officer; someone else might be the director for public health.

Q45 Dr Taylor: Is there some sort of recommendation we should make on that?

Dr Ford-Young: I think the recommendation should be that a sexual health lead in a PCT should be somebody who has some clout within that organisation.

Chairman: May I thank you for a very helpful session. We hope we can take things a bit further. We are grateful for your participation today.

Supplementary memorandum by fpa (HA 8A)

TRAINING

In his evidence, Professor Kinghorn referred to the training programme that will be needed to ensure that there is a sufficient number of professionals in GUM, family planning and general practice to deliver the Government's commitments in the White Paper for sexual health.

In addition, health trainers will require training if they are to provide sexual health advice as envisaged by the White Paper. Myths and misinformation about contraception and other sexual health issues abound. Furthermore, training for sexual health work is not only about knowledge; attitudes, values and communication skills are crucial too, fpa is the only national organisation that provides this aspect of sexual health training.

Training was not mentioned in the announcement about the funding for the sexual health component of the White Paper and currently there is not any assessment of the likely costs involved. Professor Kinghorn suggested that the Department of Health should have a budget to support the training programme. fpa totally supports his view as we believe that this will ensure quality and prevent duplication of effort.

CENTRAL FUNDING

This issue is part of a larger question about the role of the Department of Health in the implementation of the White Paper commitments and the need for the Department to have a budget for this purpose. There are certain activities that are better undertaken at a national level and that need to be funded nationally.

A key area is the provision of information for the public and to support professional consultations. For example, fpa is currently funded by the Department of Health to provide Sexual Health Direct, a comprehensive sexual health information service, which includes a helpline and the production of leaflets on the major STIs, all methods of contraception and abortion. These leaflets are a highly cost effective way of meeting the need for authoritative written information for use by professionals to back up the advice they give in face-to-face consultations, as good practice requires.

This, and similar programmes undertaken by national sexual health charities, would be threatened by any further reduction of the Department of Health's sexual health budget and this could in turn undermine the long term viability of these organisations. The Government has stressed the significance of the voluntary sector in achieving its social policy goals and it is vitally important that the role of specialist national organisations is recognised and continues to be appropriately funded.

Memorandum by Terrence Higgins Trust (HA 14)

1. TERRENCE HIGGINS TRUST

1.1 Terrence Higgins Trust (THT) is the leading national HIV and sexual health charity for England and Wales. We undertake HIV prevention, health promotions and social care for people with HIV and other STIs and for populations at particular risk; gay men, African people, people living with HIV and young people. We also undertake policy initiatives based upon our service experience and the needs and concerns of people with HIV.

1.2 THT would welcome the opportunity to present evidence in person to the Committee; in particular on the consequences of changes in charging for overseas patients and on the evidence for the current state of sexual health services and commissioning within our forthcoming survey (Clinical Trials? THT/BHIVA/PACT, 2005).

2. CONSEQUENCES OF THE NEW AND PROPOSED CHANGES IN CHARGES FOR OVERSEAS PATIENTS

2.1 THT is the largest provider of HIV-related services to people who are recent migrants to the UK (of whatever legal status) and to African people living in the UK. Through our regional offices, we support many people who are unsure of their entitlement to services in the UK, and some whose entitlement has decreased due to recent Government initiatives. Additionally, with George House Trust (GHT) we are the publishers of the only research into recent migrants with HIV in England which establishes their motivation for testing and timescale of diagnosis. We therefore have considerable experience in the practical implications of recent and proposed changes. These have led us, along with a number of other HIV and sexual health organisations, to found a campaign to change the current regulations which include HIV in those NHS services for which charges can be levied.

2.2 Prior to April 2004, all NHS treatment was available free of charge to anyone who had been in the UK for more than 12 months. It was also available free to those applying for asylum or for leave to remain. This situation, while not ideal, ensured that anyone who was clearly a long stay resident of the UK would receive the health treatment they needed. The Regulations governing NHS charging, and a number of key exemptions to them, were enshrined in the NHS Act 1977 and the NHS (Charges to Overseas Visitors) Regulations 1989. The exemptions ensured free treatment for a range of conditions on public health grounds, including TB and all sexually transmitted infections except for HIV. For HIV, there was a theoretical 12 month wait to access free NHS services, but many HIV clinicians were willing to treat people who had been in the UK for shorter periods yet were clearly settling here.

2.3 New restrictions were imposed on all hospital services from April 2004, in response to fears that people were flying in to the UK for the sole purpose of accessing NHS services. These mean that long stay visitors, anyone in the UK without documentation, and anyone refused asylum or leave to remain, but not removed from the UK (a not infrequent occurrence, in our experience) are liable to be charged for any NHS services other than those provided in an emergency or those outlined in the 1989 exemptions.

2.4 Although HIV was repeatedly named in the media as an example of treatment tourism, the only piece of extant research (THT/GHT 2003) indicated that the reverse was true. Most migrants were unlikely to be aware of their status until they had been in the UK for more than nine months. THT has subsequently become aware (see below) of the impact of these changes on some of the people using our and other services, and of their long term impact on the public health and the public purse.

2.5 As of December 2004, we are also awaiting the outcome of a related consultation by the Government on reducing eligibility to primary care services. If the outcome of this consultation parallels that for the acute sector, anyone excluded from free NHS services would be unable to access primary care for an initial assessment of their health needs to determine whether they are in emergency need. We believe that, in the case of HIV and probably in many others, this would further damage individual and public health and lead to a reversal of the recent reduction of waiting times and improved conditions in Accident & Emergency Departments.

2.6 It is clear (as of December 2004) that these changes to the regulations are already causing hardship. It is also clear in the case of HIV that, while they may result in a small short term cost reduction to local NHS budgets, in the longer term they are highly likely to have a negative effect in all three major areas—the public purse, the public health and individual health. From cases already seen by THT, or referred to us for support, the following concerns have arisen:

2.6.1 Individuals coinfecting with TB and HIV (a relatively common combination for African people) have been told that, while TB treatment is free, the HIV treatment necessary to ensure that their TB treatment is effective will be charged for. This has resulted in at least two cases known to us where patients have left hospital before the end of their TB treatment, risking the development of multi-drug resistant tuberculosis (which is transmissible) and returning to the community still able to transmit TB, as well as HIV.

2.6.2 At least two pregnant women have been told they will be charged (and thus effectively refused) for temporary HIV treatment to prevent transmission of HIV to their unborn child. This is particularly cruel and short-sighted, since such treatment is relatively inexpensive, highly efficacious, and prevents the child becoming a burden on the state in future years. A number of hospitals have chosen to interpret antenatal treatment and “emergency” or “prevention” treatment, but this is in all probability outside the strict interpretation of the new guidelines.

2.6.3 Patients taken to hospital as emergencies have not been informed of charges, usually several thousand pounds, until their discharge from hospital. In one case, they were subsequently refused access to their medical records (needed to apply for leave to remain) unless they paid their (very large) large bill first. Since the patient in question had been admitted in a coma and treated for several days in intensive care, it is difficult to see how this could be interpreted as anything but an emergency, nor how the patient in the coma could have been expected to refuse treatment if they could not afford the charges.

2.6.4 People from one of the communities of highest prevalence for HIV in the UK have begun to ask why they should test for HIV if they may not be able to obtain treatment for it. While we believe there is almost always good reason to know one’s diagnosis and thus be able to make informed decisions about both health and sexual behaviour, this view is gaining currency amongst migrant communities and is impacting on testing campaigns targeting them.

2.6.5 There have been several cases known to us of misinterpretation of the new regulations to refuse treatment to those entitled. This included a pregnant woman, refused antenatal checks despite entitlement, who without skilled outreach work would have been lost to both antenatal and HIV services. There have been other cases where the manner of questioning has discouraged people entitled to services from reattending for them.

2.6.6 NHS staff have said to THT that “people may be charged but if they can’t pay, we won’t stop treating them”. However, there have already been examples of debts of this kind being handed over to debt collection companies for pursuance. Where people have no legal means of employment and are effectively destitute, this is not only a waste of time and money but an enormous stress upon the already unwell individuals pursued.

2.6.7 Although many HIV clinicians are currently refusing to implement the changed regulations, this opens them up to disciplinary proceedings by their Trust employers. It also means that, although in many hospitals recent migrants without entitlement are still newly accessing HIV services, when they require other services within the hospital they are being identified and charged. Thus, their HIV treatment may be less effective. The wide variety in practice between different hospitals and different HIV clinics on this means that there is a “lottery” in accessing treatment, where the least skilled and least cunning—and the most honest—are most likely to lose out.

2.6.8 It has come to our attention that a number of NHS commissioners of HIV and sexual health services across England have made deliberate decisions to co-operate with their local clinics in not charging people who are clearly long stay residents of the UK, even if undocumented, for HIV services on the human, public health and financial grounds outlined here. However, as in 2.6.7, as soon as the patient in question requires other services within the hospital (as many people with HIV disease may do, especially if diagnosed late or pregnant), this decision is challenged and they are again subject to charges for all treatment which they cannot meet.

2.7 In the longer term, THT has the following concerns:

2.7.1 It is unlikely that charging for treatment (and thus effectively refusal of it) will encourage people refused asylum or undocumented migrants to return to countries they have been determined to leave, many of which have even less health infrastructure and free treatment than they would receive on emergency grounds in the UK.

2.7.2 People with HIV unable to access antiretroviral treatment and associated services will remain in the community and will be more infectious than if in treatment. HIV treatment contributes to decreased infectivity of an individual. Failure to treat will also mean that people who would otherwise encounter a range of services in a clinical setting will be lost to interventions, such as counselling and group work, designed to support people in maintaining safer sex and preventing behaviour likely to contribute to onward transmission.

2.7.3 Community discussion of charging regulations will discourage people, including some entitled to free NHS services, from coming forward to any kind of support services for fear of possible punitive financial or legal consequences.

2.7.4 People with progressive HIV-related immune deterioration will access emergency services multiple times, with increasing frequency and severity of need, resulting in many cases in far higher incident costs than a simple ongoing prescription for antiretrovirals. The annual cost of first-line combination therapy is now under £10,000; one week's stay in intensive care can cost almost as much, and this could be repeated many times, given the high standard of emergency medical care in the UK. This is not only the view of THT, but also of highly experienced HIV clinicians.

2.7.5 People coinfecting with HIV and other STIs will be able to access free treatment for gonorrhoea or chlamydia, but not for HIV, which is the more serious condition transmissible by the same route. It is a strange logic which enables people to access free treatment for gonorrhoea on the grounds of public health, but not for the potentially fatal, and equally transmissible, HIV.

2.8 For all the reasons and experiences stated above, THT believes that there is an urgent need to amend current NHS Regulations so that HIV treatment is included, alongside treatment for TB and for all other STIs, in those conditions exempted from charging on grounds of public health. This amendment is not only humane and a vital adjunct to the newly published White Paper on Public Health and the Government's recently published Plan for TB, it is also cost effective. The campaign to amend the regulations founded by THT, the National AIDS Trust, the African HIV Policy Network, the All Party Parliamentary Group on AIDS and the UK Coalition of People With HIV has, in its first week, attracted support from seventeen major national and regional care organisations. These include Citizens Advice, the Joint Council for the Welfare of Immigrants, the Medical Foundation for Care for the Victims of Torture and Providers of AIDS Care & Treatment (PACT), a body representing HIV clinical services.

3. IMPLEMENTATION OF THE SEXUAL HEALTH & HIV STRATEGY

3.1 Despite commitment from Department of Health officials and from charities and clinician groups, it has proved difficult to get sexual health prioritised at a local level since the publication of the last Health Select Committee report. Without clear standards and targets against which performance will be judged, and without performance management, there is little external motivation for local Trusts to prioritise sexual health.

3.2 Consequently, since the report was published:

3.2.1 A survey of Strategic Health Authority reports, undertaken by THT, fpa, Brook, NAT and MedFASH showed that the majority had not included any mention of sexual health in their Local Delivery Plans, without which any prioritisation was highly unlikely.

3.2.2 New diagnoses of HIV have continued at a high rate across the country.

3.2.3 Reported diagnoses of chlamydia and syphilis have continued to increase and, while those for gonorrhoea have officially gone down, laboratory reports of the condition have increased, suggesting that people are seeking treatment through routes which do not tend to make official notifications, such as GPs.

3.2.4 Waiting times at GUM departments have not improved nationally and continue to be a major cause of the high level of onward infection, since many people do not cease sexual activity while waiting weeks for their appointment.

3.3 THT, in collaboration with the British HIV Association and Providers of AIDS Care & Treatment, recently completed our third annual survey of HIV and sexual health PCT leads and clinicians. The survey shows that many services continue to flounder, with two thirds of GUM respondents admitting that they had to turn away people seeking services, and one third stating that they did so on a regular basis. However, a number of respondents clearly indicated that, where service redesign was being undertaken and where funds had been made available for new initiatives such as a young people's clinic or nurse practitioners, some relief from the pressure of need had occurred and matters were capable of improvement. THT would be happy to provide the Health Select Committee with a copy of the full findings, which will be published in early January.

3.4 The Choosing Health White Paper, recently published, provides a very important opportunity to rectify and improve the overall situation. It makes a strong commitment to improve sexual health and access to services. This is backed up by specific targets for Primary Care Trusts (PCTs) to achieve 48 hour access to GUM services and to reduce diagnoses of chlamydia and gonorrhoea. There is also a very welcome commitment to invest an extra £300 million over the period up to 2007–08.

3.5 This demonstrates strong governmental leadership in the field of sexual health and is to be very much welcomed. In order to ensure that the NHS can live up to this leadership commitment it will be important to:

3.5.1 Ensure that PCTs oversee the redesign of local services to improve access and offer a genuine choice of improved NHS funded statutory and charitable services to users. There are a range of pilot projects across England which could inform service redesign.

3.5.2 Ensure that PCTs use the additional investment which they receive to facilitate service redesign and expansion of capacity. There has been recent evidence from the British Association for Sexual Health that funding designated for modernisation and support of GUM services has been used elsewhere by hard-pressed Trusts.

3.5.3 Ensure that DH maintains a strong commitment to the commissioning of nationally delivered and funded sexual health promotion and information programmes.

3.5.4 Ensure that, in parallel with the commitments in the White Paper, work is undertaken to reduce the levels of undiagnosed HIV. This will involve resourcing both the costs of expanding HIV testing and the costs of providing HIV treatment to many of those diagnosed as a result.

3.6 Finally, THT has published “*Blueprint for the Future: developing sexual health and HIV services*” which has been widely welcomed by a range of Government and clinical leaders as a useful tool in service restructuring. We would be glad to provide the Committee with copies of this, should they so desire.

December 2004

Memorandum by African HIV Policy Network (HA 28)

1. INTRODUCTION

The African HIV Policy Network (AHPN) is an umbrella organisation which represents African community groups addressing HIV/AIDS and sexual health throughout the UK.

The AHPN is an independent charity, registered in England and Wales. It is the only nation wide African organisation operating at policy level. It is involved in informing and developing national HIV strategies and policy. It promotes research and lobbies on behalf of African community-based organisations.

The AHPN gathers and analyses information from community organisations, health care providers, researchers, NGOs and government departments and distributes what is relevant, up-to-date and accurate among its member organisations. The organisation also delivers capacity-building/training programmes and has been appointed by the Department of Health to manage the National African HIV Prevention Programme.

The AHPN believes that the current framework of proposed measures appear to be targeting those most vulnerable from the developing world. These proposals would accentuate inequalities rather address them. Charging undocumented migrants, failed asylum seekers, or visitors with AIDS, tuberculosis or malaria runs counter to public health interests. Seeking funds from those who are unlikely to possess them is neither cost effective nor productive. Such measures also run the risk of driving these diseases underground, and increase the burden on NHS A and E services.

In preparation for our submission to the Health Affairs Select Committee the AHPN undertook a small survey of service providers both in the community and clinical setting. The quotes contained in this submission reflect their respective views and experiences, which also echo the AHPN’s concerns.

Given the grave impact these proposals have already had on the AHPN’s members and constituents it is our hope that we will be invited to give oral evidence to support our written submission.

2. EXPERIENCES AND NEEDS OF AFRICAN PEOPLE LIVING WITH HIV IN THE UK

There are estimated to be more than 8,000 African people living with diagnosed infection in the UK (HPA, 2003:46). In addition several thousand more African people living in the UK have undiagnosed HIV infection since studies have shown that roughly two-thirds of African people in the UK have never tested for HIV (Fenton *et al*, 2002). HIV prevalence is many times higher among African people in the UK than among the White British majority. Compared to UK born men and women attending GUM clinics (each of whom have an HIV prevalence of 0.2%), 7.7% of African born women and 4.8% of African born men who attend GUM clinics are infected with HIV.

A recent quantitative study (Weatherburn *et al*, 2003) which included an analysis of the health and social needs of African people with HIV shows that between a half and three quarters of this group report significant ongoing difficulties in the following areas: income, immigration status, housing and living conditions, and access to training, skills and job opportunities. Difficulties in meeting these basic needs clearly leads to reduced quality of life. Similar percentages said they had significant and ongoing difficulties associated with anxiety and depression, their ability to sleep, their self confidence and their personal relationships. The same study compared the experiences of African people with HIV to their White British counterparts. Compared to other people with HIV in the UK, African people with HIV were 10 times more likely to report problems associated with their income, seven times more likely to report problems with their living conditions, three times more likely to report problems with discrimination and twice as likely to report problems with getting about (mobility) and personal relationships.

Thus, not only are African people with HIV likely to experience more health and social care needs than the general population, but they also experience more needs than British people with HIV. Social exclusion is undoubtedly exacerbated by factors associated with migrancy. It is likely that a significant proportion of African people with HIV in the UK are (or have been in the past) refugees or asylum seekers (Fortier, 2004), a group already significantly socially excluded (refugee council, 2004a). Exclusion associated with being HIV positive may be significantly compounded by pre-existing social exclusion and social need associated with being an African refugee or asylum seeker.

In order to survive and thrive, refugees and asylum seekers need to draw on their own personal resources (their ability to work for example) and need to draw on a supportive social environment in their host country. This environment is created first by the support of expatriate communities in the host country as well as in their home country and second by the provision of supportive enabling legislation policy and services by the host country. African people with HIV are likely to have all of these resources particularly curtailed.

The ability to work (whether it be legally or illegally) is essential for the survival of migrants. Being HIV positive puts certain limitations on this ability. In addition however, African people tend to be diagnosed with more advanced HIV disease and as a result, their general health and prognosis may be poorer than other groups of people with HIV (Weatherburn *et al*, 2003).

Despite a relatively long history of the epidemic in sub Saharan Africa, HIV remains significantly stigmatised among African communities in the UK and globally (Goldin, 1994, Bhatt, 1995). A recent study (Dodds *et al*, 2004) has highlighted the importance of expatriate, diasporic and global African networks for survival of African migrants in the UK. However, the same study shows how disclosure of an HIV positive identity often leads to the withdrawal of vital community support. Thus, African people with HIV in the UK are less able to disclose to and draw support from their family and expatriate communities (Erwin *et al*, 2002, Weatherburn *et al*, 2003). Stigma at a community level leads to difficulties in even the most intimate relationships. Weatherburn *et al* (2003) found that 15% of African people living with HIV had not disclosed their status to their partners and only a third of respondents had disclosed their HIV status to their children or their families.

The policy of dispersing asylum seekers away from large urban environments often means that those living with HIV are moved away from specialist HIV treatment and care centres (Creighton *et al* 2004) as well as being moved to a setting where support and contact within expatriate groups is unlikely. Home Office changes to immigration policy implemented in April 2003 also mean that a person with HIV who is on treatment will be unlikely to be granted leave to remain on medical grounds under humanitarian protection provisions. If that person is granted discretionary leave to remain it will only be for three years (THT 2003). Although particularly harmful changes to immigration legislation which attempted to ban failed asylum applicants from accessing social care and benefits (HMSO 2002: Sec 55), have been successfully challenged in the courts by refugee agencies (Refugee Council 2004b), the Government is likely to appeal this ruling at some point in the future.

In addition to this, changes made earlier this year to the provision of NHS services for overseas visitors impose strict limitations on access to hospital care for non-residents and those whose asylum applications have failed (Department of Health 2004). Broadly speaking, this means that while short term visitors, including students, and failed asylum seekers will be allowed to access HIV testing and other STI screening, long-term treatment for infection will not be provided unless it is paid for privately (Pollard & Savulescu, 2004).

The current social, legal and policy environment in the UK is not geared towards maximising the health and productivity of African people with HIV.

3. THE PROPOSED MEASURES WILL EXACERBATE POOR HEALTH AMONG ASYLUM SEEKERS

Asylum seekers are among the most vulnerable people in Britain. Displaced from their homes due to the threat of persecution, they are often subject to mental and physical violence seeking sanctuary in countries with more compassionate reputations. The UK Government's current system for the handling of asylum-seekers is not focused on helping, but rather on deterring them with present procedures such as the introduction of Section 55 as part of the Nationality and Immigration Act 2002 more punitive than compassionate in nature.

The AHPN feels that the proposed measures by the Department of Health are another example of this acting as support for changes to current Home Office and Immigration policy.

One in six refugees (17%) have a physical health problem severe enough to affect their life, and two-thirds suffer significant anxiety or depression (Aldous *et al*, 1999). In addition, many experience act as barriers in accessing the right type of health care service, such as primary care

Evidence from research conducted by the British Medical Association (BMA, 2002) has clearly indicated that on arrival to the UK the health of asylum seekers although already precarious, often deteriorates. The health problems that many migrant populations encounter are linked to poverty and social exclusion. Their vulnerability is compounded by the fact that they may be poorly accommodated, and are quite likely to face racial and xenophobic harassment.

Common problems faced by asylum seekers and refugees are psychological and may be linked to trauma, or isolation from friends and community in the UK. They also experience the physical effects of war and torture such as rape/sexual assault, landmine injuries, beatings and malnutrition and social and psychological problems related to depression, stress and racial harassment. A significant number of asylum seekers are also prone to communicable diseases such as TB, Hepatitis and HIV/AIDS.

The main reasons to explain the higher susceptibility to HIV include (Broring G *et al*, 2003):

- Refugees and Asylum Seekers may have experienced situations of risk from High prevalence areas.
- They may be particularly vulnerable to contracting HIV because of the experiences that have led them to leave their countries of origin, eg rape, sexual assault torture.
- The experience of becoming an asylum seeker may mean people are exposed to malnutrition, poor living conditions and a lack of personal safety. Poor living conditions may contribute to sex work as a means of survival.

... there have been instances where people have been asked what their residency status is, if people are singled out it makes them less likely to come forward for treatment. If the department of Health Proposal goes through then some people would not be eligible for treatment which would affect mainly people whose residency status is not secure. If primary care is not provided for people the disease it not treated which means that they will become ill again and have to be treated. If they are isolated from the community it has an effect on their health. Dr Nneka Nwokolo, Chelsea and Westminster Health Care Trust

4. A LACK OF APPROPRIATE TESTING AND TREATMENT FACILITIES IN THE DEVELOPING WORLD

The United Nations Convention Relating to the Status of Refugees, which Britain signed in 1951, states that host countries must provide those fleeing tyranny and persecution with access to health, housing, education and employment services. Despite this recent migrants continue to face problems accessing health services in the UK due to unclear immigration status and ambiguities or fears about eligibility for health treatment.

The BMA study highlighted that from the point of entry not enough is being done to safeguard the health of asylum seekers. Basic medical testing is not routinely undertaken with communicable diseases such as HIV and tuberculosis (TB) often going undiagnosed. Those suffering from the psychological effects of torture are also not always referred to specialist centres. Equally concerning is that unaccompanied children are not given appropriate vaccinations and immunisations.

The current proposal to introduce user charges to communities who by the nature of their status in this country cannot work and thus pay for medical services is both inhumane and unethical contradicting international and national legislation on human rights and discrimination.

5. AFRICAN COMMUNITIES MUST RECEIVE APPROPRIATE TESTING AND TREATMENT

The first National Strategy for Sexual Health and HIV was produced by the Department of Health in 2001. It identified that asylum seekers are a group "at special risk" for whom information and advice need to be provided. Targeted prevention work with African communities was also identified as a priority but no targets were set for improving provision for refugees or asylum despite the fact that the Department itself

highlighted need by estimating that over 60% of HIV diagnoses in the UK was among this group with over 80% heterosexually acquired in Sub Saharan Africa. The current proposals ignore the deficit in health services which meet need.

The effects would be enormous. Especially for people in African communities who have experienced immigration or who are going through the immigration procedure. It can take months or and years to sort out immigration and if during that time people fall ill they need help, they will not be able to afford treatment and at the same time fell isolated because of their immigration status. This will put them psychologically into a very difficult situation. Henry Mumbi, HAAZ

6. DELAYED DIAGNOSIS CONCERNS

If certain African communities and other migrants are denied access to treatment the end result is that they will delay attending to serious conditions such as HIV which need to be treated in their infancy. Although TB treatment will remain free diagnosis remains chargeable. Who will be responsible for the loss of life if such patients cannot access A&E or GP care? Equally concerning is that if people are unaware of HIV/AIDS status there is a risk that behaviour will remain unchanged leading to an increased public health risk.

These proposals will have an affect on people's willingness to test for HIV. It would also mean that people remain with the illness and go underground if they are not treated and don't have access to healthcare. The numbers of HIV cases are therefore likely to rise if they're underground and the disease is not treated. Gertrude Othieno—Specialist in Health Promotion, South West London

7. THE RISK TO PUBLIC HEALTH THROUGH INCREASED SPREAD OF HIV/AIDS

The UK already has the worse rates of sexually transmitted infections since the start of the NHS. Rates have doubled in the last five years. Increased rates of STI are widely regarded as a sign of potential transmission of HIV. Preventing people from accessing appropriate treatment and care, be they citizens of the UK, students, those seeking asylum or those with indefinite leave to remain is both inhumane, unjust and poses significant risks to wider public health. HIV needs to be placed at the forefront of the NHS agenda and we feel that this proposed measure will undermine efforts of agencies, like ourselves, working to prevent the spread of STIs and HIV.

A system of charging should not be introduced particularly with regard to diagnostic testing, counselling and treatment services for sexually transmitted infection and HIV/AIDS. Africans living in the UK tend to present later for HIV/AIDS testing and we feel that the proposed measures would further deter people from taking up testing services. This has evident repercussions for the spread of the epidemic which will have further and weightier social and economic cost implications.

Under the National Health Service (Charges to Overseas Visitors) Regulations 1989, anyone who has been resident in the UK for more than a year is not subject to charge for NHS treatment. Asylum seekers are exempt as are claimants under Article 3 of European Convention on Human Rights. The AHPN support these entitlements as vital to tackling HIV in the UK.

This current legislation already poses a problem for people who enter the UK on short-term visas or without a visa, who discover HIV positive status in these first 12 months. These people are currently only eligible for “emergency treatment” regardless of ability to pay, pregnancy status or how long they wish to remain in the country. The consultation document outlines that this “emergency treatment will still be made available, however reports received by sexual health agencies have stated that many hospitals consider emergency treatment as that only available in accident and emergency departments”.

There is a risk that people may be treated repeatedly for life threatening opportunistic infections eg pneumonia without accessing the underlying cause of HIV. Timely antiretroviral treatment decreases levels of virus in the body and is a more humane response. The result of the combined measures of introducing charges for primary and hospital care will be to treat fatally weakened immune systems, shorter life terms and greater economic cost as people revisit emergency services for treatment of opportunistic infection.

We already have difficulties with too many people presenting late. So it is disjointed thinking from the government in way because on the one hand we are trying to get people into the health service as possible but at the same time they are making it more difficult by introducing those policies which deny people access to healthcare. From a public health perspective it doesn't make sense because it's more effective to treat early. Dr. Ade Fakoya, Senior Programme Officer: Clinical Care International HIV/AIDS Alliance and Consultant Physician Newham General Hospital

8. PROPOSED MEASURES AS A VIOLATION OF HUMAN RIGHTS AND EQUALITY

The Human Rights Act (HRA) brings into national law the majority of the rights and freedoms set out in the European Convention on Human Rights. Withholding proper medical care from someone with a serious illness could be held to contravene Article 2 (right to life) or 3 (freedom from torture). Those rights are actionable directly in the domestic courts and create an obligation for courts, and “public authorities” to interpret the provisions of all legislation in a way that is compatible with the Convention. The NHS, Trusts

and health professionals working within the NHS are seen as “public authorities” and therefore need to be aware of the Act. Although many aspects of care remain unchanged, the HRA is likely to have a great impact on the public awareness of patients’ rights in relation to medical care.

Article 2 of the European Convention on Human Rights is concerned with the “right to life”. This policy refers to any life threatening condition not just HIV. Applications for Exceptional leave within the UK remain often made (not always successfully) under this clause. The proposed measures will undermine access to treatment and therefore this article of the convention. It states that *“Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.”*

Article 3 states that no one shall be subjected to torture or to inhuman or degrading treatment or punishment.

Article 14 of the Act is related to the Prohibition of Discrimination. Stating that *“The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.”*

The UK is also bound legislatively by the UN Declaration on Human Rights. Article 25 of this declaration recognises the right to health by migrant communities. Stating that these rights and freedoms *“shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.”*

The 1969 International convention on the Elimination of all Forms of Racial Discrimination also accords minority ethnic communities the right to access public health, medical care, social security and social services. *The proposed measures contradict all these forms of legislation.*

9. THE TONE OF THE PROPOSALS WILL EXACERBATE RACIAL TENSIONS AND DISCRIMINATION

The AHPN feels that the link made between HIV and migration in the last year has contributed to the proposed measure. It has been suggested that there are a large number of people entering the UK for reasons of “health tourism” in order to benefit from free HIV treatment on the NHS. This flawed concept has been used to introduce a range of policies that limit access to the UK, to HIV treatments and much needed social support services. Additionally, the proposed measure runs the risk of exacerbating this. Health professionals must also be careful not to breach section 20 of the Race Relations Act by discriminating against asylum seekers (by refusing to provide them with health care services, for example, or by providing lower standards of care). It is unethical to refuse to accept particular patients solely because they may require expensive treatment (so-called “uneconomic” patients).

As an umbrella African organisation we are concerned that the tone with which the proposed measures are introduced, will serve to stigmatise African communities compounding existing experiences of racial discrimination and social exclusion with that of stigmatisation as the “bearers” of disease within the British public mind.

There is no vaccine or cure for AIDS, but provided HIV is diagnosed early enough new treatments can prolong life for many. Access to essential life-saving HIV treatments is a human right. Although the National Health Service currently makes HIV treatments widely available, a range of barriers exist to equitable treatment access for some, particularly for overseas visitors. These include limited availability of information about treatment options, lack of patient support services for adherence to complex treatments, the discriminatory attitudes of health care workers, and regulatory restrictions affecting groups such as asylum seekers. Research indicates that the most common form of discrimination experienced by people with HIV in the UK is discrimination by health care providers.

Of course it’s racist to single out patient’s eligibility according to their background or status of residence. It is completely racist if you walk into a hospital because you are ill and they ask you about your immigration status. It is making things difficult for us because we’re trying to get people at first contact. So the stigma is a double edged sword because it drives them away. Dr Ade Fakoya, Senior Programme Officer: Clinical Care International HIV/AIDS Alliance and Consultant Physician Newham General Hospital

10. CHARGES OF HEALTH TOURISM ARE UNSUBSTANTIATED

The existence of alleged “health tourism” to which this measure is clearly a response has not been substantiated and has also been contradicted by a recent study conducted by the Terrence Higgins Trust among predominantly African service users of HIV services in London, Manchester and the West Midlands. The study found that:

Most people only test positive for HIV when already ill, pregnant or after the diagnosis or death of a partner. This does not suggest the actions of those who enter the country specifically for HIV treatment.

People accessing HIV treatment enter the country for a number of reasons and no one category of migrants stands above the others.

Late diagnosis is a serious problem amongst African migrant communities because most wait until they are palpably ill before using medical services.

HIV infection among UK based African people takes longer to diagnose, because many African people are here in very difficult circumstances—already experiencing racial discrimination and there is a strong resistance to facing the additional stigma of HIV.

Most HIV in African communities is transmitted heterosexually, and this has only become more apparent, because the NHS has diagnosed more women with HIV through antenatal screening programme over the last two years.

No that’s completely wrong. The UK actually has a fairly low number of migrants and who are using a small proportion of the health budget. It is not as a big problem as the media is portraying it to be.
Dr Nneka Nwokolo, Chelsea and Westminster Health Care Trust

11. ACCESS TO ANTENATAL CARE IS VITAL TO STEMMING THE EPIDEMIC

As early as 1999 government guidelines have stated that “all pregnant women should be offered an HIV test” (Health Service Circular 1999/183). To withdraw this option is to contribute to both heterosexual and mother to child transmission. THT Direct the National HIV/AIDS helpline has already had reports that many hospitals have diagnosed women as HIV positive, but denied access to treatment if they do not have the ability to pay or qualify for the 12 month rule. The AHPN consider this inhumane and would not wish to see this as an outcome duplicated within primary medical services involved in HIV testing. Most HIV among African communities is acquired heterosexually antenatal testing and referral is vital to stemming the epidemic.

12. THE IMPACT UPON UNACCOMPANIED CHILDREN

The Department of Health document does not consider the impact on unaccompanied children and young people under the age of 18. The impact upon children’s issues is of specific concern to African communities—because the majority of children currently affected by HIV, tuberculosis and malaria will, be African. The proposed policy contradicts other policy and legislation such as The Children Act 1989, Lord Laming’s recommendations following the Victoria Climbié Inquiry and the current Children Bill.

The largely invisible population of young people born overseas, who live in British cities without their biological parents will be significantly affected by restricting access to General practice. These maybe school age children who have sought asylum (usually without any knowledge of our legal system) without any adult, even a distant relative. These children have fled their homelands after civil war or state-sponsored genocide and few attend school or maintain a fixed address.

The health needs of these children can be serious and complex (psychological and physical trauma, TB, substance use or pregnancy following rape), however health services will be inaccessible to them if the proposed measures are introduced. Local Government currently acts as the “corporate parent” of these children. The AHPN feel that the proposed measures undermine the necessary role of primary medical providers for this group. These children maybe without parental support or guidance and can be exposed to commercial, sexual and servile exploitation. Access to a GP, for treatment of a minor injury, may be their first opportunity for contact with a responsible, law-abiding UK citizen. Removing this right will severely impact on their future life opportunities. It is also a violation of the right to health guaranteed under the UN Convention of the Rights of the Child.

... And the other thing is, if you have an HIV positive child you will also have an HIV positive parent so the children need to be treated but you can’t treat the children without treating the parents. That is another problem we have people going underground. If a child is on treatment and the family for whatever reasons decide to go underground, the child will go with them which means that it will stop taking the treatment. Magda Conway, Co-ordinator Children and Young People HIV Network

13. THE PROPOSED MEASURES RUN COUNTER TO INTERNATIONAL COMMITMENTS TO COMBAT HIV/AIDS

The UK formally acknowledged the gravity of the global AIDS crisis during the G8 Summit and at the UN General Assembly Special Session on HIV/AIDS in 2001. Here it was agreed to set up and financially support the Global Fund for AIDS, TB and Malaria recognising the country's responsibility in the fight against communicable diseases. This together with WHO strategies offer the best hope of providing funds for treating HIV/AIDS and for preventing new infections, in order to ensure that 3 million people access combination therapy by 2005. The proposed charges run counter to international policy and commitment made by the UK.

The proposed measures lead the AHPN to question the UK's commitment to the global consensus on HIV/AIDS under UNGASS 2001. We feel that the proposed measures run counter to international, regional and national commitments within the UNGASS report to combat HIV. Unless the UK Government ensures free access to HIV/AIDS prevention and treatment facilities it will not be working towards,

“measures to eliminate all forms of discrimination against and to ensure the full enjoyment of human rights and fundamental freedoms by people living with HIV/AIDS and members of vulnerable groups, in particular to ensure their access inter alia, education, inheritance, employment, health care, social and health services, prevention, support and treatment, information.” (UNGASS, 2001: 28)

14. THE PROPOSED MEASURES INHUMANELY TARGETS PEOPLE FROM THE DEVELOPING WORLD SUPPORTING CURRENT HOME OFFICE POLICY ON ASYLUM AND IMMIGRATION

The AHPN questions whether or not the proposed measures are solely concerned with saving NHS funds rather than acting as support to the current Home Office clampdown on asylum and immigration.

Our fear is that the underlying target of these measures and those who will suffer the most from their implementation are people from the developing world. If these measures are aimed solely at reducing NHS costs the focus should be on visitors from America, Australia, New Zealand and Japan not visitors from war torn countries. Britain received 24.2 million overseas tourists in 2003 with expenditure of £11,737 million, 4.4% of national GDP. The highest levels of expenditure included that from the US (£2,443 million), Middle East (£527 million) and Japan (£320 million). The majority of visitors to the UK are tourists and students, and as such these are visitors from the developed world who access the NHS most regularly, for conditions less serious than HIV.

We feel that these groups should be the legitimate focus of the DoH effort. From the DoH perspective it is also more likely that there will be more success in securing reimbursements when targeting these groups. We accept that the DoH must be concerned with the allocation of finite resources and encourage increased vigilance in pursuing reimbursement through visitors' medical insurance or underwriting care through inter-country agreements.

Medical conditions such HIV, TB and malaria (common in the Third World) should be underwritten by the NHS since many visitors from the developed world will have access to medical insurance and will be able to reimburse the NHS

15. CONCLUSION AND RECOMMENDATIONS

The proposed introduction of charges to overseas visitors for primary care services if implemented would exacerbate the health inequalities that exist in Black Minority Ethnic and migrant communities. Its implementation would further discriminate against those find themselves vulnerable and unable to navigate an already complex healthcare system, namely failed asylum seekers, undocumented migrants, and overstayers. These provisions would counter the strides made in public health, and would serve to push people underground, especially people with special needs like HIV/AIDS, who desperately need life saving treatment and services. Far from saving money it would further burden the system as A & E services would become their source of primary care. Further, it would force people to turn up for care when their conditions have progressed beyond repair. Introducing charges for primary care would be a retrograde from the strides made towards a preventative model of care. The introduction of charges to the most vulnerable in our society counter the very *raison d'être* of the NHS.

RECOMMENDATIONS

A system of charging should not be introduced particularly with regard to diagnostic testing, counselling and treatment services for sexually transmitted infection and HIV/AIDS. HIV treatment and care should be added to the list of diseases exempt from charges.

The majority of visitors to the UK, are tourists, students, employees and visitors from the developed world who currently access the NHS most regularly, with less serious conditions than HIV. This group should be the legitimate focus of the DoH effort since it is here that the DoH are most likely to succeed in securing reimbursements. The AHPN encourages the DoH to be more vigilant in obtaining reimbursement through visitors' medical insurance or underwriting care through inter-country agreements.

Attempts to reform the NHS should ensure that people in asylum seeking and migrant communities are informed about their rights to healthcare, by fully engaging community based organisations in advocacy and translation.

December 2004

Memorandum by National AIDS Trust (HA 20)

In this submission NAT argue for HIV treatment and care to be exempted from NHS charges because the case for charging has not been made on the basis of evidence and because any charges will have a harmful impact on public health.

NAT also call for a public health impact assessment of the new charging scheme, for a free health assessment to remain available for all in primary care, and for action by the Government to remedy the invisibility of HIV in the Public Health White Paper.

PART I—CHARGES FOR HIV TREATMENT AND CARE

I. Introduction

1.1 The National AIDS Trust is the UK's leading independent policy and campaigning voice on HIV and AIDS. We aim to prevent the spread of HIV, ensure people living with HIV have access to treatment and care, and eradicate HIV-related stigma and discrimination.

1.2 NAT welcomes the inquiry of the Health Committee into new developments in HIV and sexual health policy. Eighteen months on from the Committee's important report on Sexual Health, just a few weeks after the publication of the Government's Public Health White Paper, and quite probably only a few months before a general election, this is a timely opportunity for the Committee to review both progress and continuing challenges in addressing the country's sexual health crisis.

1.3 In the second part of this memorandum we raise some wider issues relating to HIV prevention and treatment. In this first part we concentrate on the charges being introduced for certain vulnerable groups by the NHS and the implications for HIV treatment and care and for public health. The charging issue is not just a small "niche" concern within the wider sexual health debate. It raises fundamental questions about how the Government is making its decisions on sexual health policy and its commitment to the protection and promotion of public health.

II. Background to the charges

2.1 From 1 April 2004 the National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2004 have been in force. One effect of these Regulations has been to end the provision of free NHS treatment and care in hospitals to anyone who could prove residence of over 12 months in the United Kingdom. Since 1 April 2004 if you are not "ordinarily resident" in the UK you will be charged for most NHS treatment and care, no matter how long you have been in the country. This means that certain groups such as those who have failed in their asylum application (which includes for these purposes the appeals process), those who have overstayed their visas, and undocumented individuals can no longer access free hospital treatment.

2.2 To accompany the regulations, the Department has produced guidance for NHS trust hospitals "*Implementing the Overseas Visitors Hospital Charging Regulations*".

2.3 There are some exemptions to charges. Treatment remains free in Accident and Emergency Departments. There are also certain health conditions which are exempt from charges. These include serious communicable diseases, such as tuberculosis, which are subject to public health regulations, and also all sexually transmitted infections **except for HIV**. Only the HIV test and associated counselling are free for all—treatment and care are not exempt from charges.

2.4 The provision to charge overseas visitors for HIV treatment and care has been in place for a number of years but in practice the fact that anyone could get NHS treatment and care free after 12 months' residence meant there was little difficulty in providing free HIV treatment and care for all those living in the UK who needed it. The end of the 12-month rule effectively introduces a charge for a significant number of people. For the sake of brevity we refer to "the introduction of charges" to describe the changes implemented on 1 April 2004 in hospitals and now proposed also for primary care settings.

2.5 The Government has recently engaged in a consultation on the extension of these charges to primary care (deadline for responses was 13 August 2004) and at the time of writing the Government summary of responses and its conclusion are still awaited. NAT sent in a submission to the Department of Health, available at the NAT website www.nat.org.uk—"Eligibility for HIV treatment and care".

III. *The policy context*

3.1 NAT supports the aim of ensuring a cost-effective and responsible use of NHS resources. It also supports interventions which aim to stop people who have no connection with the UK exploiting free NHS services (sometimes known as “health tourists”). Our submission will, however, show that there is no evidence of health tourism amongst those living with HIV and that those most seriously affected by these charges are those who are not “passing through” but those who are living here on a settled basis.

3.2 NAT does not take a position on the Government’s immigration and asylum policies other than a general view that all such policies have to be in compliance with human rights and international treaty obligations. Our argument against the charges is based on public health considerations.

3.3 The charges introduced must be judged on the basis of their impact on the HIV epidemic in the UK. New diagnoses of HIV are increasing at 20% a year. The number of people living with HIV in the UK has doubled since 1997 and now stands at 53,000, with over a quarter unaware of their status. HIV remains an incurable, serious and life-threatening condition.

3.4 The National Strategy for Sexual Health and HIV aims, in relation to HIV, to:

- Reduce the transmission of HIV and STIs
- Reduce the prevalence of undiagnosed HIV and STIs
- Improve health and social care for people living with HIV, and
- Reduce the stigma associated with HIV.

Targets linked to these aims include:

- To reduce by 25% the number of newly acquired HIV infections by the end of 2007, and
- To reduce by 50% the number of previously undiagnosed HIV infected people attending GUM clinics who remain unaware of their infection after their visit by the end of 2007.

IV. *Who will be affected by charges for HIV treatment and care?*

4.1 The two groups most seriously affected by HIV in the UK are gay and bisexual men, and African communities. Since 1999 the majority of new diagnoses of HIV have been heterosexually acquired. Of the 3,801 heterosexual diagnoses in 2003 three-quarters were probably infected in Africa. Of the 35,428 HIV-infected patients seen for care in England, Wales and Northern Ireland in 2003, 12,688, or 36%, were Black African. In a globalised world, with increasing mobility of persons, it is not surprising that the high HIV prevalence found in sub-Saharan Africa is beginning to have an impact in other regions of the world.

4.2 The Department of Health, NAT and the African HIV Policy Network (AHPN) have just published “*HIV and AIDS in African Communities: A framework for better prevention and care*”. The statistics in the document underline the seriousness of the epidemic in African communities. Black African men and women account for 70% of the total diagnosed infections in heterosexuals and 51% of undiagnosed infections. Diagnoses are later with serious consequences for efficacy of treatment, and there are challenges in terms of stigma and discrimination, clinical monitoring and adherence to drug regimes.

4.3 Failed asylum seekers and undocumented individuals are a very small proportion of the African men and women living in the UK. But at present it is the case that the majority of those being excluded from free HIV treatment and care are African.

4.4 In other words, the community most significantly affected by these charges is one with significant HIV prevalence and with real difficulties in accessing testing and treatment. The charges only put up another barrier, and send a hostile message, to a community which should be receiving every encouragement to address their HIV-related needs.

4.5 Charges mean for the vast majority of those affected a refusal of care since they will be prevented from working in the UK and no longer entitled to NASS benefits. Thus ill-health will be added to severe poverty. This health inequalities issue must be addressed by the Government.

4.6 Amongst those affected are failed asylum seekers who the Government accepts cannot for the present return to their country of origin. It is unjust that the Government accepts such persons must at least temporarily reside in the UK but denies them the life-saving treatment they need.

4.7 There is growing evidence that people from African and other communities who are entitled to treatment are nevertheless being incorrectly turned away or presented with charges.

V. *The evidence basis for the introduction of charges*

5.1 We do not believe there is a properly researched and validated evidence base for the introduction of charges for HIV treatment and care.

“Health tourism”

5.2 The reason given by the Government for the introduction of charges is primarily to combat “health tourism”, in other words the use of free NHS services by those with no substantive connection with the UK. The consultation documents published by the Department of Health gave, however, no indication of the scale of the problem, which NHS services are being particularly affected and where, nor of the sources of their information about the problem.

5.3 With regard to HIV, evidence researched by Terrence Higgins Trust and George House Trust amongst recent migrants using HIV services shows that by far the most common reason given for testing was the onset of symptomatic HIV. If they had come to the country with the express purpose of accessing HIV services it is unlikely they would have waited until they were severely unwell before seeking testing or treatment.

5.4 The evidence to date on HIV and these vulnerable groups suggests there is no systematic, widespread or cynical HIV-related health tourism.

Cost savings

5.5 Linked to the argument relating to health tourism is one based on costs. HIV treatment and care, with the provision of anti-retroviral therapy for those with a more advanced stage of the illness, can be costly. But no cost benefit analysis has been provided comparing the savings from not treating certain individuals with the cost of dealing with and treating those who present at A&E departments for want of anywhere else to go for healthcare.

5.6 In the case of HIV this is especially relevant. A year of ART can cost between £10,000 and £12,000, but one day in a hospital bed can cost about £500. Thus it would take only a couple of days a month in a hospital bed in A&E to equal, if not exceed, the cost of ART for that person. Without ART, HIV-positive individuals will get seriously and repeatedly ill, presenting with ever increasing frequency at A&E departments. With ART there will be a reduction in the number of inpatient days at all stages of infection.

5.7 Thus even this narrow calculation comparing ART with likely A&E care seriously undermines the case for charges as a cost benefit to the NHS. But any consideration of costs must also take wider perspective. There is a social and economic cost to someone becoming increasingly and chronically sick—they can no longer work; they might be unable to care for elderly dependants or children.

5.8 The charges, as we go on to show, also make very likely increased onward transmission of HIV. Seen simply from the costs perspective we note that the Department of Health calculates that preventing one onward transmission of HIV saves between £500,000 and £1 million in terms of individual health benefits and treatment costs.³ To this must be added the costs for treating the expected increase in TB cases resulting from these HIV charges [see below].

5.9 When considered in the long term and comprehensively, there is evidence that charges for HIV treatment and care, far from saving the NHS money, will in fact add to NHS costs.

An impact assessment

5.10 “*Choosing Health*”, the Government’s Public Health White Paper published in November 2004, commits ODPM and the Department of Health to “ensure that initiatives and programmes are health inequality ‘proofed’. This will involve consideration of whether any policy changes or remedial actions are necessary to prevent any negative effects on health inequalities”⁴.

5.11 There has not been to our knowledge any public health impact assessment of the charges introduced in hospitals from 1 April 2004 nor of those now proposed for primary care. We welcome the Government’s commitment to assess any initiative on its impact on health inequalities. This will obviously have to be done before any regulations are introduced to change the charging regime for primary care. It should also be done for the charges already introduced in hospitals.

5.12 Given the serious consequences for public health of the HIV epidemic, and given the commitments of the National Strategy for Sexual Health and HIV, we are amazed that such an impact assessment has not as yet been carried out.

³ Department of Health “The national strategy for sexual health and HIV” para 1.21.

⁴ Department of Health “Choosing Health” para 8.3.

5.13 We urge the Committee to recommend a public health impact assessment for the new charging system introduced in hospitals from 1 April 2004 as well as for that now proposed for primary care. Such an assessment should be commissioned from respected and independent public health experts and be published in advance of any further changes to the NHS charging system.

VI. *The impact on public health*

6.1 In advance of any scientific assessment of impact, there are very good grounds to believe that the charges introduced are causing, and will continue to cause, harm to public health in the UK. In other words, not only is there no positive gain from introducing charges for HIV treatment and care. Serious harm is going to result.

A deterrent to testing

6.2 DFID in its recently published HIV Treatment and Care Policy states:

“There is now an international consensus that treatment and care are essential parts of an effective and comprehensive response to AIDS. As well as the direct benefits for people receiving it, access to treatment and care can help prevention efforts and programmes designed to minimise the impact of AIDS. Availability of ART in particular gives people a reason to seek testing, and it might reduce the level of transmission in a population.”

6.3 This is backed by recent research, such as that in Taiwan where it appears that the government policy of providing HIV-positive people with free ART reduced the rate of HIV transmission by 53%.⁵

6.4 The offer of testing without treatment flies in the face of the Government’s own stated policy on the close relationship between treatment availability and testing take-up.

6.5 The aim of the National Strategy for Sexual Health and HIV is to reduce the number of those with HIV who are undiagnosed, and there is a particularly high proportion of undiagnosed persons, and of late diagnosis, in African communities. But, as DFID makes clear, to offer testing, with all its challenges and trauma, without the option of treatment is to remove one of the main incentives to test. Whilst NAT would encourage all people at risk to test, the fact is that within migrant communities there is an increasing number who question the point of doing so given the lack of access to treatment.

6.6 A further deterrent to testing is the impact of the new system on the principle of confidentiality. If henceforth at GUM clinics patients cannot receive HIV treatment in an entirely anonymous fashion but have to provide proof of eligibility there are concerns this will deter even from the initial free test those fearful of questions about residence.

6.7 Refusal of treatment will deter from testing. Failure to test will result in continuing and increasing late diagnosis—at which stage ART can be much less effective and death more likely. The result is an increase in avoidable mortality.

6.8 It is also likely that there will be an increase in transmission of HIV and thus considerable harm to public health. Neither undiagnosed individuals nor their sexual partners will be equipped to make informed decisions about their sexual behaviour. There will be no counselling or support on how to take precautions against transmission.

6.9 Whether diagnosed or not, the refusal to provide ART will mean that individuals will remain much more infectious than they would otherwise be if on the treatment. Such high infectivity, joined with an absence of ongoing counselling and considerable personal trauma, is likely to result in an increase in onward transmission of the virus.

Mother-to-child transmission

6.10 There is an additional danger for HIV-positive women who are pregnant. In order to reduce chances of “vertical transmission” of HIV from mother to child it is advised that the woman has an elective caesarean and/or be given the drug AZT during pregnancy and birth. If a pregnant woman is unable to afford any of these options, the likelihood of transmission is high—the rate of transmission in an untreated population of breast-fed infants is 25–35%. The use of AZT reduces the transmission rate to below 1%.

6.11 We know of at least one pregnant woman who has been refused free temporary HIV treatment to prevent HIV transmission to her unborn child, and we understand there may well be others. More generally, in relation to women who may or may not be HIV positive, we have heard of another woman who fled when asked to pay charges for ante-natal screening, and of two other cases where it appears ante-natal care is either not going to be commenced or is going to be suspended because of inability to pay bills. Many more of such cases are never noted or reported by clinicians since they do not get to hear of them. The individuals are refused at an early stage by the overseas manager in the hospital.

⁵ Journal of Infectious Diseases August 15 2004, Chi-Tai Fang, Jung-Der Wang.

6.12 Given the increasing evidence of refusal of free ante-natal screening and care to pregnant women, and the evidence of refusals to provide ante-natal HIV treatment, there is every likelihood of an increase in avoidable infection amongst newborn infants.

6.13 Whilst the infected child might then receive free HIV treatment, the continuing refusal to treat the infected mother, who will only become increasingly ill, will mean she will be unable to provide the care and support to the child that she knows it needs.

TB infection rates

6.14 TB cases have increased by nearly 20% in England and Wales over the last two years, with London now a “TB hotspot” and accounting for nearly half of all UK cases at around 3,000 a year. The recently published TB Action Plan from the Chief Medical Officer is a welcome and important step in addressing the threat of TB to public health. It does not, however, address the problem raised by the failure to treat HIV in failed asylum seekers, visa overstayers and undocumented individuals.

6.15 TB is one of the diseases exempt from charges under the Regulations. There is also a close link between TB and HIV. The figures are very similar (with about 6,000 new diagnoses for both conditions and around 400 deaths a year). The two conditions often affect similar groups. Those with HIV are also especially vulnerable to TB infection.

6.16 The offer of free treatment for TB and refusal of free treatment for HIV is already creating problems with reports of people co-infected with TB and HIV leaving part way through their treatment when faced with a bill for the HIV-related aspects of their care. This means people go back into the community at risk of transmitting both HIV and TB.

6.17 Those who are TB/HIV co-infected are more likely to develop the active form of the illness and pass it on to others. The Action Plan states that a person with active TB will typically infect between 10 and 15 people a year. Thus the failure to treat HIV, as well as increasing HIV transmission to others, will result in an increase in TB infections. These TB infections will be amongst HIV-negative people as well as HIV-positive people. One recent study has shown that HIV infection dramatically increases incidence of TB, with a direct increase in those who are HIV infected but also a doubling of TB incidence in those remaining HIV negative amongst the group studied.⁶

6.18 To fail to treat HIV is to risk increased TB infection rates in the UK.

VII. *Extending charges to primary care*

7.1 The proposed extension of the new charging regime to primary care will be extremely harmful to the fight against HIV in the UK. It also undermines attempts to treat other serious or emergency conditions free of charge.

7.2 GPs remain a vital first port of call for those concerned about their health. GPs can often diagnose serious conditions on the basis of apparently minor symptoms, or at least identify the need for further investigation and tests. Early symptoms of HIV may well remain undetected if people are denied access to an assessment in primary care, resulting in delays in diagnosis with the attendant harm both to the individual and quite possibly to others.

7.3 Without some health assessment available in primary care, other conditions which require urgent treatment might well be missed. At the same time, many with relatively minor conditions will present at A&E as the one place where they might have hope of free treatment, overburdening the A&E service and increasing waiting times and pressure on resources in A&E.

7.4 There is a compelling case for there to remain a free health assessment available in the primary care setting and we recommend accordingly.

PART II—OTHER SEXUAL HEALTH ISSUES

1.1 We wish to concentrate in our memorandum on the charging issue since we believe it to be an urgent matter where the intervention of the Health Committee could make a real and important difference to public health and HIV incidence.

1.2 We would, however, also comment briefly on the recently published Public Health White Paper, “*Choosing Health*”. Many of the concerns raised by the Committee in their report on Sexual Health are addressed in the White Paper and there is much to welcome and commend in the Government’s proposals. Renewed efforts in public education, a 48 hour GUM waiting time target, targets for gonorrhoea and chlamydia will all be of great benefit. We believe that the White Paper may well increase a concern for sexual health both in the public at large and amongst PCT commissioners in particular.

⁶ “HIV and pulmonary tuberculosis: the impact goes beyond those infected with HIV” Sonnenberg *et al*, AIDS 2004 Vol 18 No 4.

1.3 We must point out, however, the relative invisibility of HIV in the White Paper—the word is only mentioned two or three times in the body of the document. There are no targets relating to HIV prevention or treatment. Though there is discussion in general of health inequalities, there is no account of the health needs of gay or black African communities.

1.4 We remain very concerned that the White Paper will not provide the looked-for leverage to get commissioners to prioritise the fight against HIV with targeted prevention in vulnerable communities. It is necessary for PCTs to know they will be judged against their performance on HIV if we are to see progress in this area. We hope the Health Committee will raise with Ministers and departmental officials how they plan to ensure that HIV is not forgotten in the sexual health agenda, how it receives adequate funding, and what steps they propose to achieve the HIV-related goals of the National Strategy.

1.5 NAT plans in 2005 to conduct a survey of PCTs to assess the resourcing and quality of HIV prevention work at the local level, information which is not currently available but which is vital if we are to understand and improve HIV prevention in England. We would propose to send our findings to the Health Committee for your information and consideration, and hope this is material the Committee would welcome and find useful.

December 2004

Witnesses: Ms Lisa Power, Head of Policy, Terrence Higgins Trust, *Dr Max Sesay*, Chief Executive Officer, African HIV Policy Network and *Ms Deborah Jack*, Chief Executive, National AIDS Trust, examined.

Q46 Chairman: May I welcome our next group of witnesses and thank you for your willingness to come before the Committee. Obviously, we are looking in particular at the background to HIV charging for overseas visitors. I wonder if Deborah Jack could give us a brief background to what you believe to be the main issues and problems with regard to the recent introduction of charges for HIV treatment.

Ms Jack: First, we would like to thank the Committee for taking forward our suggestion to look at charging because we do believe it is a really important issue. The first point to make, having talked about the Sexual Health Strategy, is that one of our real concerns about the changes in the charging regime is that potentially they are going to undermine what we are trying to achieve for the strategy in terms of encouraging people to come forward for testing, particularly within the African community. That is a fundamental point, the interrelationship between testing and treatment. If treatment is not readily available, people are going to be reluctant to come forward for testing. They are going to be unaware of their diagnoses. If they do not have access to treatment, they are likely to be more infectious; they are less likely to access advice on how to avoid onward transmission; and they are also going to be more susceptible to other infections like TB. There are an awful lot of risks there. Another really important point that we picked up is that there has been no evidence of HIV related health tourism which is often quoted. In fact, the evidence we have, and Lisa Power can talk more about this, shows quite the reverse is happening. There have been no financial cost benefit analyses of the impact of introducing charging. The estimates we have done show that the cost of acute treatment in A&E if people who are HIV positive become quite seriously ill is likely to outweigh the ongoing cost of them having treatment. You have to add to that the potential cost of new infections, which the Department of Health is saying is anything between £0.5 million and £1 million a year. Obviously there are fairly significant public health issues but no public health impact assessment had been done before introducing the changes.

Q47 Chairman: You are saying that there has been no evaluation by the Government whatsoever of the implications from the public health perspective?

Ms Jack: No, they have not done the sums and they have not done a public health evaluation either of the implications of it.

Q48 Mr Burns: If one divorces it simply from HIV-AIDS, because that tends to emotionalise the issue, and talk about health care across the board, why should it be that, except for those countries around the world where we may have reciprocal agreements in one shape or form, anyone should receive free NHS treatment, given that British subjects travelling to any country in the world where we do not have any reciprocal agreements would have to pay for their treatment there?

Ms Jack: That is an issue we could debate for an awful long time. I am worried that what we are looking at is specifically HIV in the context of this issue.

Ms Power: The simple answer is that we are responsible for the public health of the UK and not the public health of those other countries. The arguments for exempting HIV alongside the other exemptions which already exist—and I think the Committee is probably aware that all other STIs and tuberculosis are exempted from all treatment charging in the UK for anyone on the ground of public health—are compelling for HIV to join those other conditions and be treated. We have the evidence to show you on that. I think we need to take that on the evidence for the UK because it is our country and these are our budgets.

Dr Sesay: There are broader social arguments for that. I think the charging will be targeting the most vulnerable communities. We are talking about failed asylum seekers, undocumented migrants and of course people who overstay as well. We are looking at the consequences of such a policy on, for example, the spirit of a community based organisation. So we have to bear the brunt of the people who cannot present at their statutory services—that is the whole issue of the exacerbation of a stigma around HIV—and also to a certain extent the heightening tensions around racial harmony within society because the

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impression or the messages that will be sent will be of foreigners and African communities being not welcome in this country. What is even more serious is the issue of late presentation which is already happening with African communities. I think the evidence suggests that in fact, far from people flying in to access the services in the UK, there are actually problems of late presentation, problems of getting Africans to services, and this is significantly going to undermine all the efforts that have been made at community level to try to get people to present at services. Above all, I think it would have the consequence of driving the infection underground, and therefore the public health we are talking about is actually put at risk.

Q49 Mr Burns: If one takes that logically, do you think that this policy has the effect with regard to race relations within this country that, rightly or wrongly, there is a view that people are having to wait longer for their own health treatment here because of the demands being placed by other people seeking help who have not contributed at all financially to the paying of the service or its practices or whatever?

Ms Power: I think the issue is an important one, and the fact is that we would like to curb the spread of HIV; otherwise we are going to have far greater problems with access to HIV and sexual health services in the long run. We have undertaken research, because nobody else had done it: we have looked at 60 people who were recent migrants who had approached the Terrence Higgins Trust or George House Trust for support—and both of our organisations give basic support to any person with HIV who approaches us, so their immigration status would not matter in approaching us. The research showed that 75% of the people who had recently migrated were not diagnosed until they had been in the UK for at least nine months, which does not suggest treatment tourism in the least. Only five per cent of those people had been diagnosed before entry or immediately upon entry and 58% had only been diagnosed once they were actively unwell. Once someone is actively unwell they are more liable to be able to pass on the virus and they are also harder to treat and more expensive to treat. I think it is extremely important that we are aware that we have people in this country who have a condition which is transmittable and it is more expensive to not treat than to treat. For example, there was a long-stay visitor in North London who was rushed to hospital with pneumonia. This is a case that was brought to our attention at Terrence Higgins Trust. She was diagnosed as HIV-related and therefore billed after four days for £2,000. Because of that billing, she discharged herself, went home and self-medicated, and after several days collapsed and had to be admitted to intensive care, where her further costs came to £23,000 for that episode alone. HIV treatment for one year now in the UK is less than £10,000. The simple fact is that it is cheaper to treat someone for HIV than it is to allow them continuing

revolving-door episodes in intensive care for which they will run up bills that they cannot possibly pay and for which the NHS will become responsible.

Q50 Dr Naysmith: As far as HIV treatment is concerned, is there any evidence for health tourism, meaning people who come to this country—

Ms Power: This is literally the only survey which has been done, which showed that for one in 20 people there may be some case. We are very clear that we are not debating the issue of health tourism in general or government actions around that. We are here to talk about HIV as a public health issue and a public purse issue.

Q51 Dr Naysmith: Certainly that is the way we have always treated it. But this is something that is said and we need to know if there is any evidence you know of.

Ms Power: That is the evidence we know of.

Q52 Dr Naysmith: I accept you do not want to promulgate it, but does anybody . . . Deborah? Dr Sesay?

Dr Sesay: No.

Q53 Dr Naysmith: What do you say when people say that to you?—that it happens.

Ms Power: Nobody is debating that it may happen sometimes, but the only evidence which is provided on the other side is anecdotal and occasional. This is a matter which has been supported by the British Association for Sexual Health and HIV and providers of AIDS care and treatment, who are the two key bodies of clinicians and managers in the health service who are working with HIV.

Q54 Mr Bradley: You have already started to experience some of the evidence in your memorandum regarding the effects that have been coming through for the changes. Would you like to elaborate a little bit more on that? Also, have you any evidence that it is adversely affecting those who are eligible for NHS treatment as well as those who are not?

Ms Power: Yes, we do have. One West Midlands' client of the Terrence Higgins Trust was wrongly billed for treatment. Her asylum case had been refused, but she was allowed to remain in the country because her country of origin was too dangerous to return to, and thereupon she was wrongly billed for treatment. She left treatment and fled the hospital. When we attempted to negotiate that with the hospital and to discuss the fact that we believed they were billing her incorrectly, they passed our details on to a debt collector and we were then required to cite confidentiality issues because the debt collector began to try to pursue that person through us. We also talked to a leading North London hospital in HIV who had reported to us that patients were increasingly being lost to follow-up because of the fear of being billed. Our own helpline reported to me yesterday, when I asked about this, that we have seen a serious increase in the number of people who are calling, from maybe a couple of

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people a week to several people a day, asking about eligibility issues, because they are afraid, because they fear they may not be able to go in, and they do not want the shame of being told that they cannot have treatment unless they pay.

Q55 Mr Bradley: In your memorandum, you have made some reference to that. Could you supply us with up-to-date figures on those sorts of inquiries that you are getting?

Ms Power: I can certainly supply them to you after today. At the moment that is just the communication I have had verbally with them yesterday.

Q56 Dr Taylor: I think you have made the case absolutely, utterly, completely. One of the huge arguments is to persuade people to spend money now to make a saving for the future. I think the work your Terrence Higgins Trust has done—particularly, thinking of your booklet on clinical trials—is absolutely invaluable. I am rather widening it from just overseas people coming here because I think that has been answered. It is absolutely essential that they do not have to pay. I think their surveys are so valuable that it is worth quoting some of the things out of these—and it is really going back to the first session: 15% of PCTs do not have consortia arrangements; almost one-third of PCTs do not include HIV or STIs in their local delivery plans; some still do not have a designated sexual health lead; 40% of PCTs have insufficient capacity to make any progress at all. This is an incredibly useful document with the background in it. Really I find it hard to ask questions that have not been answered already, related particularly to African people living in this country. Could Dr Sesay spell out actual issues that come before some of the Africans living with HIV here?

Dr Sesay: With African communities generally we are talking about communities which are already socially excluded within the United Kingdom context. A lot of them would be asylum seekers; a lot of them would be unemployed—they have a high representation in these numbers of the unemployed; and a lot of them would have been separated from families as well and they come to this country traumatised as a result of experiences from where they come. Some of them do not even know how to access NHS services. It takes quite a while, it takes quite a lot of work at the community level, in terms of providing information, in terms of providing direction, and then imagine, when they try accessing services, what they would encounter is that they will be refused.

Q57 Dr Taylor: If they go to a general practice and if they are registered with one, will they be signposted in the right direction or may they not even be—

Dr Sesay: I think the charging proposal is going to be extended to primary care, which means that they may even be finding it extremely difficult to get a GP at that level. So when we talk in central government planning around improving our reducing health

inequalities within society, this simply cuts across and drives right into the base of central government policy of encouraging people to present to services.

Q58 Dr Taylor: So the impact is disastrous.

Dr Sesay: It is completely disastrous.

Q59 Dr Naysmith: I just want to pick up something that Richard was talking about a little bit earlier, without in any way disagreeing with the fundamental public health principle he was promulgating that it benefits us all if people are not discouraged from seeking treatment. When we were doing the inquiry a couple of years ago, a lot of people told us that one of the things that was happening of course was that funding for HIV/AIDS was being transferred from a special budget to general funding. That must explain at least some of the results that were picked up in your survey that Richard was quoting about some PCTs not spending any money on HIV/AIDS. That should be something that went through a transition, and maybe when these figures were compiled it was still moving. Is that the case or are there some PCTs who do not spend any money in this area at all?

Ms Power: I think it is important to point out those survey figures are from last year, so they are extremely up-to-date. That is a brand new publication. I think there is a real issue ongoing—I am sorry, this is harking back to the earlier session—around the implementation of the White Paper in order to ensure that PCTs take the issue sufficiently carefully. But I think it also spills over—

Q60 Dr Naysmith: This special budget for HIV/AIDS which was seen as separate from—

Ms Power: The ring-fenced budget. The money is still there. It is not ring-fenced, but the money should still be there, plus there are a number of special allocations. The question is to encourage primary care trusts to use that money for the purpose for which it was identified and not to move it into other budgets.

Q61 Dr Naysmith: Some are moving it into other budgets, is the implication of what you are saying.

Ms Power: Yes, that is right. And that spills over into the system in that primary care trusts throughout England are actually taking very different attitudes around this, and the cases that I have given to you are cases which we have been able to support, and sometimes we can get people treated in one place and not another because there is absolutely no uniformity of implementation around this and it makes healthcare an extreme lottery. It also means that clinicians are being encouraged to ignore government regulations, which is extremely unfortunate and not a good situation, and it means that there are severe health inequalities emerging for many African people, as Max has been talking about.

Dr Sesay: The African HIV Policy Network is an umbrella organisation that has member organisations, most of them African-led organisations, providing services across the country.

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We have also established African forums and bringing together regional organisations to work together and to provide services. Since the removal of the ring-fence, what we have realised, what we have seen from our membership and what we have got from the membership of the AHPN, is that a lot of the organisations have collapsed. They have shut down. These have been extremely vital and crucial conduits to very hard to reach communities. They are simply not getting the funding that they need to be able to provide services to the communities at a time when the government strategy should be to enhance the capacity of these affected communities. Those are the contradictions that we are having at the moment.

Q62 Chairman: Simon touched on the politics of this whole area earlier on and Richard's comment was that you have made the case completely, and I would concur with what he has said. Having said that, and in the run-up to a general election where asylum, immigration, race will be undoubtedly, as we can see already, play a key part, how do you address the *Daily Mail* agenda on this issue and actually get across the important points that you have put to this Committee today?

Ms Jack: I think one general point is we need to divorce this discussion we are having today from general policies on asylum and immigration, because we are talking about people who are living in the UK already with HIV and, irrespective from any other debates around immigration, this is about a real and immediate problem which is not going to go away if those policies change. I think that is a challenge for us, but I think it is really important, because, once it gets sucked into those wider issues, you actually lose the ability to look at it as a very specific problem that can be addressed quite simply by making HIV exempt in the same way as other STIs and TB.

Ms Power: This is not just an HIV issue. A very large part of this for us is co-infection with HIV and TB. We have a number of cases where people have abandoned their TB treatment, because they have been billed for the HIV portion of it, within a couple of weeks of starting it and walked out into the community still infectious to both conditions and with TB quite possibly multi-drug resistant because of partial treatment. That is a very immediate concern. This is about a change of regulations, not primary legislation. I think it would be something that could be put in with the next set of regulation changes which we know are about to happen, and I think it is really important we encourage the Government to put the public health of the nation first on this.

Dr Sesay: We would encourage politicians to be conviction politicians.

Q63 Chairman: That is a pretty old-fashioned concept!

Dr Sesay: I know this can be extremely difficult with an upcoming election, but I think that, if politicians are provided with the evidence, I would encourage them, no matter how difficult it is, no matter . . . well, I do not want to say no matter what the political price, because that may well be a high political price to pay, but, when they are presented with the evidence, it is a case of arguing out the evidence and establishing a policy, putting in place a policy that is based on the evidence. One of the things we discussed at the Independent Advisory Group of the Sexual Health Strategy a couple of days ago was exactly that, that we know that sometimes the political terrain can be extremely hazardous for politicians, but if it is based on firm evidence they should be able to get the facts across, and we can only encourage politicians to go down that route.

Chairman: We are most grateful to you. Thank you very much for your evidence.

Supplementary memorandum by Terrence Higgins Trust (HA 14A)

CALLS TO THT DIRECT REGARDING ELIGIBILITY FOR TREATMENT

THT Direct is a nationally available phone line for anything related to HIV which receives on average around 600 calls a week. These are on a wide range of matters and, while data is collected systematically, when the system was set up eligibility enquiries were so infrequent that they did not merit a data category of their own. Thus, they are usually a subset of immigration enquiries and are not collected independently.

Anecdotally, staff and volunteers estimate that enquiries about eligibility for NHS services have gone from around one to two a week (a year ago), to one to two each day (currently); a sevenfold increase. They state that, in general, the majority of these enquiries relate to whether someone will be entitled to NHS services, rather than from people who have already been refused them, and are within a wider range of enquiries rather than being the sole reason for calling—They also state that a substantial number of these calls are from people who are eligible for NHS services, but who are afraid to approach services directly because they do not want the shame of being refused.

CHARGING POLICIES IN OTHER COUNTRIES AND "HEALTH TOURISM"

Although there has not been time to do a comparative overview of other developed countries, and no accurate table of requirements currently exists, enquiries have established that the UK's nearest neighbour on the European mainland, France, has a much more liberal eligibility requirement than the UK for health services. In France, since 1997, all health services are available free to anyone who can show that they have

been living within French territories or dependencies for the past three months and where someone has a serious health condition for which treatments are not available in their country of origin, they cannot be deported back to there. Therefore, if anyone with HIV was intending to migrate to Europe in seek of HIV services, they would be substantially better off going to France than to the UK. There is no evidence to show that this has, in fact, occurred because most people immigrating who subsequently approach the NHS for HIV-related services are unaware of their HIV status upon entry (THT/GHT 2003).

Appended please find the overview of this piece of research, which also may be of use to the Committee in its entirety.

RECENT MIGRANTS USING HIV SERVICES IN ENGLAND

Policy, Campaigns and Research Division at Terrence Higgins Trust, October 2003.
Data supplied by Terrence Higgins Trust (THT) and George House Trust (GHT).

This snapshot, undertaken in October 2003, used basic, anonymised information from recent users of THT and GHT services who are also adult migrants to the UK. It aimed to map:

- when they arrived;
- how they entered;
- when they were diagnosed with HIV; and
- under what circumstances that diagnosis was made.

METHODS

The records of 60 recent users of services were examined by the following agencies: Lighthouse Kings (part of THT) in South London (14), George House Trust in Manchester (24), Terrence Higgins Trust in the West Midlands (22). The identifying factors for selecting records were that they should be of the most recently presenting migrants with HIV who had asked for support and who had provided enough information about their circumstances for staff to be able to complete the survey with confidence.

COUNTRIES OF ORIGIN

In all, 17 different countries were represented, 15 of them African. Of the 60 people whose case notes were revisited, just over 50% (31) were of Zimbabwean origin. One in 12 (five) was from Uganda. Only 7% (four) were not from Africa, of whom three were Jamaican and one Afghani.

DATE OF ENTRY

Just over 18% (11) had arrived in the UK before 2000. Ten entered in 2000, nine entered in 2001 and 20 (33%) entered in 2002. Only five had arrived in the first nine months of the current year, 2003. Five people did not have dates of entry in their case notes. The numbers appear to rise in 2002 and then return to a steady level, and this may be explained in part by the preponderance of Zimbabweans. 2002 was a particularly turbulent year in Zimbabwe, with many people fleeing persecution and others taking advantage of work or study opportunities to stay away from the violence and intimidation in their home country. Other data on migrants and people seeking asylum in 2002 confirms an across-the-board rise in the number of Zimbabweans entering the UK in that year.

Method of entry

Despite many suppositions to the contrary, only 13 (22%) in all were recorded as having entered the UK to seek asylum. Almost half of these were Zimbabwean (6), with others being from Uganda, the Congo, Sierra Leone and Afghanistan—all areas of acknowledged political turbulence within the last few years. Another 12 (20%) had entered to study. A similar number, 13 (22%) had entered as visitors for unspecified reasons, with a further seven (12%) coming to join family already here. Others had come on work visas, to join the army or to get married. Method of entry to the UK was not known in 11 (18%) cases, but this was incomplete data records on the part of the responding agencies rather than failure to disclose. Most HIV support agencies only collect data necessary to respond to someone's support needs and reason for original entry to the UK may not have been relevant to these in all cases.

These findings indicate that there is no identifiable single way in which people subsequently diagnosed with HIV are entering the UK; rather, the picture is a complex and diverse one. It strongly suggests that making testing a condition of work visas (a common move amongst industrial countries to quiet popular fears about HIV and migration) would have very little impact upon the issue. It is also clear that the commonly made link between asylum and HIV is a tenuous one.

DATE OF DIAGNOSIS

Five people were diagnosed with HIV before 2001, with a further four diagnosed in 2001. Ten people were diagnosed in 2002, with the vast majority, 41 (68%) diagnosed only recently, in 2003. To some extent, this may reflect the fact that recently diagnosed people may be those most likely to access community services, but it also reflects the pattern of diagnoses amongst African immigrants to the UK and recent testing campaigns targeted at those communities. There is also a likely link to the rising efficiency of antenatal testing, through which an increasing number of heterosexual women with HIV are being identified.

TIME BETWEEN ENTRY AND DIAGNOSIS

In order to examine the contention that people are entering the UK with the specific intention of obtaining treatment, two other pieces of data were examined; length of time between arrival in the UK and diagnosis, and circumstances of diagnosis. Only five people (8%) were diagnosed within three months of entry to the UK. The most common timespan between entry and diagnosis was 10 to 12 months, with 14 people (23%) diagnosed at this time. In all, at least 45 (75%) waited more than nine months to test after their entry. One third of people in the cases examined (20) had tested more than 18 months after entry. In six cases (10%), it was not possible to determine the length of time between entry and testing due to missing data.

This data militates against the argument that people are coming to the UK in order to obtain treatment. Were this the case, one would expect to see a far swifter progression in the overall data from arrival to testing, rather than three quarters of people testing after nine months or more. This view is strengthened by the final category of data collected below.

IMPETUS TO TEST

Possibly the most interesting data was on how people came to be tested. This data, was available for all 60 people, as something highly likely to have been, relevant to the reasons they initially sought help from the organisation. By far the most common reason given for testing was the onset of symptomatic HIV, with 35 people (58%) testing when they became actively unwell. Almost half of these people (27% in all) fell severely ill before diagnosis, as measured by CD4 counts, emergency admission to hospital, or conditions such as TB. Ten women were diagnosed antenatally (17%) through routine offers of testing to all pregnant women. Another nine (15%) tested only after the death or diagnosis of a partner. Only two people reported being diagnosed prior to entering the UK, and only one person (less than 2% of the sample) was diagnosed as the result of an unprompted visit to a GUM clinic. Other ways in which people came to test included testing following sexual assault, army medical and a medical for a visa.

This data shows that people discovered their HIV status by a wide range of methods common amongst those who are unaware that they have HIV. More than a quarter became severely ill before being diagnosed with HIV, some having presented at hospital with mystery symptoms a number of times or succumbing to life-threatening conditions before HIV was suspected; not the mark of people undertaking “treatment tourism”. In only one case out of the 60 examined had someone attended at a GUM clinic for sexual health screening without an obvious external trigger, the action most likely by someone who might be already aware of their HIV status and wanting to access services for it.

Obviously, this is a relatively small sample and there is a need for further investigation of a wider cohort. However, it is clear that the picture is a far more complex one than most coverage of the issue has suggested.

- People with HIV arrive in the UK in a wide range of ways for many reasons.
- Many are diagnosed in a manner that contraindicates any previous knowledge of their condition.
- The majority do not obtain a diagnosis early upon arrival in the UK, but in the course of ordinary living over an extended period of time.
- Many are spurred to test by the onset of ill-health associated with relatively, late stage HIV.

Terrence Higgins Trust would welcome further factual investigation of this issue, in order to conduct the debate about migration, treatment tourism and sexual health in a more constructive and rational manner.

Memorandum by the Health Protection Agency (HA 35)

ABOUT THE HEALTH PROTECTION AGENCY

The Health Protection Agency is an independent body with the remit to protect the health and well-being of everyone in England and Wales. This includes protection from infectious diseases. Staff at the Health Protection Agency Centre for Infections include specialists in communicable disease control; public health specialists; microbiologists and epidemiologists—who monitor the spread of disease, including diseases caused by HIV and other sexually transmitted infections.

PART 1

The consequences of the new and proposed changes in charges for overseas patients with regard to access to HIV/AIDS services

1. We are concerned that the new and proposed changes may impact on the clinical and public health management of HIV infection in overseas born individuals diagnosed with HIV in the UK.
2. Early diagnosis and treatment of HIV infection (where appropriate and according to clinical guidelines) is beneficial both to interrupt transmission of the virus in the community and to the health of those who are HIV-infected.
3. Surveillance evidence indicates that within the UK HIV epidemic a greater proportion of HIV infected patients who are diagnosed late in the course of their infection, die due to their HIV infection, or remain without their HIV infection being diagnosed, are overseas born—compared to those born in the UK.
4. Since 2000, CD4 counts made at the time of diagnosis of HIV infection show that those born overseas consistently present at a more advanced level of immune suppression than those born in the UK. (Data supporting these statements can be provided.)
5. Underlying HIV infection is an important consideration in the management and treatment of tuberculosis (TB) and failure to address this can lead to inadequate treatment of TB, running the risk of reactivation, the potential for developing drug resistant TB and ongoing potential for transmission. Since 2000 TB was diagnosed as an AIDS defining illness in two in five of those born overseas who were diagnosed with AIDS in the UK, compared with fewer than one in 20 of those diagnosed with AIDS who were born in the UK.

PART 2

Progress to date in implementing the recommendations of the Committee's inquiry into Sexual Health (the Committee's Third Report of Session 2003–03)

Evidence relates to recommendations in square brackets which are numbered as they appeared in the Recommendations and Conclusions of the House of Commons Health Committee Report "*Sexual Health*" Third report of Session 2002–03

[Health Committee para 1. While we have some reservations about some of the detail in the Strategy (and indeed about areas where there is scant detail) we regard as entirely commendable the decision of the Government to produce the strategy. We would like to see measures going well beyond what it proposes, but would want to acknowledge that the Strategy represents an excellent starting point and a foundation which can be developed.]

The Sexual Health Strategy included a number of goals and standards, which can be measured directly or indirectly through surveillance and prevention monitoring activities undertaken by the Health Protection Agency (Centre for Infections—Communicable Disease Surveillance Centre). These have been published in tabular form as an Appendix in the Annual report "*Focus on Prevention: HIV and other Sexually Transmitted Infections in the United Kingdom—An update: November 2004*".

[Health Committee para 3. We recommend that the Army Medical Services forwards to the PHLS its figures for STIs. We also recommend that the PHLS looks at how a more comprehensive surveillance system can be developed to cover all areas of sexual health and possible service providers. This will give a more complete picture of trends, prevalence and service utilisation.]

The Health Protection Agency has sought to widen its coverage of STIs diagnosed in primary care, in particular diagnoses of Chlamydia. HPA has been working closely with the DH on the development and piloting of the Sexual Health Services Common Dataset, an expanded patient-based dataset which, once approved as a mandatory information standard, will be collected from all sexual health services (this is likely to be as part of the National Programme for IT).

[Health Committee para 5. In respect of the monitoring of trends in both STIs and HIV/AIDS we would like to pay tribute to the work of the PHLS. Their monitoring ensures that the UK has the best data in the world, and this in turn give great credibility to their research. It would be most regrettable if the absorption of the PHLS within the new Health Protection Agency were in any way adversely to affect its work. In particular, we would be alarmed if the close networks developed between the regional and local laboratories and clinicians and epidemiologists were to be impaired as a consequence of the move to NHS management of the laboratories.]

Although it is still early in the history of the HPA and the earlier recommendation on statutory laboratory reporting has not been acted upon, to date HIV and STI surveillance activities have continued to a high standard. For HIV surveillance in particular this is tribute to the goodwill, and continuing collaboration of many laboratory and clinical colleagues who contribute to the voluntary reporting of this infection. Increasing workloads have increased the burden of this activity and HPA acknowledges and thanks reporters for their continuing participation. The roll out of the collection of more specific data from GUM clinics (disaggregate KC60 reporting) has been problematic but a revised surveillance system, described above, is now being implemented and it is hoped that this will proceed more smoothly.

[Health Committee para 6. Although we support the Government's drive to improve sexual health services via the Strategy, without wholesale advances in sexual health provision these targets will be tokenistic.]

We feel that given the further marked increase in clinic workload since the strategy was published—both in the numbers of patients seen and in the numbers being diagnosed and treated for HIV infection (both overall numbers markedly increasing and the complexity of the caseload)—this statement is even more pertinent than when it was originally written. The delay in diagnosis of HIV and STIs will result in further transmission and hence the need to strengthen sexual health provision remains urgent. This should be across a variety of clinical settings (including but not restricted to GUM clinics).

[Health Committee para 10. While any increase in funding needs to be fully justified and accounted for, in the context of the current disastrous impact on public health of the nation's poor sexual health, these figures do not strike us as excessive. It should be stressed that there is not just a shortage of consultants: nurses with expertise and training in this area, health advisors and laboratory technicians are all needed and these should not be left behind in any increase in funding . . .]

HPA laboratories count among their activities: Bacterial and viral reference services, surveillance of incident HIV infection, HIV population prevalence studies, surveillance of antimicrobial resistance in gonorrhoea and antiretroviral resistance in HIV. Funding for these activities has not increased in line with increasing workload although some funding increase was obtained from the Department of Health to further improve HIV and STI surveillance in the 2002–03 financial year.

[Health Committee para 13. We welcome the fact that the Department is developing a waiting times indicator as a means of monitoring the effect of its recent investment on access to clinics. However, this will merely duplicate existing activity since the PHLS and the Specialty Societies for GU Medicine already monitor waiting times, and evidence of the extent of the problem is not wanting. So we are unconvinced that this measure alone will do much to address what amounts to a public health crisis. We recommend that there should be a presumption that anyone wishing to access genitourinary medicine should be able to do so on the day of, or day after, presentation to a clinic. If a target of 48 hours to see a GP is appropriate then a target of 48 hours for the treatment of what is potentially a communicable disease is essential . . .]

The GU waiting times survey, was piloted and then conducted nationwide by the HPA in collaboration with the British Association for Sexual Health and HIV (BASHH). The first complete survey took place in May 2004. Results showed that lower proportions of women and young people were seen within 48 hours—and that nationally 72% of emergencies, 79% of walk-in patients and 18% of routine appointments were seen within 48 hours. The surveys will continue six-monthly and results are and will continue to be published on the HPA website: www.hpa.org.uk/infections/topics_az/hiv_and_sti/epidemiology/wtimes.htm.

[Health Committee para 15. We do not think that it is necessary to wait for the results of the reinfection study before introducing nationally the chlamydia screening programme. Any additional information that the reinfection study provides is, in our view, likely only to lead to modifications in the programme rather than fundamental reforms. Accordingly we recommend that the NHS must as a matter of urgency, move to provide such screening in all family planning clinics, infertility clinics, termination of pregnancy clinics and GUM clinics and for women having their first cervical smears. We also believe that GPs should routinely offer testing to those aged under 25 years without attempting to second-guess patients' sexual behaviour.]

Attendees at Genitourinary Medicine clinics have always been offered chlamydia testing as part of their routine sexual health screen. The decision to implement the National Chlamydia Screening Programme, which targets non GU settings, was taken by the Department of Health following recommendation by the CMO. HPA has closely collaborated with the DH in the initial roll out of the programme. The first phase of roll out included 10 areas, with a further 26 also included in 2004—coverage is now 30% of sexually active 15–24 year olds in England. The programme uses the sensitive NAATS (Nucleic Acid Amplification Tests). In the first phase of 16,500 screened (10% of women were positive and 13% of men). The Public Health White Paper clearly outlines chlamydia screening as a priority for improving sexual health, with a commitment of £80 million over the next three years to see this programme to full national coverage by 2007. The next report on chlamydia screening is scheduled to be available towards the end of summer 2005.

[Health Committee para 18. We are concerned by the trends in HIV and support the Government in its aim to reduce the prevalence of undiagnosed HIV and in turn to safeguard public health. Early diagnosis of HIV not only reduces the chances of it spreading within the community but it also greatly improves outcomes for those infected. On the basis of the evidence we have heard . . .]

Figures contained in our 2003 report suggest that nationally we have made some progress in reducing the undiagnosed fraction of HIV in the UK. This will continue to be monitored—especially through unlinked anonymous serosurveillance of newborn infant dried blood spots and attendees at selected Genitourinary Medicine clinics.

Witnesses: **Dr David Asboe**, Consultant in Genito-urinary Medicine, Chelsea and Westminster Hospital, **Dr Barry Evans**, Health Protection Agency, **Ms Pam Ward**, Co-Chairman, Overseas Visitors Action Support Group, and **Mr Peter Nieuwets**, Chairman, English HIV and Sexual Health Commissioning Group, examined.

Q64 Chairman: May I welcome our final group of witnesses this morning and express the Committee's gratitude to you for your participation in this inquiry. Perhaps I could ask you to introduce yourselves briefly, starting with you Dr Asboe—a very interesting name in the current—

Dr Asboe: It is probably Scandinavian, but I am from New Zealand.

Q65 Chairman: We might be related!

Dr Asboe: I am a consultant in genito-urinary medicine based at Chelsea and Westminster Hospital. I lead the HIV out-patient department there.

Dr Evans: My name is Barry Evans. I am from the Health Protection Agency and one of the HIV epidemiologists within that organisation.

Ms Ward: I am Pam Ward. I am co-Chairman of an overseas action and support group for overseas managers nationally.

Mr Nieuwets: I am Peter Nieuwets. I am an HIV commissioning manager for West Sussex. I am the lead for Kent, Surrey and Sussex and I am the Chair of the national HIV and Sexual Health Commissioners.

Q66 Chairman: Thank you very much. Could I ask Dr Evans, first of all, what is the size of the problem regarding HIV patients who need treatment and care but are not eligible? You were present for the

previous session, you have heard the evidence that we picked up there. What are your thoughts on the extent of the problem?

Dr Evans: The data we have within the Health Protection Agency does not give us information on eligibility directly and we have to make assumptions across other data sets. We do know that the number of people who have acquired infection in Africa has been growing very rapidly over recent years. The number of people with heterosexual diagnoses was around a thousand in 1999 and about 4,500 in 2004—or will be once we get our latest reports in. That increase has been very marked. Also, with heterosexual new diagnoses, about 80% are in African people, people who acquired infection in Africa, about ten per cent in other parts of the world and 10% have acquired their infection heterosexually within the UK. One has to then make some assumptions about how many of the African people who have been newly diagnosed within a UK context may or may not have been eligible for treatment. So the numbers are rising very rapidly, the problem is in knowing how many of those people might or might not have been eligible for treatment.

Q67 Chairman: Do you have any observations on the evidence that we have heard in the first session? Would you concur with the picture that was portrayed by the witnesses?

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Dr Evans: I would concur with the problems around tuberculosis and the interaction on HIV and TB and of tuberculosis being an increasing public health problem and of not treating HIV-infected people. The majority of people from Africa will have come across tubercle bacilli sometime in their history—I mean, if they grew up in Africa. That does not mean to say they have active TB. But, in the presence of HIV and with the immune suppression of HIV, it is likely, when the immunity drops to such a level, to reactivate the TB and they will then become infectious with tuberculosis as well. If people are treated at the right time, hopefully they will not become infectious with TB, but if you do not treat them, they are going to reactivate their TB—and TB as an initial AIDS-defining illness is rising in the UK, even with current patterns. The other issue is an issue of concern with mother to child transmission. We have not talked about that in the evidence so far. It seems to me, if you are diagnosing women in pregnancy, you have at least the moral right to offer them treatment, and not just treatment in terms of preventing mother to child transmission but ongoing treatment, and yet if you do not diagnose them in pregnancy a significant number of those children will become infected. Round about 800 women in 2003 were infected with HIV and pregnant. The majority of those were diagnosed in that pregnancy; some were diagnosed previously; and some unfortunately did not get diagnosed at all during the pregnancy. The majority were diagnosed and consequently 100/150 children were prevented from becoming HIV infected by the treatments that were offered during pregnancy. Those children would become infected if one did not offer the antenatal screening. The NHS has done well in terms of rolling out. We go back to the days of the mid- to late-1990s, when the vast majority of pregnant women in this country did not have their HIV diagnosed, and that has consequences for the women and for the babies, about 25% of whom, if the women breastfeed, will become infected without treatment for their HIV.

Q68 Chairman: Coming back to your earlier point about TB and HIV, you do not dissent from the concerns expressed about the difficulties for public health if we have the kind of picture that was portrayed by some of these witnesses previously of people with TB and HIV disappearing as a consequence of being billed for the HIV elements of their treatment.

Dr Evans: That is a serious concern. At the moment the overlap of the TB and HIV epidemics is not very great. The majority of our TB patients in this country have acquired TB overseas but are from the Indian sub-continent, where there is less of an overlap with HIV. With African patients, clearly there is some overlap, but less so. Five to 7% is our best estimate of the TB patients who are probably HIV infected, so there is not a big overlap, but there is sufficient overlap. And that will get worse if we do not treat HIV, so that TB becomes a bigger issue there. The exact qualification of all that I think is

difficult but there is concern that it will get worse. There are concerns about multi-drug resistance if people are partly treated for tuberculosis. There are concerns that, even if one treated the TB, then people need their own immunity to completely eliminate the tubercle bacilli. If you do not treat them for HIV, they may at a later stage again react the tuberculosis.

Q69 Dr Naysmith: I was going to ask Dr Evans about the public health consequences of what happens if charging puts patients off under four separate headings. We have already dealt with two of them, mother to child transmission and the spread of TB, and presumably the same would apply to other sexually transmitted infections. I would just like to ask you what would be the effect, if this is a discouragement on people seeking treatment, on the spread of HIV within the wider population in this country—which you have partly touched on already—and also the impact of this policy on HIV testing initiatives.

Dr Evans: I think in both those areas it is again difficult to quantify, but on the issue of the onward spread of HIV we have reasonable data now that shows that the spread of HIV is strongly related to viral load. Viral load rises with the progression of the infection. As the CD4 count, the level of immunity drops, the viral load rises, and with high viral load is much more likely to transmit. If people are not diagnosed and they continue to be sexually active, they are more likely to transmit the higher the viral load. There are other co-factors affecting transmission, including other sexually transmitted infections and so on, but viral load is a powerful indicator of transmission potential, so that if you do not treat individuals and they remain in this country and are sexually active in this country, then the transmission is bound to go up. The quantification of that and the total amount of transmission within the UK is going to be quite difficult and would need some fairly complex modelling.

Q70 Dr Naysmith: You said it is bound to go up. It will go up, of course, but it will be reduced a little bit if people use protective measures. What is the evidence that people coming to clinics will be advised about this as well as receiving treatment and will then not be advised about possible ways of limiting the spread of their own disease?

Dr Evans: I agree with that: they can be advised. I think the advice, though, needs to be seen within a total care package and if you cannot offer treatment within a total care package then I think it becomes much more difficult.

Q71 Dr Taylor: Is there any argument in favour of charging for HIV treatment and not charging for the other communicable diseases? Is there any argument against? Is it purely and simply financial?

Dr Evans: I think the only argument that I can find is that of public purse. We would not be here having this debate if with HIV treatment one could treat it for a fortnight and cure it, if it was like syphilis or

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other sexually transmitted infections which with a course of antibiotics or antiviral treatment you cure the patient. It is a public purse argument largely, and the complexity of HIV treatment and the need, as you are well aware, to keep people on treatment long term. We do not have a cure; we just have a means of suppressing viral load.

Q72 Dr Taylor: Do any of the witnesses have any idea how we get this across, that in fact it is not a money-saving exercise because of all the long-term consequences? How do we get this across?

Dr Evans: The only thing I can think of, in terms of having thought and grappled with this—and we have had no evidence that this occurs—is, if people know they can get treatment, this issue of potentially could we be seen as a magnet to attracting more people in terms of treatment tourism in the future. There is no evidence that it is happening now—very, very small anecdotal reports, but nothing now—but if in the future the HIV epidemic worldwide continues, are we encouraging people if we are seen as offering treatment to everyone? That seems to me the only reason. There are powerful public health arguments against that. If people are living here, there are powerful public health arguments to treat them appropriately.

Q73 Dr Taylor: Have you hit on the real hidden reason? Because obviously one could see a government being absolutely terrified of attracting huge numbers of people to this country just because they get treatment free.

Dr Evans: Then the issue of appropriate migration . . . Even people treated in this country, who come to this country and are treated, in general those are people who are going to get into work on treatment and who will contribute to the British economy. They are people who cost money in terms of their treatment, but the total public purse argument needs to be taken into account.

Q74 Dr Taylor: In a way you cannot separate it, as you tried to, from the whole immigration issue.

Dr Evans: I am not a politician.

Q75 Chairman: Neither is Richard!

Dr Evans: I am thankful I am this side of the table and not that one.

Q76 Mr Burns: As you are aware, there are a number of categories of groups of people who are now ineligible for free secondary care in this country and, possibly, depending on where the Government's consultations go, that might be extended to primary care. What advice did your agency give the Government in the consultation process on primary care and on the Government action on secondary care?

Dr Evans: I am not sure what advice we gave and whether we submitted written advice. I am sorry, I should know that.

Q77 Mr Burns: Presumably, as the Health Protection Agency you did input to the Department of Health as part of the consultation process.

Dr Evans: Yes, we did, and there was concern about the rising number of sexually transmitted infections and increasing diagnoses of HIV—and that was in the submission, I know—but I do not know the detail and I am fairly sure we did not raise the issue of migration.

Q78 Mr Burns: As part of your work, do you monitor what goes on elsewhere in the world to see if you can learn anything?

Dr Evans: We submit the UK data to a European centre, and we look at what is happening in terms of other countries via UN AIDS data that comes out on a regular basis, yes.

Q79 Mr Burns: Are there any other countries in the developed world that you know of that will allow people to come from outside their borders then to get free treatment for things like HIV/AIDS?

Dr Evans: There are some countries. There are countries who have screening at point of entry. There are some countries that it is difficult to know: they do not separate HIV from other long-term chronic illnesses. But, for instance, if people are seeking to emigrate to Canada, they would treat HIV as the same as they would renal failure—

Q80 Mr Burns: I do not want to get into screening because other colleagues of mine, I know, will be raising that. I do not want to get into emigration either because that is a slightly different issue as well. I am asking if you have evidence of any other developed country in the world where, if one turned up inside their borders, on holiday or whatever, and then presented oneself at a hospital and it was diagnosed that you had HIV or a number of other conditions, one would be able to get free treatment.

Dr Evans: I am not aware of that, but I would not be expected to know, quite honestly. I do not know what other countries' policies are on that.

Q81 Mr Bradley: Peter, we have heard some evidence on costings. What is the up-to-date cost of HIV treatment? How does that compare with someone falling ill and using emergency services? How does that compare with an attempt to prevent someone having further infections?

Mr Nieuwets: There are a few answers and a few things I cannot answer. First of all, combination therapy costs approximately £7,000. But that is just the combination therapy, that is not the sum on-cost, because most of the time on-cost for a patient is £12,000 altogether. That is what a patient approximately costs. If you can prevent that—and prevention, it is said, could cost up to a few pounds—if you look at what a PCT spends on prevention on HIV and what it spends on the actual cost of treatment, those two have no relationship to one another. One PCT could spend up to £3 million on treatment, and very little on prevention because HIV does not have a star rating. Teenage pregnancy has. They will try to prevent teenage pregnancy, but

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not HIV because it is not seen as important. On the other side, in some PCTs they still say—and sometimes I am surprised—“We don’t have any gay men, we don’t have any black people” and then you have to say to a director of public health, but the SOFIT data proves you have.

Q82 Mr Bradley: With the emergency services—
Mr Nieuwets: I do not know exact costs on that, but if people come in through A&E they are much more expensive because it is also the time and everything being spent on them and they become an in-patient. It is very clear if people also have HIV and, for instance, they are dying of HIV. It was estimated a few years ago from Dr Beck that it costs up to £50,000 to £60,000 a year for somebody dying of HIV, not everything else, because somebody just does not die, it takes a long time. That is one of the problems that also some of my other colleagues put forward. It is, like, if you cannot treat, people will get ill and will need lots of A&E treatment, which is expensive, and then leave and will turn up after months again. One of the problems is often that people will shop around because they will be fearful to go to the same hospital because hospitals, lots of them, have administrators with good memories. If a name comes up, they say, “This patient hasn’t paid their bill last time.” Then you get into the issue of: Is it treatment or is it payment? What is the most important: to treat or to pay? Some people are very wary about that. They say, “But if I don’t pay, they don’t treat.” It is also an enormous amount of tension within hospitals between administration and medical staff: Treatment or payment? Who has the loudest voice within the hospital? And it creates an enormous amount of problems for a community. According to the strategies, we are working against social exclusion, we are targeting vulnerable groups. The effect of this, in a way, is that we are targeting vulnerable groups but socially excluding them, not including them, and financially this has enormous problems. If you look at the numbers, numbers of HIV go up by 20–25% across the country. The costs, what PCTs get, go up by 10%, so the pressure on the services is growing, and a PCT says, “We don’t have money,” “Yes, they have money,” says the Government. “It is in the baseline.” But the baseline is based on SOFIT data of 2001 and has not changed. So there is a problem there.

Q83 Chairman: Mr Nieuwets, you mentioned tensions between doctors and managers in this whole area. Dr Asboe, without being specific about Chelsea and Westminster, would you concur with that picture? Is it one that you pick up from your colleagues elsewhere?

Dr Asboe: I think in many areas there is a conflict. First of all, the criteria on which patients’ eligibility is assessed are complex and difficult. In many situations, you are asking clinicians at the coalface, you know, at the point of entry, when patients are being tested, to make that assessment, an assessment that is difficult. Patients are often very traumatised in that setting and clinicians are not trained to make that assessment. It also puts them in conflict with

their primary role. Making the basic assessment at that level can be very difficult. There is also a situation where patients may not be eligible for treatment, and it is not only that they are not eligible but the guidance is that if treatment is deemed to be necessary in order to save life or to prevent a life-threatening illness, then treatment must be offered immediately. But you may have one commissioner in one hospital who takes a criterion of a CD4 count of under 200—so a patient is very immune compromised, but not at this very point in time having a life-threatening illness—who will make the decision that treatment is warranted under those circumstances and you may have a clinician in a different hospital or on a different day who makes a different assessment. Then there is not only conflict between clinicians because the criteria are not very clear but you have conflict between the clinicians and the management, either of the trust or, at a higher level, the PCT level. So I think this conflict often is difficult and will be more severe in different trusts.

Q84 Chairman: If a patient is being treated for a range of conditions and certain of those conditions are free and certain chargeable, what impact does that have on you as a doctor treating these people? Who actually works out how much is free and how much is chargeable?

Dr Asboe: That is very true. I work in the sexual health service as well and so obviously patients coming into that service, the sexual health or the STI component of it, excluding HIV, is completely covered. Okay. But as part of that service we are offering testing to everyone, and a proportion of those patients will test HIV positive. Then you have to turn round and say, “Well, we can treat your syphilis but we cannot treat your HIV.” I think it comes back to the whole point: in a way—

Q85 Chairman: Could I just intervene. You can treat it but it would be chargeable.

Dr Asboe: It would be charged for.

Q86 Chairman: How do you work out the proportion which is chargeable where surely there is an overlap between the treatment of the conditions?

Dr Asboe: The treatment of HIV is very specific. You have combination antiretroviral therapy which is specifically for that condition. The only overlap with those drugs is the treatment of hepatitis B, and sometimes that is an issue. Some patients may be able to have their hepatitis B treated but not their HIV. In terms of their other sexually transmitted infections, actually the treatments are quite disparate and separate but obviously they can occur in the same person.

Q87 Dr Naysmith: You are acting as a kind of gatekeeper in this situation, are you not? You are deciding who has to pay and who has not. Is that a role that you are happy with?

Dr Asboe: Absolutely not. It is very clear that the General Medical Council says in the duties of the doctor, the very first one, that you must make the

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primary care of the patient your first concern. You must work with your colleagues to ensure that the patient's best interests are served and that is in direct conflict with some of these decisions that are needing to be made. You may say you can refer them to the overseas officer, but, in fact, where is the clarity about who gets referred, how they are assessed and how often they are assessed? So there is major conflict.

Q88 Dr Naysmith: You must know that sometimes you are denying treatment to patients who do not have the money to pay.

Dr Asboe: In practice, if we had a patient attending our service about whom we felt, from our assessment and in conjunction with the overseas officers within the hospital, there were questions about their eligibility, we would refer them onwards to see specialist legal advice, usually from the Terrence Higgins Trust.

Q89 Dr Naysmith: Does that cause you any other problems apart from the sort of ethical one?

Dr Asboe: I think it is a problem for the patients. It may have been difficult for them to attend the service, they need to go outside the service to get this legal advice, and then often they are lost to follow-up because they never actually make it back into the service, they become part of the hidden population who are a threat with all the problems that HIV can lead to.

Q90 Chairman: In reality, again without asking you to comment about your own position, would it be fair to expect perhaps rather a lot of medical colleagues in your circumstances to turn a blind eye to requirements on charging and carry on treating? Is that not a reasonable assumption to make?

Dr Asboe: I am sure that happens. That is because, in talking to my colleagues, we feel that is our duty as a care giver. We know that may put us in trouble with the trust, but, equally, the converse of that is that if you withhold treatment you may be in conflict with your duty as a care giver.

Q91 Dr Taylor: The impression is that it is unenforceable. You have said one is allowed to use treatment where it is necessary to save life. Is there a sort of time limit on that?

Dr Asboe: I should say that it is your duty to use that treatment now to save life. It does not mean the patients will not then be charged for that treatment. It is not that it is free, but the circumstances in which you would invoke that and just get on and treat the patient—and then obviously trusts will have a variety of different views about whether they will chase the person for the money, how hard they will be chased, and where the patient stands on this, in terms of having been diagnosed with a life-threatening illness and being chased by debt collectors and the like. But I do not mean to give the impression that treatment under those circumstances is free.

Q92 Dr Taylor: Thank you for clearing that up. You have mentioned also that you refer things to the Terrence Higgins Trust for legal advice. Do you delay treatment while you get the advice, or do you treat and then go for the advice?

Dr Asboe: Again, I think you would make a clinical assessment and if you felt treatment was immediately necessary, either for the person or, quite often, as we have heard—

Q93 Dr Taylor: Public health.

Dr Asboe: Or in order to prevent vertical transmission—so if a pregnant woman came in we would get on and do that and then ask the questions later, of course.

Q94 Dr Taylor: What would you ask for legal advice about? Would it be simply: “Can I treat this patient?”

Dr Asboe: We may have got a decision from the hospital side of things that this patient is or is not eligible for treatment, but I think it is very important that a different organisation, perhaps who will act in an advocacy role, also will—

Q95 Dr Taylor: When would you get that decision from the hospital, from the trust?

Dr Asboe: If a patient comes in for HIV testing, let's say in a sexual health clinic, if it is thought that eligibility may be a problem, that would be discussed with the individual presenting for testing before they go ahead and have the test. They then proceed with the test and the result comes back positive. Then again it will be discussed. We will discuss it with the hospital overseas officer to get their view, and then, if it is a problem and there is no urgent medical problem, we would refer the patient to the Terrence Higgins Trust, first to clarify whether that was Terrence Higgins' view or whether there was a discrepancy there, and then obviously they would advise the individual about what their different options were.

Q96 Dr Taylor: Could you clarify the position when there is no urgency.

Dr Asboe: That is a clinical decision.

Q97 Dr Taylor: Does that go on the protection of other people from the spread?

Dr Asboe: No. Generally that would be an individual clinical decision about that person as an individual.

Q98 Dr Taylor: So it is an absolute minefield for you to work through.

Dr Asboe: It is a minefield.

Q99 Dr Taylor: Could I go back a little bit to Peter. We are told that government targets are aimed at reducing newly acquired HIV infections; they are aimed at reducing undiagnosed HIV infections. What effect will these changes have on those targets?

Mr Nieuwets: They become very difficult. Several people said when those targets came out, “We might achieve them if you build a very big wall around

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England—a very big one which no one can get through, neither getting in nor out.” Then it might be achievable. But if it is an open country, it is unachievable—even probably within the country it would have been very difficult. Especially one of the factors now is that people go underground: you do not even know any more how big your undiagnosed group is. One of the other problems with the effect of these regulations is that with lots of partnership arrangements within community care, between people from the black African community and organisations, HIV organisations and other organisations, the trust within those very fragile structures is also falling away, so people do not trust each other any more. They do not trust medics, they do not trust PCTs, and everybody asks: “Who is doing what?” The chance of offering good community care is even going down the drain with this, so it becomes very difficult even to keep that on a level, especially then, over time, if money gets less and less. Because all the money is pumped into combination therapy and PCTs understand lots of times that money has to be paid to treatment. Community care is really the stepchild of this. It is like nobody is really bothered about this: “That is not really necessary.” If you ask clinicians what is the most important thing about treatment, it is adherence. Good adherence is lots of times helped by good community care. If there is no community care, the adherence will drop and you will have even bigger problems, and financially it becomes a bigger problem. One of the issues is also that the way HIV is funded within PCTs across the country is very different. In some areas it sits very clearly within specialist services and it is more or less still ring-fenced. In other areas, it is in the PCT and has to compete with anything else that is in the PCT while it still officially sits in the specialist services’ list. But decisions are made within PCTs and they are given power so they can do that.

Q100 Dr Taylor: You have given us so many arguments, that if there is any logic in the political world at all we cannot fail.

Mr Nieuwets: But first of all money.

Chairman: We tried to build a big wall a few years ago to keep the Scots out, but they appear to have got through!

Q101 Dr Naysmith: I think it is time we brought Pam Ward in. She has been sitting there very patiently waiting to be asked a question. One of the things that was in the original consultation paper gave examples of how loopholes in the law allowed overseas visitors to come here, to bring their dependents with them and, according to the White Paper, to abuse the National Health Service. The examples included people living here, flying their wives to the UK for short period to access maternity services, for instance, and people working in the UK bringing their dependents for access to complex and sometimes expensive surgical operations.

Ms Ward: That is correct.

Q102 Dr Naysmith: How typical do you think these examples are? Do you know of any other examples?

Ms Ward: The regulations as far as HIV and the charging have not changed since 1988. The only thing that has changed is the definition of ordinary residence.

Q103 Dr Naysmith: We will come to the HIV in a minute. Would you deal with the White Paper.

Ms Ward: The loopholes you are talking about are quite correct. Because, if you were a student and you had a student visa, that was fine, you could come over on an agricultural course for 12 weeks and you could bring your four children and very pregnant wife, and, as spouse and dependents, they would be entitled to receive treatment at the same time, so they would be exempt. The regulations have changed to say that the dependents have to come for the duration of the stay of the exempt person. Now if you are coming on your six months’ agricultural course and you have to bring your wife with you, she has the right to be here as your dependent and stay the duration of your stay. If she just comes over for a fortnight’s visit and wants to deliver her baby—which does happen—then she is chargeable.

Q104 Dr Naysmith: How widespread do you think this is? Is it a big problem?

Ms Ward: It is across the country. In our group we have representation from a vast majority of NHS trusts, and this is the feedback we have at our meetings, that these are the issues that the overseas managers face. These were of course highlighted and taken on board. So, yes, there is this abuse, though it has now changed and it makes it a lot easier to manage.

Q105 Dr Naysmith: You are saying it poses problems for managers to deal with. Dr Asboe was talking about the limit. What did you think about what he was saying?

Ms Ward: I quite agree. The difficulties from an overseas manager’s point of view in a trust is that you have to remember the guidance has to be implemented at a local level and it would be the responsibility of the trust and the way they manage it and set up a structure to manage it. The consensus of a lot of overseas managers is that actually to get access into information in GU clinics and sexual health clinics is taboo: we are not allowed in. There is a lot of hostility against overseas managers even to want dialogue with people in GU clinics. We could not say if we identified patients entitled for treatment or not. There are very good pockets and a lot of people are doing a lot of good work, but generally it is very hard to get access into patients receiving treatment. We just have to work very generally. It is difficult. There is no formal training. You have to decide on the patient’s residency—and that is the question. Is this person a resident of the UK or here for a viable purpose and can prove to you that they are here for that purpose? We need documentary evidence to do that. You have to make an assessment

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on that documentary evidence and what you are being told. Yes, errors do happen and people get charged by mistake, but you should always review patients and the trust has the right to refund money if they feel they have acted wrongly. It is a difficult area for us to deal with. We have to rely on a clinician's decision. An overseas manager can interview a patient, they can have the documentary evidence, and it can be decided then that this person is not a resident of the UK, he is only here for a viable purpose, so they are chargeable, however, we would have to go the clinician and advise him of that and the treatment then would be provided as to its need. Yes, an invoice would be raised and the trust has the responsibility to try to retrieve this money; otherwise we are covering the burden of treating a lot of people who are non resident in the UK.

Q106 Dr Naysmith: You were saying that you have trouble getting access to GU clinics in general.

Ms Ward: Yes.

Q107 Dr Naysmith: There is a very good reason for confidentiality.

Ms Ward: That is correct.

Q108 Dr Naysmith: If there is not confidentiality, it can put people off going to clinics. Are you suggesting there is more than that or is it just the normal confidentiality?

Ms Ward: It varies. You can have hostilities against you because of your role in your trust. As a trust employee, of course, we have signed a confidentiality list. We are part of the same trust; we are all working in the same organisation. We are not asking for confidential information; all we are wanting is to have some mechanism where our stage one questioning of the patient could be identified. If their HIV test comes positive, then perhaps they are referred for a further interview to establish their residency. Once that is established, of course, it will be on the advice of the doctor whether they were a resident or not, chargeable or not. But, yes, it is difficult to get in there generally.

Q109 Chairman: Would you give us some examples of the practical problems you and your colleagues have faced with the HIV charging arrangements. When we had this consultation process, were these examples and concerns put to government?

Ms Ward: I think a lot of work is being done in small pockets with the large trusts in the larger areas. Trusts have various problems according to their demographic location, so it depends on where the hospital is sited as to what your clientele would be. But I have a trust member's information here, and she has various people attending from asylum seekers, students, visas. It is difficult to get the message across. She is now doing a presentation to her trust board to show them the size of the problem. But, as you rightly say, the treatment for AIDS could go on to be quite costly as an in-patient or a drug regime treatment is very expensive. It can cost

the trust quite a burden, if we are not identifying these patients and only treating the patients that are rightly resident here.

Q110 Dr Taylor: I think we have covered the areas I was going to ask about but I have another question, if I may. Could I explore a bit more with you, Peter, your job. You describe yourself as Commissioning Manager for West Sussex.

Mr Nieuwets: No, it is five PCTs.

Q111 Dr Taylor: That is five PCTs which work together.

Mr Nieuwets: No, they do not work together actually.

Q112 Dr Taylor: Then Commissioning Lead for Kent, Surrey and Sussex. Is that a strategic health authority?

Mr Nieuwets: It is a strategic health authority with, I think, 15 PCTs in it.

Q113 Dr Taylor: Then Chair of the English HIV and Sexual Health Commissioning Group.

Mr Nieuwets: Yes.

Q114 Dr Taylor: What does that consist of?

Mr Nieuwets: That is a group of people where are a number of stakeholders, the Department of Health and all commissioners for sexual health and HIV are invited to attend. We are restructuring at the moment to become a more independent group. It is also one of the very few fora in the country where commissioners can sit together and discuss the problems they have, problems around: Where has the funding gone? Where has the prevention money gone? How do you deal with the department? How do you deal with your strategic health authority? Because the strategic health authority has been given a role but most strategic health authorities are struggling with their role and lots of PCTs have no clue who within the strategic health authority is struggling with their role. The communications are not always that clear.

Q115 Dr Taylor: But this is an extremely important body.

Mr Nieuwets: Yes.

Q116 Dr Taylor: Are your decisions acted on? Are your messages taken up?

Mr Nieuwets: We are listened to.

Q117 Dr Taylor: Right. How can we help you to be not only listened to but, in the words of Hazel Blears, "valued and acted upon" your views?

Mr Nieuwets: We are working on ways to make our voice stronger and also to have a much stronger role. We are working on that with some of our stakeholders.

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Q118 Dr Taylor: But bodies exist to improve things.
Mr Nieuwets: Yes.

Q119 Dr Taylor: At least that is a start.
Mr Nieuwets: Recently we had a meeting and one of the people was not allowed to come because her PCT had a deficit and people were not allowed to travel outside the PCT area. It is one of the problems at the moment that many PCTs are struggling financially—and struggling financially across the board. As I have said before, sexual health does not have a high priority. HIV has some priority because it is a big bill for London ending on somebody's desk, so they have to secure money for that, but in general very little money is secured.

Q120 Chairman: Are there any other comments? We probably ought to wish Mr Nieuwets all the best with his future career after that! Could I thank you all for a very interesting session. I am sorry, Mr Evans, did you want a final word.

Dr Evans: Just one thing on the data. We saw this great rise between 1999 and 2003, and the provisional 2004 data does indicate we have not been going up 20% here but have levelled off. This is new diagnosis for HIV. There is some evidence that we are eating into the undiagnosed fraction and we are beginning to level off. At high levels—we are probably going to end up with 78,000 new diagnoses last year—but we are no longer in the 20% rise a year. That may have political consequences of we are no longer on the steep trajectory of an increasing issue.

Q121 Chairman: Have those figures been made available to the Committee?

Dr Evans: They have not as yet. We will make sure they are. We are about to publish those figures and we will make them available to the Committee.

Chairman: I am very grateful to you. Thank you all very much for a very useful session.

Thursday 10 February 2005

Members present

Mr David Hinchliffe, in the Chair

John Austin
Mr Keith Bradley

Dr Doug Naysmith
Dr Richard Taylor

Witness: Ms Julie Bramman, Head of Curriculum, Specialism and Collaboration, Department for Education and Skills, examined.

Q122 Chairman: Good morning, everybody. Can I explain that this morning's session is partly reviewing our Sexual Health Report and the progress made since we produced that report 18 months ago and looking at certain issues around HIV and AIDS. For the first part of the morning we have got a witness, Julie Bramman, from the Department for Education and Skills. We are very pleased that you have been able to come before us. Would you briefly introduce yourself to the Committee, Ms Bramman.

Ms Bramman: I am Julie Bramman. I am Head of Curriculum, Specialism and Collaboration at the DfES.

Q123 Chairman: I think you are aware that when we undertook our inquiry, we did take evidence from your Department and one of the areas of concern to us in sexual health was a feeling that part of the problem that we have in what we described as a 'crisis' at the time and what our witnesses in the last couple of sessions have said has got worse was partly down to the lack of preparedness among children and young people, and I think there was a feeling that our sex education is too little and it is too late. We certainly got evidence that where there was good-quality education, it appeared to delay the onset of sexual activity, so, despite what people think, that if they are explicit and talk to children at a younger age, they will "do it", the evidence actually was completely the opposite. As you are aware, we made some recommendations about including sex education in the core curriculum. Obviously I am aware that since we made those recommendations the Ofsted report has come out a little while ago which was quite critical. What do you feel can be done arising from the Ofsted report and arising from our thoughts about this issue, bearing in mind that we certainly see that what is happening appears to be even worse now in terms of STIs and STDs, the overall problems of sexual health, than it was when we looked at the situation 18 months ago?

Ms Bramman: I think the key points that come out of the Ofsted report are around teacher confidence and teacher competence in actually teaching sex and relationship education within PSHE. Where they were looking at specialist teachers, they found really good practice there both across the primary and the secondary sectors, and I think that our priorities have been to increase the level of competence we have and the number of specialist teachers we have who have PSHE as a specialism. Within that, we are running a continuing professional development

accreditation process and we have 2,000 teachers on that this year and we have places for a further 2,000 next year. We think that that is really what we need to be doing, making it part of a specialist process, which it has not traditionally been, with geography and history, as it is quite clearly a specialist subject, rather than leaving it to form tutors which seems to be the majority of practice at the moment.

Q124 Chairman: Are you weathered to the concept that it has to be teachers because one of the things that we generally wrestled with was whether there might be more appropriate people from outside to come into schools? I have talked to health professionals in my own area where use is made of them by the schools and I think some of them feel that they may be better able to do the job, which is not in many areas being done, than teaching staff. The picture we got from many of our young witnesses was that the staff were ill-prepared and embarrassed, and the pupils picked that up, and that often the feeling was that perhaps somebody from outside would be more appropriate. I have seen in the past in young offender institutions health visitors and midwives go in and talk to some of the lads in, I think, a very helpful way from an outside perspective, not somebody based within that institution, and I felt that that offered a model which we might be looking at.

Ms Bramman: Most certainly. We are also running an accreditation programme for community nurses now and have in the first year over 300 community nurses on the scheme to enable them to teach in schools or present in front of a class, as they are not to use the word "teach", as well as encouraging co-location of health services into schools for our Extended Schools programme, including the full service of extended schools, of which there are over 100 at the moment. We have set out in our strategy in one of the five aims that the Department has for young children and young adults, that of being healthy. I think we are forging much closer links with the Department of Health to achieve that objective and clearly it is very much in our minds as a way forward. The general workforce reforms that we are looking at, as a Department, encourage lots of para-professionals into schools so that it is not so much the domain of teachers.

Q125 Chairman: In terms of the relationship between education and health, can you just briefly describe whether the steps that are being taken which you have just mentioned are primarily being

driven at national and ministerial level or is it that you are encouraging these relationships at a local level with schools and PCTs or is it both?

Ms Bramman: I think it is both and I think, particularly through the Healthy Schools initiative that we have where it is regionally based and we have set out some very clear strands and objectives that we have within the Healthy Schools agenda, that is encouraging local networking. It is one of the things that the Ofsted report picked up on, that very good connections were being made locally between the health services and schools and that was a good thing on both sides.

Q126 Chairman: So at a ministerial level, and obviously, as you appreciate, we have got the Minister coming here, who do you relate to in the Department of Health? Where is the connection? It is a big department, so who are the people who are driving it forward from your point of view?

Ms Bramman: It is very wide-ranging. The two departments now have a protocol on how they will work together and what their joint priorities are. With regard to the curriculum in schools, we are setting up a joint Healthy Schools team which will sit within the Department of Health building, but will have DfES officials as part of it as well, so it really is very much joint working and we work closely with our Young People health colleagues on a wide range of issues, not just sexual health obviously, but drugs and many other aspects that come within the PSHE and other parts of the curriculum.

Q127 Chairman: So there is a good working relationship between the departments in moving this forward?

Ms Bramman: Yes, there is.

Q128 Chairman: In terms of structures that you work to, the Public Health White Paper proposed certain changes at Cabinet level. I am not going to ask you to comment on those, but can you anticipate all the changes that might take place structurally that would be helpful to that working relationship moving forward, as we are talking about this morning?

Ms Bramman: Structurally, in the Department we are looking at how we can better co-ordinate across our own structure on health issues because clearly it covers from early years, from SureStart right through to Lifelong Learning and we are very aware that at the moment we have, for want of a better word, lots of silos that could be far better co-ordinated in our interface with the Department of Health, but officials have met recently to discuss how we might restructure ourselves so that we can interface better and reporting through to individual directors general.

Q129 Dr Taylor: You mentioned that you are getting some accredited community nurses and you are getting accredited teachers. Is there any evidence, any pointer, as to which are more effective?

Ms Bramman: Not to my knowledge.

Q130 Dr Taylor: Any comments from students who have had both types of teaching?

Ms Bramman: The only feedback I would know about is around the confidentiality with community nurses. It is clearly easier in some respects for young people to talk to someone they are not in contact with within the school full-time and, therefore, I think it is a different relationship.

Q131 Dr Taylor: With the 2,000 teachers in training for accreditation, are these from a wide range of other subjects or are they people who are going to be absolute specialists in teaching PSHE?

Ms Bramman: It is both. Some are taking it as their main specialism, so they will be PSHE teachers and will teach across the school age. Others are taking it as a second specialism.

Q132 Dr Taylor: Would the pure specialists go round different schools or would they just be attached to one school?

Ms Bramman: They will be attached to one school, but we encourage very much collaboration between schools through many of our other programmes, such as the Specialist Schools and Leadership Incentive Grant and Excellence In Cities, very much on the theme of collaboration.

Q133 Dr Taylor: So if you had got a specialist, you would make the most of that person?

Ms Bramman: We would expect the most to be made of that person, yes.

Q134 Dr Taylor: The paper we had from Ofsted dated January 2005 actually said that some schools do not provide PSHE in any form and it goes on to say that the position of these schools is untenable. What are you doing about that?

Ms Bramman: That would be picked up in the individual school's report. This was a subject report of course, but when Ofsted visits for a whole school inspection, it will be picked up there and become part of the conversation that we had under the new relationship with schools and we will clearly have to have very serious conversations with the school about ensuring it has adequate PSHE just as in the same way as if it did not have adequate mathematics or English.

Q135 Dr Taylor: So that would be enforced pretty quickly?

Ms Bramman: It would be enforced pretty quickly. The report was unhelpfully not specific.

Q136 Chairman: I think you have also accepted in what you have said before that having a form tutor doing the PSHE role as well as everything else he or she has got to do is not acceptable.

Ms Bramman: What I said is that it is probably not best practice. I had not said that it is not acceptable.

10 February 2005 Ms Julie Bramman

Q137 Dr Taylor: And you will aim to replace that by these accredited teachers, so how far will 2,000 accredited teachers go across the country?

Ms Bramman: There are around 3,000 secondary schools, and many more primaries of course.

Dr Taylor: Moving on, we talked to a number of young people during our inquiry and there was the definite feeling that it is okay to talk about sex and sexual health, but you have got to have the round, full picture and you have got to go into relationships because one without the other is certainly lacking something. Is there any evidence to say that this is actually being covered by PSHE or SRE—I get muddled up with the initials—that it is the relationship that leads to the sexual activity which is so incredibly important, so is that being taken up?

Q138 Chairman: Can I just say that we actually suggested that SRE should become RSE for reasons that you might understand. Maybe it is indicative of the age of the Committee, I do not know, and probably we are a bit old-fashioned, but we put that forward as a serious suggestion.

Ms Bramman: Well, it is sex and relationship education and we do underline the relationship aspects within all of the guidance that we produce. That is why it is so important to teach it within PSHE rather than as something that is separate or just the science aspects of sex.

Q139 Dr Taylor: The fact that young people raised it with us made us wonder how effective that amalgamation was, but obviously you are aware of it.

Ms Bramman: We are aware of it and it is something, as I said, that we cover in all resources and the guidance that we produce.

Q140 John Austin: There is a lot of difference in the figures as to what age sex education begins, but certainly I think there is general agreement that relationships education starts at the very earliest stage. It is relationships education which is the most important and when children get to a certain age, then the sexual side of that comes in, does it not?

Ms Bramman: I think that is very right and the evidence that we had back from the QCA monitoring reports on the subject tells us quite clearly that primary schools rank PHSE as their fifth most important subject behind English, maths, science and ICT, so I think that that gives some indication of how important primary schools generally understand about developing the whole child and, within that, including understanding relationships. We are currently, through QCA, consulting on Key Stage 1 and Key Stage 2 end-of-stage assessments in PSHE so that we can guide teachers about what a child of that age typically should understand and know about relationships as well as the other aspects of the subject.

Q141 Mr Bradley: Is it, therefore, the intention to make such teaching a compulsory part of the curriculum?

Ms Bramman: We are not intending to make PSHE statutory. We do not think that that is necessary or possibly even desirable in terms of continuing to allow schools flexibility on how to deliver PSHE and, within that, SRE in consultation with parents and the communities that they serve, but there is a clear expectation that PSHE should be delivered, so I do not think there is an intention to change the statutory basis of it, but clearly we expect it to be delivered.

Q142 Mr Bradley: Yes, but expectation and having it as part of the curriculum, there could be huge gaps, therefore, in the provision, could there not?

Ms Bramman: That is what Ofsted inspections will tell us. What we are coming up with is a non-statutory framework for PSHE covering guidance and best practice, as I have said, around the Key Stage end-of-stage assessments throughout all of the Key Stages to give further guidance on how teachers should be delivering and monitoring and assessing the progress of their pupils.

Q143 Dr Taylor: Ofsted have said that it is untenable not to have PSHE and you tended to agree with me when I brought that up, but then you said that you are not going to make it obligatory. It has got to be obligatory, has it not?

Ms Bramman: At the moment PSHE is not part of the statutory national curriculum, and sex and relationship education is statutory, but what is not statutory is the content.

Q144 Dr Taylor: So SRE is?

Ms Bramman: Yes, it is statutory. It has a statutory basis with—

Q145 Dr Taylor: So is SRE not the most important bit of PSHE?

Ms Bramman: I think that might depend on which committee you are sitting in front of!

Q146 Dr Taylor: Should they not both cover the same thing?

Ms Bramman: PSHE is wider than sex and relationship education. It will also cover things like drugs education, for instance, and wider health issues and wider social issues that relate to an individual.

Dr Taylor: It seems to be absolutely obvious that SRE and drugs education ought to be obligatory, the whole lot, ought it not? That is certainly my view.

Q147 Chairman: Your title as head of various things included collaboration.

Ms Bramman: That is right.

Q148 Chairman: I am not sure whether Richard touched on this because I was talking to a colleague when he asked his first question, but one of the things that really impressed us in the sexual health inquiry was the TicTac project which no doubt you are familiar with in Paignton and there are other similar models in different parts of the country.

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Ms Bramman: Yes.

Q149 Chairman: I wonder whether you felt able to encourage that sort of approach through your responsibilities at a local level because it struck me that in my own area that would really be so beneficial. I think all of us who went there really felt it was a model that ought to be looked at and it was doing a really first-class job, not just in terms of sexual health, but wider support and advice to youngsters going through adolescence.

Ms Bramman: We are encouraging that kind of project to be co-located with schools where schools wish to do it. Clearly it is a matter for individual schools rather than the Department whether or not to go down that track, but it is something that we encourage. We have, through the Teenage Pregnancy Unit, produced guidance and materials

about this which include case studies, like the TicTac project and the benefits of it, and our understanding is that that kind of co-location is continuing to blossom really.

Q150 Chairman: Can you see that as a logical kind of extension of the collaboration that you described at a local level?

Ms Bramman: Absolutely and a logical extension of the Extended Schools policy where we are looking for schools to become the heart of their local community and co-locating health and social services as well as other activities for the pupils and parents to do.

Chairman: Can I thank you, Ms Bramman, for this brief session; we are most grateful to you. You are very welcome to stay for the rest of the session if you want. Thank you very much.

Memorandum by the Department of Health (SH 1)

SUMMARY

1. This memorandum sets out evidence from the Department of Health on the consequences of:
 - the new and proposed changes in charges for overseas patients with regard to access to HIV/AIDS services.
 - an update on progress in implementing the recommendations of the Committee's inquiry into Sexual Health (the Committee's Third Report of Session 2002–03).

CHARGES TO OVERSEAS PATIENTS FOR HIV/AIDS SERVICES

Background

2. The concept of charging patients who do not live in the United Kingdom for NHS treatment they may need, while staying here temporarily, is not new. Section 121 of the National Health Service Act 1977 gives the Secretary of State powers to make Regulations concerning charging anyone who is not ordinarily resident in the UK for services provided under the NHS Act 1977. "Ordinarily resident" in this context is a common law concept interpreted by the House of Lords in 1982 as someone who is living lawfully in the United Kingdom voluntarily and for settled purposes as part of the regular order of their life for the time being, with an identifiable purpose for their residence here which has a sufficient degree of continuity to be properly described as settled. In this context, neither nationality nor the past or present payment of UK taxes or National Insurance contributions have any relevance.

3. The section 121 powers have so far been used to make regulations only in relation to NHS hospital treatment. The National Health Service (Charges to Overseas Visitors) Regulations 1989, as amended ("the 1989 Regulations"), place an obligation on providers of NHS hospital services to establish whether each patient is an overseas visitor and if so to make and recover a charge for any hospital treatment provided, unless the patient is covered by one of the specified exemptions from charges. The 1989 Regulations define an overseas visitor as "a person not ordinarily resident in the United Kingdom" (Reg. 1(2)).

4. It is important to understand that S121 of the NHS Act 1977, and the 1989 Regulations made under it, relate to the power to charge for services that are provided under the NHS Act 1977. They are not the powers which determine whether the services are to be provided. Furthermore, overseas visitor patients who are deemed chargeable under the provisions of the 1989 Regulations remain NHS patients subject to the same clinical prioritising as any other NHS patients. The fact that they are required to pay for the treatment received does not allow them, for example, to bypass waiting times or be treated in any way preferentially.

NHS Hospital Treatment

5. The conditions relating to exemptions from charges for overseas visitors contained within the 1989 Regulations fall into three broad categories:

- (i) eligibility for the full range of free NHS hospital treatment because specified conditions are fulfilled;

- (ii) eligibility for treatment the need for which arises during a temporary visit to the UK, or in relation to the exceptional humanitarian grounds exemption, because certain specified conditions are fulfilled; and,
- (iii) eligibility for free NHS hospital treatment because there is a need for certain specified services which are exempt from charges.

6. The first category covers a considerable range of circumstances including, for example, people here to take up employment with a UK-based employer, overseas students here to study a course of at least six months' duration, and those who have been living lawfully in the UK for at least 12 months immediately preceding the treatment being provided. All the exemption conditions in this category also apply to the exempt person's spouse and dependent children if they are living in the UK with the exempt person on a permanent basis.

7. The second category includes people from other European Economic Area member states or people from other non-EEA countries with which the UK has bilateral health care agreements, as set out in Schedule 2 of the 1989 Regulations, who fall ill or are injured whilst on a temporary visit to the UK. Some of the conditions in this category can be extended to the spouse and dependent children of the exempt person in the same way as for the first category, others cannot. This category also includes the specific exemption for exceptional humanitarian reasons.

8. The third category applies to specific services which are always free to all. This includes, among other things, any treatment provided solely in the Accident and Emergency Department of a hospital, compulsory mental health treatment, and treatment for certain specified diseases set out in Schedule 1 of the 1989 Regulations. Tuberculosis is one of the diseases in the Schedule. This category also includes the initial diagnostic testing for HIV and associated counselling, but not subsequent treatment if the test proves positive. Thus an overseas visitor who does not meet any of the other exemption conditions in the 1989 Regulations should be required to pay for any HIV treatment required beyond the initial testing and counselling. It is important to appreciate that this is not a new requirement, but has been in place since the 1989 Regulations first came into force.

9. On 1 April 2004 the National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2004 ("the 2004 amendment Regulations") came into force. The amendments these made to the 1989 Regulations included provisions to close loopholes that had been identified during a review of the hospital charging regime. A full public consultation on the proposed changes took place between 29 July and 31 October 2003. The 2004 amendment Regulations made no changes to the existing rules on charging overseas visitors for HIV treatment described in the previous paragraph.

10. One of the amendments to the 2004 Regulations was to tighten the 12 months residency exemption, which covers those overseas visitors who do not meet any of the other exemption conditions, providing exemption from charges once they have been living in the UK for 12 months. This exemption now specifies that in order to qualify for the exemption the person must have been living in the UK legally for that period. This means that illegal immigrants, failed asylum seekers, visa overstayers and others living here without proper authority cannot now take advantage of free NHS hospital treatment. In order to do so a person must be able to show that they had been living here legally.

11. During the consultation on the proposed changes, a number of respondents pointed out that whilst tightening the 12 months' residency exemption was the right way to go, provision needed to be made for those who were already undergoing a course of free treatment because they were exempt from charges at the time the treatment began but whose status subsequently changed. (This might include, for example, asylum seekers, who are exempt from charges as long as their application, and any subsequent appeals, are being considered. Only once they have finally been refused do they become chargeable). We accepted the validity of the argument that requiring such patients to begin paying for the remainder of their treatment could result in them feeling unable to complete it. Amendments were, therefore, included in the 2004 amendment Regulations so that where a patient has begun a course of treatment free of charge, that course of treatment remains free until completed, even if their eligibility status changes. Treatment for a different condition, or starting a new course of treatment for the same condition, becomes chargeable when the status of such a patient changes.

12. It is also worth pointing out that guidance on implementation of the revised charging regime, issued at the time the 2004 amendment Regulations came into force, makes clear that where treatment is deemed by a clinician to be immediately necessary, either to save life or to prevent a condition from becoming life-threatening, then that treatment must be given without delay, irrespective of whether the patient is, or may be, chargeable. If it is subsequently established that the patient is a chargeable overseas visitor, then they should be advised of this as soon as is practically possible, and appropriate recovery action taken. The guidance is also explicit that, because of the potential risks to both mother and baby, hospital maternity services should always be considered as immediately necessary treatment. This could include HIV treatment where it was considered clinically necessary.

Primary Medical Services

13. The current legislation on the eligibility of overseas visitors for primary medical services (ie GP services) allows GP practices discretion on whether to accept any application to join a practice's NHS list of patients. A person may be accepted onto the list either as a permanent registered patient or as a temporary resident (ie, where a person is in an area for more than 24 hours but less than 3 months). Existing guidance HSC 1999/018 "Overseas Visitors' Eligibility to Receive Free Primary Care" encourages practices to register overseas visitors as temporary residents, if at all.

14. Where a practice decides not to accept an application, the person can be offered treatment on a private, paying basis. As with hospital services, however, where a healthcare professional believes that treatment is immediately necessary, it must be provided without delay, even if the patient is not registered with the GP practice. It must also be provided free of charge.

15. The Department of Health has recently conducted a public consultation on proposals:

- (i) to strengthen and clarify the rules on the eligibility of overseas visitors to free NHS primary medical services so that they better match, as far as practicable, those on the eligibility of overseas visitors to receive free NHS secondary care as set out in the 1989 Regulations; and
- (ii) for those overseas visitors who are not eligible for free NHS primary medical services to be offered treatment by practices for which they would be charged.

16. Two charging options were considered:

- (i) using existing legislative powers—section 121 of the NHS Act 1977—to introduce NHS charges; or
- (ii) treating overseas visitors who are not eligible for free NHS care as private patients—this would be a private contractual arrangement between the practice and the patient.

17. Ministers are currently considering the responses to the consultation with a view to deciding the best way forward.

Overseas Visitors and Access to HIV/AIDS Treatment

18. Access to HIV/AIDS treatment remains as it has been since 1989. It is for individual practices to decide whether to accept any person, whether or not they are an overseas visitor, onto the practice's NHS list. For hospital services, under the 1989 Regulations anyone deemed by the NHS body providing the treatment to be ordinarily resident, will be automatically entitled to receive any and all hospital treatment free of charge. Similarly, the initial diagnostic testing for HIV, and any associated counselling, is free to all. If, however, the patient is established as an overseas visitor under the provisions of the 1989 Regulations then any subsequent hospital treatment will be chargeable unless they meet one of the exemption criteria.

19. An overseas visitor who does not meet any of the exemption criteria but is nevertheless living here lawfully, would be liable to be charged for their hospital treatment until such time as they accrue 12 months' lawful residence. After that they would be eligible to receive all future hospital treatment free of charge as long as the patient's residence here remains lawful.

20. If, however, a clinician is satisfied that the hospital treatment is immediately necessary, then it will be given without delay, irrespective of whether the patient is chargeable. Any payment issues will be dealt with as soon as practicable.

21. Where an overseas visitor patient has started a course of HIV treatment free of charge because they were found to be exempt from charges at that time, that course of treatment will remain free of charge, even if the patient's immigration status changes in the meantime so that they are no longer eligible for free treatment.

PROGRESS ON THE RECOMMENDATIONS OF THE COMMITTEE'S INQUIRY INTO SEXUAL HEALTH

22. The Health Select Committee published the report of its inquiry into sexual health in June 2003, with 51 recommendations (references to recommendations are shown in footnotes, where applicable, below). The Government's response to this report was published in September 2003 (command paper CM 5959) setting out how the recommendations were being addressed, including a proposed additional investment of £11.4 million. Since then, the Department of Health (DH) has made considerable progress in continuing to implement the National Strategy for Sexual Health and HIV, and additional significant measures to modernise sexual health services in England have been set out more recently in the Government's Public Health White Paper: "Choosing Health, Making Healthy Choices Easier", published on 16 November 2004.

The priority for sexual health¹

23. The Committee recommended that the Government take urgent steps to ensure that sexual health was prioritised and resourced. The Government has recognised that, given the scale of the problem, more action is now needed and has, therefore, signalled a major step change for sexual health to boost delivery. The White Paper, sets out a number of commitments, backed by £300 million new funding, which will improve access to services, raise awareness of risks and boost prevention efforts.

The White Paper on Public Health

24. The White Paper consultation demonstrated that people wanted to take responsibility for their own health and that generally people did not want interventions from the Government “telling them what to do”. People do, however, want the Government to support them in making healthier, informed choices in life. This principle is at the heart of the key commitments on sexual health set out in the White Paper. These include:

- (i) A new £50m sexual health campaign over 3 years, targeting young men and women, aimed at getting the messages through loud and clear about prevention, the use of condoms and the serious implications of Sexually Transmitted Infections (STIs) such as Chlamydia and HIV.
- (ii) Services, in future, to be delivered through a flexible, multidisciplinary workforce, in a range of settings. This includes STI testing in the community, targeted at those most at risk.
- (iii) Modernised Genito Urinary Medicine (GUM) service provision, including new capital and revenue funding (£130 million over 3 years), coupled with a goal that by 2008, all patients seeking appointments at GUM clinics to be offered one within 48 hours, and underpinned in the Local Delivery Plans being prepared by Primary Care Trusts (PCTs) from April 2005. A comprehensive service review on GUM is already underway to support GUM modernisation.
- (iv) A new thrust to turn around STI rates, supported in Local Delivery Plans through measuring the rates of Gonorrhoea as a proxy indicator for overall STI rates.
- (v) Acceleration of the National Chlamydia Screening Programme, to cover the whole of England by March 2007, plus new pilots, in partnership with the private sector, to explore chlamydia screening in pharmacies, backed up by a further £80 million and underpinned in future Local Delivery Plans.
- (vi) An audit of contraceptive services in early 2005, followed by investment of £40 million to meet gaps in services and strengthen the delivery of the full range of contraceptive services to better meet patient needs and choice
- (vii) DH will pilot health services dedicated to young people and designed around their needs, including primary care and specialist services in locations which are convenient for younger people.
- (viii) Ensure a broader reach of information about sexual health for young people, with increased support for parents in talking about sex and relationships.
- (ix) Renewed support for Teenage Pregnancy Partnership Boards to strengthen delivery of their strategy in neighbourhoods with high teenage conception rates.

25. Even before publication of the White Paper, DH had already taken a number of actions to ensure the NHS gave a higher priority for sexual health in local services. The new planning framework for the NHS, “*National Standards, Local Action: Health and Social Care Standards and Planning Framework*”, published in July this year, includes the first ever national Public Service Agreement (PSA) target for sexual health, alongside the Government’s PSA on teenage pregnancy so that the Government’s PSA goals in this area are now “to reduce the under-18 conception rate by 50% by 2010 as part of a broader strategy to improve sexual health”

26. This planning framework states that the NHS, together with Local Authorities, will need to take the sexual health strategy into account when developing their policies that will contribute to the delivery of the national target. It also highlights the sexual health areas which will be particularly relevant for PCTs and their local authority partners to cover in their plans, including STI rates, access times and contraceptive and sexual health service provision.

Links with the Field

27. Every PCT now has an appointed sexual health lead. DH hosts an annual conference to discuss strategic development and support them in their role. DH officials also meet regularly with a network of sexual health co-ordinators, at Strategic Health Authority (SHA) level, who play a central role in working with the PCT sexual health leads to take forward the strategy and service modernisation across the country. And DH is looking at ways of strengthening regional coordination to help further improve local delivery.

¹ Recommendations 1, 6, 13, 47, 48, 49, 50, 51.

28. At national level, the Independent Advisory Group on Sexual Health and HIV, established in 2003, has developed into a valuable source of expert, independent advice and means of communicating the importance of sexual health. They published their first annual report in October 2004, and representatives of the group have begun a programme of visits to local services around the country, to spread good practice and feed back issues of concern to the centre.

Investment and resources²

Funding Announced with Government's Response

29. The additional funding announced with the Government's response to the Health Select Committee in October 2003 is already bearing fruit. For example, £5 million was added to the budget to introduce the preferred NAATs test for chlamydia to all parts of the country, providing more reliable results using a more convenient and less invasive urine test.

GUM Capital Funding

30. The Secretary of State for Health announced further funding of £15 million to improve GUM in November 2003, to boost the modernisation of premises and facilities within clinics. Following a bidding process, this funding has been allocated to those areas which can make best use of the money, including those who are working towards fully integrated sexual health services. This has been strengthened by further investment in capital, as referred to above, through the White Paper.

Modernisation and improvement of sexual health services³

31. We have acted on the Committee's recommendation for a maximum waiting time of 48 hours as one of the White Paper's key commitments, backed by major investment and inclusion in Local Delivery Plans. The Health Protection Agency's (HPA) recently published data on the current state of play on waiting times, which show that SHAs and PCTs have much to do to meet the goal of 100% being offered an appointment within 48 hours by 2008.

32. Work has also progressed in establishing 10 GUM development pilot sites in areas with little or no GUM services, or services where there are very limited staff and resources to cope with demand. The intention is that we will disseminate findings and learning from these 10 sites to other areas of the country.

33. In April 2004, the Society of Sexual Health Advisers published "*The Manual for Sexual Health Advisers*", with funding from the Department of Health. This document provides clear, practical guidance on issues such as partner notification, counselling, working in community settings and the legal and professional framework.

34. The DH has commissioned the Medical Foundation for AIDS and Sexual Health (MedFASH) to undertake a national review of GUM services which will be led by Prof. Mike Adler. The review, which started in Summer 2004, will undertake an assessment of all GUM services, to identify and spread good practice and help boost modernisation. The review will include workforce issues, such as difficulties arising for single-handed consultants, and training.

35. The National Training Working Group is working in partnership with the Sheffield Centre for Sexual Health and HIV to look at clinical and non-clinical training, across a range of health professions, and taking forward the implementation of the sexual health training plan.

IT, Data and Patient Involvement

36. The DH is also developing a Common Data Set for Sexual Health to support the implementation and monitoring of the National Strategy for Sexual Health and HIV. This aims to provide a single, standard structure for collecting data on sexual health and will apply to all settings providing sexual health services.

37. A draft specification of the data set already exists and further detailed work is being undertaken to complete the specification which must then be formally agreed by all stakeholders and finally approved by the NHS Information Authority.

38. As well as the move towards patient focused services outlined in the White Paper, the sexual health standards, currently under development (see below), include a standard to empower people who use services to have confidence, personal control and choice in managing their sexual health care and in making the best use of services. In addition, the Independent Advisory Group on Sexual Health and HIV, is helping to ensure user involvement in national policy making, through the inclusion of service user representatives among its membership. These include HIV service users, and the group is in the process of recruiting a young person's representative to join the group.

² Recommendations 7 to 12.

³ Recommendations 2, 3, 4, 5, 14.

Recommended Standards

39. Recommended standards for the treatment and care of people with HIV were published in November 2003 in partnership between DH, MedFASH, the British HIV Association and the National Association of NHS Providers of AIDS Care and Treatment. MedFASH were then commissioned to produce similar standards for sexual health services, which are now being finalised, with publication planned for Spring 2005. These standards will help to drive up the quality of services and provide a clear benchmark of good practice. They cover a broad range of issues including the development of sexual health networks, workforce development, promoting good sexual health, empowering service users and improving access.

Testing for chlamydia and other STIs⁴

40. Good progress has been made on the roll-out of the National Chlamydia Screening Programme, now significantly boosted by the White Paper to accelerate the completion of the roll-out to March 2007. The White Paper also sets out a commitment to introduce and evaluate the effectiveness of screening in pharmacies as part of the national programme. A pilot will be carried out in pharmacies, in partnership with the independent sector, to test the effectiveness and acceptability of screening in this setting.

41. The Government is already responding to the concerns raised about switching as quickly as possible to the superior Nucleic Acid Amplification Test (NAATs), and £7 million pump-priming money was invested in 2003–04 to ensure that all major laboratories in each region of England use the most effective technology. Funding has now been allocated to ensure that there is access to NAATs in every SHA in England. The DH has been working closely with the Purchasing And Supply Agency. NAATs technology should be in place across England by Spring 2005.

42. The first annual report of the programme for 2003–04 has now been published. Screening in the first year of the programme, found 1 in 10 sexually active young women and 1 in 8 sexually active young men were infected with Chlamydia. This data will help us to understand the distribution and determinants of chlamydia infection, as well as providing lessons which will enhance the subsequent phases of the roll-out.

43. Joint working between the DH and the Defence Science and Technology Laboratory on near patient testing technology is progressing. This new technology will give a chlamydia result within one hour, and will be piloted in the clinical setting in the first quarter of 2005.

HIV and AIDS⁵

44. The latest data on HIV was published by the Health Protection Action in November. This shows that prevalence of HIV infection in the UK (diagnosed and undiagnosed) in adults increased by 7% over 12 months. This compares to an increase of 20% reported in HPA's annual report for 2002. For the first time, heterosexual men and women were the greatest number of patients seen for HIV care.

45. However the reduction in the proportion of HIV remaining undiagnosed from almost a third (31%) in 2002 to just over a quarter (27%) for 2003 shows some positive progress. This is still too high and we remain committed to reducing this further for example by targeted HIV campaigns encouraging HIV testing for African communities. In GUM clinic attenders, uptake of voluntary confidential testing for HIV among men who have sex with men increased from 47% in 1997 to 64% in 2003. In heterosexuals, voluntary confidential testing for HIV increased from 27% in 1998 to at least 55% in 2003.

46. Diagnoses rates of HIV in pregnant women continue to increase since the introduction in 1999 of the universal offer and recommendation of an HIV test to pregnant women in England as a routine part of antenatal care. In England in 2003, it is estimated that at least 92% of HIV-infected women were diagnosed before delivery. Antenatal diagnosis allows pregnant women to take advantage of interventions to prevent mother-to-baby transmission, such as antiretroviral drug therapy, elective caesarian delivery and avoidance of breast feeding. As a result the proportion of children exposed to maternal HIV infection is decreasing, eg in London in 2003, 5% of children exposed to maternal HIV infection would have been infected, compared to 16% in 1998.

47. Asylum seekers are offered health assessments and screening for tuberculosis (TB) at Home Office Induction centres to identify their immediate health needs and to protect public health. Testing for HIV is offered on request or where medical history indicates they have been at risk.

48. Following the Committee's recommendations, the DH is funding the Terrence Higgins Trust, working with GUM professionals, to undertake a 12 month pilot project aimed at assessing the feasibility and acceptability of HIV testing and syphilis screening for the groups most at risk of HIV (gay men and black Africans) in non-clinical settings, such as clubs, bars and voluntary organisation's premises. Sigma Research are evaluating the pilot and if successful, we will look to disseminate the findings and learning more widely.

⁴ Recommendations 15, 16 and 17.

¹ Recommendations 1, 6, 13, 47, 48, 49, 50, 51.

49. The recommended standards for NHS HIV services offer guidance on managed service networks. Each standard offers an evidence-based rationale; key interventions; implications for service planning; guidance on practice; and suggested audit indicators. The recommended standards will serve as a tool for planning and auditing service development, a framework for commissioning and a resource for partnership between service users and providers.

50. The DH is funding the Children's HIV Association and Royal College of Paediatrics and Child Health to map and develop networks for paediatric HIV services outside London. This is progressing well and will lead to the publication of good practice guidance on the development of networks for the provision of children's HIV services nationwide.

51. The DH has reviewed the formula for the AIDS Support Grant (£16.5 million) paid to local authorities. In line with changing social care needs this now prioritises women and children living with HIV. We have also funded the National AIDS Trust to produce a guide on the needs of people living with HIV which was distributed in October.

Commissioning of services⁶

52. The strengthening of performance monitoring arrangements outlined above will lead to improvements in commissioning and enable closer monitoring of consortia development and regional commissioning by SHAs.

Primary care and access to services⁷

53. Since April 2004, we have seen the introduction of 4 primary medical services contracting routes new General Medical Services (nGMS), Personal Medical Services (PMS), Alternative Provider Medical Services (APMS) and Primary Care Trust Medical Services (PCTMS), in addition to the development of Specialist PMS and Practice-led Commissioning. They provide flexible frameworks for multi-professional, interagency statutory, voluntary and commercial organisations to be creative in delivering a sexual health agenda to meet local needs and diversity of population. Implementation of levels 1 and 2 sexual health services through core services provided in general practice, whichever contracting route is utilised, requires support from primary care organisations to ensure access to the appropriate training, education and competency assessments to ensure sustained quality delivery and positive sexual health outcomes.

54. Stakeholders from key organisations are working together to produce national standards for delivering sexual health services in any setting. These are being compiled by MedFASH and due for publication at the end of February. National quality training standards are being developed and a multi-professional national group is examining the competencies required for delivering enhanced services in general practice. These two initiatives are expected to be completed by Spring 2005. Work is also being undertaken to negotiate sexual health training into pre and post graduation medical and nursing training programmes.

Contraceptive services and termination of pregnancy⁸

55. The key role played by contraceptive services in protecting against both unplanned pregnancies and STIs is highlighted in the White Paper. To support this, the NHS will also strengthen the infrastructure for sexual health and contraceptive services in primary care. We will undertake an audit of contraceptive services in early 2005 to identify current provision of contraception by GPs and community services, to examine staffing and training issues and any restrictions in access to services and methods. We will also be investing centrally to meet gaps in local services and investment available will total £40 million.

56. A contraceptive services group has been established and one of the group's key actions is to develop an action plan for improvements to access services and the full range of methods. The expert group on contraception has now met 4 times and is making good progress in drawing up an action plan, which will help to deliver the White Paper commitments. A NICE guideline is being developed on long-acting methods of contraception which should raise awareness and support appropriate prescribing and usage. To help improve capacity and access, a distance learning programme for nurses has been developed. We are also supporting the development of a UK version of the WHO Medical Eligibility Criteria for evidence based contraceptive prescribing.

57. The £1 million for contraceptive services for 2004–05 was allocated to 162 clinics based on a formula. Funding can be used for training and improved access to long acting methods of contraception.

58. On abortion, an audit of waiting times and commissioning policies has been undertaken and the results should be available shortly. We are planning to use the results of the audit to commission development of best practice guidance for commissioning abortion services.

⁶ Recommendations 25 and 26.

⁷ Recommendations 27, 28, 30.

⁸ Recommendations 29 to 33.

*Sexual dysfunction*⁹

59. The draft sexual health standards, currently being developed, highlight the need to include issues of sexual dysfunction as part of a broader, holistic approach to sexual health. They set out the need for practitioners to be aware of the prevalence of sexual problems such as dysfunction and psychosexual distress, and the difficulty patients may have in seeking help for these conditions.

*Sexual health promotion*¹⁰

60. The Government agrees with the Committee on the importance, and cost-effectiveness, of prevention to improve sexual health. The White Paper highlights this and signals a major new sexual health campaign, targeted particularly at younger men and women, to ensure they understand the real risk of unprotected sex, and persuade them of the benefits of using condoms to avoid the risk of STIs (including HIV) and unplanned pregnancies.

61. Chlamydia screening and targeted HIV prevention have continued to be supported by DH and have received additional investment, as set out above.

62. In July 2004, the Department of Health, jointly with the Department for Education and Skills (DfES), published “*Best practice guidance for doctors and other health professionals on the provision of advice and treatment to young people under 16 on contraception, sexual and reproductive health*”.

*Sex and relationships education*¹¹

63. The Government is committed to delivering high quality sex and relationships education (SRE) within the framework for PSHE, recognising that young people need more than simply the facts about human reproduction which are covered in the science curriculum. Within PSHE, the focus is on managing relationships and giving young people the knowledge and skills to: resist pressure to have sex early; practice safe sex if they do become sexually active; and manage risks, not only in relation to sexual behaviour, but also drugs and alcohol.

64. The Government continues to review the evidence on the delivery of PSHE from OfSTED inspections, monitoring by the Qualifications & Curriculum Authority (QCA) and through its Regional PSHE advisers, but at this stage is not persuaded that making PSHE statutory is necessary. It believes that the key to improvement is through: improving teachers’ skills and confidence in teaching SRE, embedding PSHE as a key component of the National Healthy Schools Standard (NHSS)—for which there was a further boost in the White Paper—by providing clearer guidance to schools on its expectations for what each young person should learn through PSHE in each key stage of learning.

65. The Government continues to roll-out the PSHE certification programme for teachers. In 2003–04, over 500 teachers successfully completed the programme and approximately 2,000 teachers are participating in the programme in 2004–05. In addition, the Government has begun the roll-out of a linked certification programme for community nurses who contribute to the delivery of SRE in schools and other settings. Following a successful pilot in 2003–04, 325 community nurses are participating on the programme in 2004–05.

66. Following consultation with the Teacher Training Agency (TTA) new standards for Initial Teacher Training (ITT) now ensure trainee teachers are familiar with the PSHE framework. To support this, the Government’s Teenage Pregnancy Unit has commissioned a “Best Practice Toolkit on PSHE” for ITT providers.

67. DfES and DH are currently reviewing the NHSS, with the intention of including the requirement that the school has a high quality PSHE programme as one of the key qualifying conditions. The White Paper sets out the goal that all schools will be, or will be working towards, being a healthy School by 2009. DfES has published a “*Healthy Living Blueprint*” for schools, which further emphasizes the priority which the Government places on healthy Schools.

68. DfES has asked the QCA to develop “end of key stage statements” for PSHE for Key Stages 1-4, setting out what students are expected to have learnt by the end of each Key Stage. This brings PSHE in line with other curriculum subjects. As part of this work, QCA is also developing assessment guidance for schools and exemplar classroom materials. This “package” of materials will be available to schools from April 2005.

69. Specialist SRE teaching resources for young people with learning difficulties and young people with physical disabilities are being developed in partnership with voluntary and community sector groups serving these young people and their families.

⁹ Recommendation 34.

¹⁰ Recommendations 35 and 36.

¹¹ Recommendations 37 to 46.

70. DfES has developed a dedicated area on the PSHE teaching website about doing more to support boys. It contains specific lesson plans for teachers, training courses and links to resources. In addition, the Teenage Pregnancy Unit (TPU) has supported Working with Men to develop the Building Bridges SRE resource. This is for work with boys in key stage three and four, and aims to increase their engagement with SRE in schools and improve their uptake of local advice services.

71. Supported by TPU, Parentline Plus continues to implement the "Time to Talk" initiative aimed at helping parents develop confidence and skills in talking to their children about sex and relationships. The PR work in a range of national and regional media is supported by the Parentline Plus free helpline and website. The TPU has also supported the fpa's "Speakeasy" community-based education project aimed at enabling parents to talk to their children about sex and relationships. The main aims of the courses are to encourage parents to provide positive sex education in the home and encourage parents to take on the role of "sex educator". In addition, TPU supports the "Parent to Parent" peer support project pilot, with Sheffield City Council.

Department of Health

Witnesses: **Miss Melanie Johnson**, a Member of the House, Parliamentary Under-Secretary of State for Public Health, **Ms Elizabeth Ryan**, Section Head, Injury Costs Recovery and Charging for Overseas Visitors, and **Mr Geoff Dessent**, Deputy Division Head, Sexual Health and Substance Misuse, Department of Health, examined.

Q151 Chairman: Good morning. Can I welcome our next group of witnesses. Minister, I particularly welcome you. We are most grateful for your attendance today. As you are aware, this session in a sense is partly a follow-up to our sexual health inquiry and also looking at the HIV/AIDS issue and the charging regime. Can I ask each of you briefly to introduce yourselves to the Committee please.

Miss Johnson: I am Melanie Johnson and I am the Minister for Public Health.

Ms Ryan: I am Elizabeth Ryan and I lead on charging for overseas visitors within the Department.

Mr Dessent: I am Geoff Dessent, the Deputy Head of Sexual Health and Substance Misuse in the Department of Health.

Q152 Chairman: We are very grateful for your co-operation in the inquiry. Can I say, first of all, that I think it is important to place on record that we appreciate the steps that were taken by the Department in response to our Sexual Health Report. We picked up a number of areas where the Government have acted and we generally appreciate the fact that what we suggested has been listened to. Having said that, one of the areas that we talked about, as you are aware, Minister, was the 48-hour access and that was an area where the Government has indicated that steps have been taken to try and ensure that people do have that access at a reasonably quick period from when they know they have got a problem. The evidence that we have got is that that is not actually working. The evidence that we have got from the witnesses that we have had in this short inquiry is that the picture that we got 18 months ago is now considerably worse. I think you will have seen the evidence that the demands upon the service are such that in a sense this 48-hour access is meaningless. How do you see it working and do you feel that there is a need to take further steps to address the problems that are being picked up?

Miss Johnson: Did you say at the end of that that you thought the 48-hour target was meaningless? I am just checking that I heard you.

Q153 Chairman: I do not think it is meaningless. I think the picture that we are getting is that it is not working because the GUM centres are basically so overwhelmed that they cannot meet that target. Let me just give you an example. Last week I had a meeting with a sexual health project in west Yorkshire, called Yorkshire Mesmac and they particularly help gay and bisexual men. They were talking in particular about the 48-hour target and they were saying that it is meaningless. They said, "For example, at least one clinic in west Yorkshire 'guarantees' an appointment within 48 hours. However, this is achieved by not answering the telephone once all the following two days' appointments are full", and this is from Tom Doyle the Director of Mesmac. They are genuinely worried that people continue to be turned away when they are attempting to access services, knowing that they have got a particular problem.

Miss Johnson: Well, you have highlighted one apparent problem there which I am not aware of and I will certainly look into that. What I say overall is that obviously the 48-hour target is very far from meaningless. One of the ways in which we have driven improvement across the Health Service much more widely is by the judicious use of targets in key areas where we need to drive up performance, and all the evidence is that actually that has brought about a remarkable improvement, along with the investment and the reform, in the standards of service, the access times and so forth, so improving the quality of services to patients. I am sure that that will apply with the 48-hour target. The 48-hour target is for 2008 and we realise, because we started from a low base and there is a problem which we have acknowledged and your report has highlighted of sexual health, that investment is only recently going in to sexual health, so that is a target for 2008 which we are working towards. We have got for the first time, as a result of the survey which we have undertaken on that, a good understanding of what the current waits have been. We will get updated information based on the recent survey on that. I believe that that shows a small improvement is likely

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to be taking place in fact in the waiting times, but we will have to see how that looks and what direction that is going in, but overall £130 million extra has just gone out only yesterday to primary care trusts as part of their funding through the announcement the Secretary of State made in the House yesterday and that money is specifically designed to do things like improve access and GUM facilities and is going to PCTs for that purpose. Now, I know, before you raised the question with me, that there is always a question raised about whether this money goes on and is used for the purpose for which it is meant, but for the first time ever we are actually making sure that the local delivery plans, the LDPs, for the PCTs have to include a reference to what they are doing on sexual health and they will be assessed against that and it will have to reflect the local needs and local demands. I am sure for one thing that your example earlier on is something that is going to be of interest to the commissioners of services in the area of the clinic that you mentioned.

Q154 Chairman: One of the problems I was going to ask you in terms of the delivery plan is that I think we gained a feeling when we looked at sexual health that the SHAs, in the healthcare commissioning, needed to play a much stronger role in ensuring that these plans mean something and that the resourcing that has been made available, and we will probably talk about, in particular the resourcing of primary care, actually goes to where it is supposed to go. Can I come back to your point that you seemed to be surprised at the evidence that we have received. You were referring to your MedFASH review presumably, were you, the information in that review, which we have corresponded to you about?

Miss Johnson: Well, there was no data on waiting times at GUMs, as I know you are aware, and for the first time last year we actually commissioned a survey of those waiting times, I think in May of last year.

Q155 Chairman: Is this separate from the MedFASH review?

Miss Johnson: Yes. The MedFASH review is also being conducted, an overall audit separately, which is another source of information about performance and provision which we will obviously be using to inform for the future, but that is not yet completed and we do not have that information.

Q156 Chairman: But have you seen the evidence that we got from the Health Protection Agency and the British Association for Sexual Health and HIV which shows that only one-third of patients are being seen by the GUM within 48 hours of trying to access that? Are you aware of that information?

Miss Johnson: The HPA published the information, but it was actually information which the Department had commissioned.

Q157 Chairman: So you are aware of that?

Miss Johnson: Yes, certainly and that is the baseline that we have got. We know that there is a lot of improvement to be made on that. We fully

acknowledge it and that is why we have made record levels of investment. Altogether, £300 million has been identified for the purposes of campaigning or improving sexual health, so actually in terms of information and provision, we are accepting that a lot needs to be done and that is what we have done through the White Paper, the investment to follow that and the investment that went out to PCTs to start making the improvements on the back of that.

Chairman: One of the things that you are doing in sexual health is an education campaign and obviously we all want to see that. I have a vivid memory of going to Manchester to the GUM clinic there in the Royal Infirmary and being shocked by some of the issues that they raised with us, so shocked that we left Dr Taylor behind in the ladies section of the GUM clinic and we found out when we got to Bolton that he was not on the bus! It was a terrible situation!

Q158 Dr Taylor: It is a myth!

Miss Johnson: I think these things should be fully written up!

Q159 Chairman: Anyway, one of the issues that I remember from Manchester was that we had the public health people and the GUM specialists together in the GUM clinic and we were talking about the issue of education and screening in particular. The public health people were raising the importance of doing this and the GUM people were kind of putting their hands up, saying, "No, for goodness sake, don't do that because we won't be able to handle the amount of work we'll get arising from this campaign and this screening". That does seem to be an issue. Professor Kinghorn, who came before us in the previous session, I am sure you will know of his work, said that an education campaign, if it did not go hand in hand with capacity increases, would drive already overstretched services to a state of collapse. Could you outline the planned timing of the campaign and how you are taking account of that anxiety that the campaign needs to be linked into being able to deal with the demand you are going to generate?

Miss Johnson: Well, that is an absolutely accurate analysis, that we need to be careful about that. Obviously the investment is now going out and to some degree there are issues around facilities, although we have also made investment already, some additional investment on the capital side of things, so there is some additional historical capital investment gone in. On the service side, we obviously need the service to be able to respond. We are thinking at the moment about the design of the campaign and we are in the early stages of doing that. One of the things we need to do is to raise awareness of the risk and a part of that is preventative. It does not necessarily have to lead only to people thinking, "Ah, I might have a sexually transmitted infection. I had better go and get checked out or screened", so there is an element, a very big element probably actually, particularly as for each new age group coming through, the sort of 19 to 25-ish greatest period of being at risk, as it

were, there is a particular need to educate them, so we have got to get the balance right, you are absolutely right, between educating and information and using that as a preventative tool and simply stoking up demand, some of which may be the worried well as well, so we need to get that balance right and that is what we are thinking about in terms of the campaign which we will be running later on this year.

Q160 Chairman: Do you think there are any lessons which can be learned from the AIDS campaign in the 1980s and 1990s? One of the areas that we recognised was a problem was that in the 1980s and 1990s the public were much more aware of what AIDS could mean and many of us knew people who had died of it, let's be blunt about it, and the AIDS campaign at the time, the education campaign, was pretty explicit.

Miss Johnson: Yes, I remember it. I am old enough to remember it!

Q161 Chairman: Yes, I know how old you are! It was your birthday, I saw it in the paper and it mentioned your age! What I wondered was whether we have learnt any lessons from that and will we recognise the need to be pretty blunt and pretty explicit and to talk in terms that kids understand as part of this campaign?

Miss Johnson: I think one of the things that we have done historically is to target the 18-to-24 age group. I think that everybody accepts that we need to target a wider age group really and I think that one of the features of the HIV campaign, the tombstones campaign, was actually that everybody became aware of it and I think there may be a need to make sure that everybody is much more aware rather than us only targeting the most at risk in the population. I think we also need to do more about actually working with young people before they get into that age range so that they are aware of the risks too. In a sense, although obviously we would not want to return to those days in any way, it was easier to scare people about HIV when in this country people were dying of it regularly and although people still sadly die of it, in a lot of cases their lives are very considerably extended and, who knows, even indefinitely, as it were, by the complex drug treatments that are now available. I think we have to reckon that it is going to be a little bit more difficult to worry people on that score, but we are already running sexually transmitted infection campaigns which are aimed to frighten and make people aware and to lodge it in their memories, to use good handles for doing so and to make sure that they really do register in the minds of those that we are targeting at the present time, and we need to make sure that we extend that effectively to a wider group, I think.

Q162 John Austin: The Chair mentioned earlier the study you have commissioned from the Medical Foundation for AIDS and Sexual Health, which is something which we would welcome, but I know that that is a two-year study.

Miss Johnson: Yes.

Q163 John Austin: But the first phase is complete and you have the results.

Miss Johnson: I have not personally had them to me with advice from officials as yet, so we are very happy to share them with you in due course.

Q164 John Austin: The results of that study do give the most accurate, up-to-date snapshot of how GUM services are functioning.

Miss Johnson: Yes.

Q165 John Austin: That information is available. You may not yet have seen it, but it is in your Department.

Miss Johnson: Yes, I am sure that it will be with me soon.

Q166 John Austin: Your officials may not have had a chance to interpret the findings, but the findings are there.

Miss Johnson: But that is the case, that normally there is a process of digestion really in any government department when it goes through looking at things. I think what we have got is—

Q167 John Austin: But would not the most up-to-date information available be very useful to the Health Select Committee in conducting an inquiry into the state of the sexual health services in the country?

Miss Johnson: I do not know without looking at the information. I am not sure that the picture is going to markedly change. I think we have all got the broad idea about what the picture is and I am sure you are very well aware of what the picture is actually, so I do not think that this is an area where there are likely to be dramatic changes one way or the other. I think what the MedFASH survey is is an ongoing audit of individual services, as I understand it, and actually what we will do at the end of that is we will get an overview at the end of two years about what the picture is out in the field. Obviously I believe that the teams are communicating back, as they are out there doing the audit work, the results of their work, as it were, back to the places that they are looking at. I understand that that is going on, but I am not familiar with the detail of it. I do not know whether Geoff would like to comment on the process of the review.

Q168 John Austin: Perhaps he might be able to tell us when the Department received the data and how long it will take to interpret the findings.

Mr Dessent: We received the data quite recently and, as the Minister said, what we would normally do is look at that in the context of all the other information we have got and then put it to the Minister so that we can decide how best that informs the study and indeed as to whether there is a case to release stuff earlier rather than later in terms of informing where we are.

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Q169 John Austin: How recently is recently?

Mr Dessent: Well, I was only aware of it a few days ago.

Q170 John Austin: Perhaps we might find out later how long you have had it.

Miss Johnson: I think that was a few days, but we can give you a precise date.

Q171 John Austin: It still does strike me that it is rather curious that there is this air of secrecy about the raw data which, if one values the work of Parliament and scrutiny, the Health Select Committee and its report, it would seem sensible for the Committee to have the most up-to-date information, would it not?

Miss Johnson: It is normal practice in fact. Firstly, this is a rolling snapshot, so there are some questions about getting to the end of the business of taking those snapshots anyway and having the whole film, as it were, and that is one issue. The other issue is that it is a series of snapshots. I think it was only as a result of something said to the Committee that we really became aware that there were things emerging from the findings, so actually you knew about some of that, as it were, or were told about some of that before we were. We were the commissioner of the data, but actually the data has only just come to us on the back, I think, of what had occurred at a previous hearing or what was said to you in some way or another by way of briefing, and I am not quite sure which it was here, so it is not any attempt to keep anything secret whatsoever. As I say, I doubt very much if it will fundamentally alter the problem that we are facing. I think we all understand very well what the problem is that we are facing and what the main things are that we need to be doing to address it and that is why we have got the course of action that we announced in the White Paper and why we are pursuing that through the funding announcements of yesterday and the problem is very well known.

Q172 John Austin: But the information contained in there, which is somewhere within the Department, will at least be able to tell us whether services are about the same, improving or deteriorating.

Miss Johnson: Well, the 48-hour target monitoring is also being conducted every six months, so we will get a second read-out on that shortly too and we will certainly be publishing that.

Q173 Dr Taylor: Minister, can I go back to the funding issue to try and sort of tease out some of the details. In your very helpful paper, you have summarised the money that comes from the White Paper, which is the £50 million over three years for the sexual health campaign, the £130 million which you have already mentioned, £80 million to help with the Chlamydia work and £40 million to help with the contraceptive work, so that is the £300 million.

Miss Johnson: Yes.

Q174 Dr Taylor: Yesterday the Secretary of State announced the amounts going to primary care trusts and in round figures, from memory, because I have not brought the paper with me, if a primary care trust was getting, say, about £120 million and an average rate of increase is about 10 per cent on last year so that means the increase is £12 million, is that £300 million or a PCT's share of that £300 million part of that total increase or is it on top of it?

Miss Johnson: I think it is part of that total sum of money, although the percentage you are quoting I think is a one-year percentage because I think the 10 per cent or thereabouts is the average for 06/07 and the following year has a similar additional percentage increase on the budgets as well, so they will vary between sort of 8 and 13/14 per cent on each of those years, roughly speaking.

Q175 Dr Taylor: So working on very rough round figures, if a PCT that has got an increase of 10 per cent in fact has got an increase of about £12 million, that is to cover absolutely everything in its local delivery plan?

Miss Johnson: That is correct.

Q176 Dr Taylor: Is there any compulsion on what is in the local delivery plan?

Miss Johnson: Yes, that is what I was saying earlier on in relation to what the Chairman was asking me, that is to say, that the local delivery plan has to include coverage of how they are going to meet the sexual health needs of their population and they will be assessed on their performance against that and their delivery of that as part of the delivery plan, as part of the performance management that is undertaken and as part of the Healthcare Commission work on monitoring them, so for the first time ever in fact there will be a demand that they deliver, as it were, in outline on sexual health. Obviously the exact nature of what goes in there needs to reflect local needs and local circumstances and that is entirely in line with our policy, that you need to get it local and the decision-making local. Then on top of that there will be the normal performance management of that and account taken of the delivery of it by the Healthcare Commission.

Q177 Dr Taylor: So even though there is not an NSF or particular NICE guidance on this, there has been compulsion on them to put this in their local delivery plan?

Miss Johnson: Yes, it is a strategy, and I know we have had this discussion many times, but the strategy is not very much different from actually having an NSF.

Q178 Dr Taylor: You have already touched on the fact that we have doubts. If the money is given direct to GUM clinics, it gets there, but if it is given to PCTs, it tends to sort of leak out. Are you really quite confident that this method will spot that it really is going to what it is meant for?

Miss Johnson: Yes, because we have never had this degree of performance management on sexual health provision before and, coupled with the monitoring that we are doing now six-monthly on the 48-hour target, the extra investment that is available which was not available for them before, both the overall quantum of investment where the envelope is much bigger and much more generous on top of historical generosity, as it were, and they have already got a lot of investment gone in historically, they have got a very large extra increase which has just been announced for 06/07 and 07/08 and, within that, there is specific money which we are expecting them to deploy for this purpose and on which their performance will be monitored if they do not deliver it. I think also, as it happens, that the public anxiety around this subject, the attention that the Select Committee has given it, the House has given it, we, as ministers, the Department are giving it and the Government is giving it is sending a very strong message in any case to commissioners that this is more important than they may have thought it was historically and that will be reflected in changed behaviour on its own, but, on top of that, there will be these much more formal and much more fierce, if you like forms of monitoring and performance management.

Q179 Dr Taylor: I am absolutely sure we all welcome this huge amount of money going in, but has there been any estimate of the cost of local delivery plans in total? Again I am speaking sort of locally. I know that local PCTs have debts and overspends amounting to several million which will mop up the first bit of their extra money. Is there any assessment of what a typical PCT's local delivery plan would cost if they funded everything in it?

Miss Johnson: Obviously we have sent out money, having had some look at the centre at what that money is going to be spent on and how reasonable that is, what the pressures are, salary increases and other structural changes which may lead to them needing more money for things, so we have looked at all of those demands and, within that, the plans have been formulated and the money has been allocated. The money, as you know, is also for the first time much more closely correlated actually to the needs in a given area, so there has been a much greater focus on getting more money to those areas with the greatest need and some of those needs will be reflected across the board and will impinge on sexual health needs too because some of the areas with the greatest deprivation are probably some of those areas with the greatest sexual health needs as well. Manchester, for example, with £113 million extra going into it has got, we know, a number of needs on this front and it has a number of other health needs, so we have got all of that background to this. You asked me something else as well, I think.

Q180 Dr Taylor: Firstly, perhaps I could follow that up. Would it be possible if we, as a Committee, or I, as an individual MP, put in a PQ to ask for a list of all the PCTs' costs of their local delivery plans?

Miss Johnson: No, I do not think that is possible because the local delivery plans are formulated by them. We have looked centrally at what we think the needs of the services are across the country. We cannot divide that up against the local delivery plans. They will cost out their own delivery plans. I know what I was going on to say. You mentioned deficits, but historically the Health Service has been in financial balance over the last four years, so this position about deficits is a bit of a moot point and at this time in the financial year the apparent deficits always look rather worse than the outturn at the end of the year as well. I think because it is such a moving picture, it is very difficult to be clear about this, but we regard the money that went out yesterday, including this money, as additional money, not needed to meet any so-called deficits and actually available for the improvement of services and access and all the other things that we have been talking about.

Q181 Dr Taylor: So the only way for us to find out the cost of each PCT's local delivery plan is for each MP to contact their own PCT and find that out?

Miss Johnson: Well, I assume the cost of their delivery plan will be their budget. They have got a sum of money and in order to deliver that, they will be producing a delivery plan actually to meet up with the budget that is available to them.

Q182 Dr Taylor: I would have thought that the development of a local delivery plan goes through a process before that. You decide what you want and the cost of that and then you have to cut that down to the money that is available.

Miss Johnson: This is a normal process at all levels of anybody controlling any expenditure in any arena of life. I think we would all wish to have fantasy sums of money available to do all sorts of things which we are never going to be able to do, so I think we have to accept that we would all be able to sit around and think of things that we could do with more money, publicly or personally, but that is not the reality of the world. There are record sums of money going out to the Health Service. The increase has been absolutely phenomenal in Health Service funding.

Q183 Dr Taylor: No, I am not arguing with that and I am clearly not thinking of fantasy either, but I can see a picture where the demands of sexual health services are possibly at the bottom when they are pitted against the demands for developing cardiac surgical services and cancer services. That is all I am trying to get at.

Miss Johnson: In the days in 1997 when there were 18-month waits for hospital inpatient treatment for some people, there was a lot more difficult weighing up of priorities to be done, whereas now our aspiration is to get to 18 weeks from start to finish of that process and where we are already under nine months and will be under six months by Christmas, so of course there is always a weighing up of priorities. Everybody has to weigh up priorities. The Government has to weigh up priorities. Whoever you are, you are weighing up priorities, but I would

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say that having been a local authority member in difficult times in the 1970s, 1980s and 1990s, actually I know that those difficult decisions were actually in the arena of cuts and actually where you cut, not where you expanded and how much you could expand. There is a very different climate for people running the services today in the public from what there was in, say, the late 1980s or early 1990s.

Chairman: You talked about the mechanisms that you have put into place to ensure that the funding is actually spent on the purpose, and we welcome that and want to see some positive outcomes. One of the things that really caused me concern when we looked at sexual health was the way in which the service in some areas was so substandard that I think all of us were shocked at what we saw. What we were trying to establish was how that could happen, how it could be that those organisations responsible for that service had allowed that service to deteriorate to such an extent that some of the facilities were, frankly, appalling. Obviously we came to some conclusions, one of which was that this is an area which is, and I was going to use the words, “not sexy”—

Miss Johnson: Yes, I do know exactly what you mean.

Q184 Chairman: It is not an issue that you or I, as local MPs, would get constituents writing to us about. Therefore, politically we are not under pressure to do a lot about this area. In the context of the move towards devolving decision-making, and I personally support the direction the Government is going in, how do you square that problem that possibly in certain areas they will not want to make, as Richard says, investment in this area because it is not something they are under pressure to do, how do you balance that with trying to reduce the amount of central directives which to some extent you have just described and how do you square that up with devolving the power to local people and letting them make the decisions in their own back yard?

Miss Johnson: Well, there is always a balance to be struck, is there not, so, for example, we have taken the decision that there are improved tests available for Chlamydia, that we want those tests rolled out, that we want a national screening programme, that we are going to have that, that that is going to be put in place, that resources have been deployed behind that investment and that that is not a matter for local decision-making, as it were, and that there is going to be a national campaign because we think campaigns need to be run nationally rather than regionally or locally, although they could be backed up in that way, so some of those things need to be done on a national basis. Some of the frameworks, some of the demands and standards and the monitoring all need to be done nationally and, within that, I think we want to devolve as much as we can to a local level. I agree with you that I think historically sexual health and particularly the clinics themselves have been a forgotten area and they have certainly not been sexy, in the way that you are saying, and it is exacerbated by the fact that people do not write to us, complaining that they had to

attend the clinic and how appalling it was or whatever historically. It has now come, I think, very much to everybody’s attention that more investment needs to be made and that is why we have made the investment. We need continually to monitor that, but I think for the first time now as well that the commissioners of those services, and we have to remember historically that a lot of what we are dealing with goes back many years and indeed the Portakabins or whatever go back many years as well that it was taking place in, or still is in some areas, actually it was not the PCTs commissioning in those days. They have got sexual health needs now in the PCTs, we are building networks for the sexual health needs, we are doing more to look at information about training sexual health workers and we are doing a lot of things to support the service, to network the service and to make the commissioners much more aware of the demands on them, plus the formal performance management side of it, which I went through earlier on and I will not repeat again now.

Q185 Dr Naysmith: In evidence to this Committee Dr Ford Young, who is a general practitioner who has a special interest in sexual health, told us that in the area of sexual health there had been a great missed opportunity when the new GMS contract was being negotiated. Do you share that view?

Miss Johnson: No, I do not. Why did he feel that because that was a statement, it was not a set of reasoning?

Q186 Dr Naysmith: Well, one of the arguments he had was that the essential services element of the new GP contracts should have included sexual health and that there would have been an opportunity there to take all sorts of steps that there is no incentive to take now for GPs. It is not incentivised at all under the new GP contracts, that GPs should involve themselves in this sort of area, and there are lots of things that GPs could do in this area.

Miss Johnson: Well, PCTs can contract in a whole variety of ways for this. They can use a lot of the medical contracting routes available to them from general practice sexual health services which can be tailored to meet needs using various different routes, the GMS route, the PMS route, the alternative PMS route and the PCT-led medical services, so there is a whole lot of avenues there that are open for contracting purposes, and there is the enhanced services aspect as well, so there are a lot of ways in which sexual health services can be delivered and practices indeed are continuing to offer consultations and examinations and so forth as well.

Q187 Dr Naysmith: Apart from all these acronyms, you obviously said that the PCTs “can”.

Miss Johnson: Well, I have already dealt with the issue about what the pressure is on the PCTs and I hope it is clear that there is a lot.

Q188 Dr Naysmith: I know, but the argument was that this ought to have been part of the essential services because, as you know, the essential services are things that PCTs must do.

Miss Johnson: Yes.

Q189 Dr Naysmith: Infections, and some of them can be life-threatening infections, should be treated, should they not?

Miss Johnson: They certainly should be treated. If they are ill, they certainly should be treated.

Q190 Dr Naysmith: Instead of just saying, "You've got to go down to the Portakabin down the road."

Miss Johnson: In fact, the vast majority of these are not life-threatening, although they are things that we want people to be treated for. They are mostly one course of treatment, as I know I do not need to explain to you, with the exception of HIV/AIDS.

Q191 Dr Naysmith: So what you are saying is that syphilis and gonorrhoea, both of which seem to be on the increase in some parts of the country, are also life-threatening diseases, as well as AIDS. Are you saying the Department is quite happy with the situation and does not intend to review anything to do with the GP contract?

Miss Johnson: I am sure over all we will be looking at the way in which the GP contract is working, but it is not to say that we anticipate any formal reviews, including formal review in this particular area.

Q192 Dr Naysmith: What steps can PCTs take then to incentivise GPs to undertake some of this work?

Miss Johnson: They will be the commissioners of service, so they are in the same position as really anything else. If local GPs do not want to offer a number of services now, they are not obliged to offer them. The PCTs, however, have the money and the money follows services, as it were; it follows the patient. This is increasingly going to be a powerful tool in the Health Service, I believe, for delivering the quality of services we want, delivering the access that we want and we should get, and also being able to use the money flexibly to deliver that in a number of settings. In this particular case, I think the role of the clinics is very important and we want to see the clinic provision maintained, with a better quality and better access, but equally well, there are a number of other avenues. We have recently been going out to tender on some publicity on some of the Chlamydia testing arrangements, and there are opportunities for some of these services to be provided in a very different way in the future, a way that I think will suit the generation that we are particularly focusing on, and a way which will make it more tailored to people's everyday lives and what suits them in terms of ease of access, timings, and so forth.

Q193 Dr Naysmith: Mr Bradley is going to ask some questions about Chlamydia in a minute or two, but this is an absolutely obvious area, because there is evidence that large numbers of GPs, maybe as many as 50 per cent, are interested in providing

Chlamydia, but at the moment there is no incentive at all; there is no reimbursement for GPs under the current circumstances for doing it. Are you saying GPs are going to be allowed to be part of the bidding process to provide Chlamydia screening?

Miss Johnson: We have arrangements in process for rolling out the testing for Chlamydia screening. We have not got through all the detail of how that will be done at the moment, but the aim is to get all of the Chlamydia screening across all of the strategic health authorities by April 2006¹, so we want to have all of that screening in place. The GP does not have an incentive to treat me particularly when I turn up with whatever everyday complaint there is. I am not quite sure . . . You know, they are paid.

Q194 Dr Naysmith: They are paid to diagnose and send off to consultants where it is something tricky and they want a second opinion and so on, but there is quite a lot of sexual health which can be treated in primary care, and there is no incentive in the contract, we were told, at the moment for GPs to do that. Perhaps we could ask Mr Dessent if he knows—obviously, with your permission, Minister, since you are in charge of that end of the table—whether when the contract was being negotiated the area of sexual health was considered as something that might be included in essential services.

Miss Johnson: Before he makes any comments on that, can I just say there are a lot of different providers who are clearly very keen to provide, and when you say GPs can obviously do this, obviously GPs can, and we hope that they will continue to do so, but we are looking for a mixed economy so that there is a variety of patterns of provision that both meet the individual needs of that particular community, as it were, rural, urban and all the rest of it, but also meet the needs of different sections of the population. For example, community pharmacies may well be one route in a community setting. The GP is one community setting alternative for the provision, but it is by no means now the only alternative, because clearly, there are a whole variety of other forms of provision growing up, which are increasingly very well supported by the public and which they find very convenient and which we want to increase where that is appropriate.

Q195 Dr Naysmith: I do not know if Mr Dessent wants to answer the question, which was not just about Chlamydia but about general sexual health services.

Mr Dessent: Obviously, in terms of the development of the GMS contract, yes, of course we were involved in discussions about that, and made the case for where it might be introduced. I probably should say that there will be at some point a formal

¹ *Note by witness:* The commitment made in the public health white paper, *Choosing Health* . (Department of Health, 2004) Is that " we will accelerate implementation of a national screening programme for Chlamydia, to cover the whole of England by March 2007. However, additional investment to help laboratories switch to the nucleic acid amplification test for Chlamydia has already been allocated in advance of this roll-out, and it is anticipated that all areas will have access to this method of testing by April 2006.

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review of the GMS contract, and we will be making those same arguments again to see whether there are particular avenues that might be explored that would start to address some of the points that you are raising, and certainly Chlamydia is one of the issues that we particularly recognise as being relevant to this.

Miss Johnson: We will have at that point a lot more provision on the ground than we currently have, and it would be interesting to see how that is developing.

Q196 Dr Naysmith: The other thing, changing the topic a little bit, is that if we are going to have these increased services, there has to be an increase in the amount of training that goes on.

Miss Johnson: Yes, indeed.

Q197 Dr Naysmith: It has been suggested to us that, if we are going to have this increased capacity within primary care, GUM clinics and contraception services as well, we need a separate training budget and a formal national training programme for doctors and nurses, both at the pre-qualification level and the post-qualification level. In particular, it was suggested to us that GPs and practice nurses have a pressing need for training in this area. Are you aware that there is a problem, and do you have any plans for addressing this?

Miss Johnson: It is quite interesting, because, as you know, we have recruited about 80,000 extra nurses over recent years to the NHS as a whole, and what I have been quite struck by as I have gone about my travels is the number of people I meet in primary or community care settings now who are ex-hospital. They may be cardiac nurses, now doing cardiac rehabilitation in a community setting, when they were formerly working in the cardiac units in the DGH or whatever, or other people who have moved out to provide other services in other settings. I have come across quite a lot of these people in treatment centres, in the community, working for GPs, working in out-reach work. I am not sure what the work force patterns would show but my suspicion would be that there might be a bit of a drift of people from acute settings, with a lot of very relevant experience, now providing an allied or very closely related service in a community setting. But, of course, because we want more provision in the community, we do need more work force in that area. There are work force planning arrangements, and strategic health authorities have a role in this regard. I think in a lot of communities growing people on through roles in the NHS and allowing them to get qualifications is a very important part of that. I met somebody working in mental health, who was responsible for a unit, who had started off as an untrained nurse and had been allowed to go off as part of that and get the training, and then return to the unit. This is where it is having advantages for those communities, that people are being skilled up by the NHS, who are a major local employer in many settings, and particularly in areas where employment options are still not as rich as they may

be in other parts of the country. I think there are a lot of avenues there. On the sexual health side of things specifically we have . . .

Q198 Dr Naysmith: A lot of the things that you have just been talking about have involved specialised training for these nurses and doctors in the NHS, and we are saying we need it in the sexual health field.

Miss Johnson: Yes, I am just going to answer that point. We have actually undertaken a mapping of training needs and produced some recommendations and an action plan on that. There has been a day held with stakeholders which led to a national working group—this is on training—being established in partnership with the Centre for Sexual Health in Sheffield, so I think this is very much meeting up with the point you are making, and its terms of reference are to do things like take forward the action plan for training, agree quality standards, make sure there is consistency in training—this is for sexual health professionals—and to work towards national accreditation. There is a distance learning package as well for nurses, that has been published and accredited by the University of Greenwich, and there are also some key competencies published for sexual health nurses. I think increasingly we are looking at diversifying our work force and giving them specialist skills in particular areas of provision. Sexual health is probably just one example of that, and I think the wider skills mix that we therefore need is something which, across the Health Service, we are having to address, but in this particular way we are addressing it like this.

Q199 Chairman: Before we move away from training, I mentioned that last week I had visited this sexual health project in my own area. It is a West Yorkshire-wide sexual health project. I asked them about the use of primary care, saying that one of the things that the Committee felt was that we could make more use of alternatives to GUM within the community. You have mentioned pharmacies. I certainly felt that GPs could probably do a lot more than they do now. Their response, particularly from the perspective of dealing with lesbians and gays, was that they had had some very negative experiences. The local service co-ordinator faxed me subsequent to the meeting to say the reason he would always direct to a GUM clinic—that is, his clients—is completely due to the number of poor consultations that service users have experienced at their GP's. I think he is talking of West Yorkshire, not just my own area. He gave me one or two examples of quotes given to him by users of the service. One young girl was told, and I quote, "You are too young to know you are a lesbian." This is, obviously, a GP, according to the person. Another girl was told "You are gay. Have you had any counselling?" A young man who used the service said, "I told the doctor I was gay and he immediately wrote 'HIV?' in my notes." What they are saying to me is that there is a need for training of GPs to include not purely medical screening, STI screening or whatever, but sexual health consultation, which

in their view in many instances in my part of the world is done rather insensitively. We might be an exception to the rule, and I suspect we are talking about a minority, but would you feel that this kind of area could be addressed in looking at the training needs that Doug has referred to?

Miss Johnson: I think that is a bit different because if you are talking about training of GPs, that is really a matter for the curriculum; both the initial curriculum and post-graduate training is really a matter for the Royal Colleges. They are in charge of a lot of what happens on all of that, both the nature of it and how it is delivered as well. We obviously do have dialogue with them about training, and various parts of the Department and through the Chief Medical Officer, we have links into the Royal Colleges and what they are doing, but it is a matter for them, and I think it would probably be most useful to discuss those issues with them. Obviously, we are always concerned if GPs are not giving patients an appropriate response, and I take it that the PCT may be interested to know that and may want to pick those issues up with some individuals or some practices themselves in an informal way.

Chairman: These may be isolated examples, but, as I am sure you will appreciate, if that is the kind of response you are getting, it is not exactly encouraging a person to continue using the Health Service when they may need to.

Q200 John Austin: Can I just come back to something on the GP contract and GP services in relation to contraceptive services? The FPA in their evidence suggested that the GP contract's lack of quality points for the provision of contraceptive advice undermines this aspect of the contract and does not incentivise general practice to provide a comprehensive contraceptive service. They have also raised concerns about the introduction of PBR, payment by results, and suggested in the area of contraception, as an example, it could militate against the provision of longer acting contraceptives in favour of repeat prescriptions of oral contraceptives instead. Would you accept either of those criticisms?

Miss Johnson: I would have no reason to believe that, but I would be happy to write to you on the second point. On the first point, we have recognised through the White Paper and through the investment that is going in that we do think more investment needs to go into contraceptive services. That is why we have an audit of what contraceptive services are available going on, and that is why we have already made £1 million of investment anyway this last year to improve contraceptive services. There is £40 million additional being supplied to address gaps in the service on the back of the audit that is being undertaken. We have also established a group to develop an action plan for improvement to the services, so there is a nice guideline being developed on long-acting methods of contraception which we think will raise awareness and usage, and we have also allocated money, £200,000, to support nurses to undertake the distance learning programme specifically on contraception. That will

train 2,700 practice nurses in basic sexual health skills and supplying of condoms and emergency contraception. There is a range of provision going on. I think we do need to see improvements in contraceptive services, and that is why we identified the money to do so.

Q201 John Austin: So the audit will include general practice contraceptive provision as well as family planning clinics?

Miss Johnson: Yes, yes.

Q202 Mr Bradley: Minister, can I go back to Chlamydia screening? You have made some comments already on it. We have had evidence that 45 per cent of Chlamydia tests are still being performed using the suboptimal test. Can I take it from your previous answer it is the intention that the NAA test should be applied in all cases by April 2006?

Miss Johnson: Yes, that is the intention, because the other test has many more false results on it, particularly false negatives. We do not want to continue to use it longer than we have to, but obviously people need to be trained, the facilities need to be there to use the new test, and staff need to be trained in doing so. It is like any of these changes on national screening; you have to have a roll-out period, unfortunately.

Q203 Mr Bradley: That roll-out period is April 2006.

Miss Johnson: Yes, that is the aim, to get 100 per cent coverage, all the strategic health authorities involved by that date.²

Q204 Mr Bradley: Secondly, therefore, if we are going to have a national screening programme, it should apply to all ages and both sexes. You are obviously agreeing with that, so why is the current emphasis on women under 25s and not men?

Miss Johnson: It is not, actually. In the interviews I have done myself in the last few days I have been emphasizing young men as much as young women. Obviously both sexes are infected, otherwise the problem would not be there at all. We need to make sure that both sexes come forward. In fact, we have specific screening programmes running around prisons and also MoD facilities, so there is some specifically targeted largely at the male population, but we want to see both sexes come forward for screening. I think the risks are broadly the same for both of them. I do not think there is quite so much evidence of the infertility for males but there is still evidence of a serious risk of infertility there, as there is quite a lot of evidence that it has that consequence for women and, because it is asymptomatic, we are very concerned that people are tested, and it is so easy to get treatment.

Q205 Mr Bradley: So the campaign, when it is launched, will cover the whole spectrum?

² See footnote 1.

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Miss Johnson: It certainly will, yes. I think one of the things, again, about making facilities available: young men are not frequent attenders at GPs, for example, and unless they have had a need to go to a clinic, are they likely to necessarily know where their clinics are? They will know where things like pharmacies, etc, are so we need to think about the locations where people are going to be. We need to look and see as well whether we can run screening through colleges, for example, and other areas like that where a lot of young people may be gathered in the relevant age group at the same time and do things on a much wider scale.

Q206 Dr Naysmith: I just wonder, as well, Minister about the concentration on under 25s, simply because there is a lot of anecdotal evidence—I do not know of any really hard evidence—that people are sexually active to a much later age.

Miss Johnson: Considerably later than 25, probably.

Q207 Dr Naysmith: We know that Chlamydia is sometimes used as an indicator of other potential hazards and risks being undergone. Is it wise to concentrate on the under 25s? I know it is because of the fertility aspect, but is it wise to concentrate on the under 25s and not have a general screening programme?

Miss Johnson: I think that goes back to the question about the national campaign to a degree, and I agree; I think we need to extend the range that we are covering. It really does go up to about 30 though, the age groups that we are targeting through magazines and holiday-related publicity, pubs, clubs and all the rest of it. It has picked up up to the 30s. But the reason for targeting Chlamydia is because there has been a massive increase, because people are unlikely to know they have it, because about one in nine or ten sexually active young women is infected with it, and probably a similar number of men, and what we wanted to do was to actually raise awareness of it, so that people did not think “Chlamydia” was some unusual women’s name. There was a degree of ignorance about it at one stage which meant that everybody had heard of gonorrhoea or syphilis or HIV/AIDS and not everybody apparently had heard of Chlamydia, and because there were not the symptoms, I think it was right and it is right to focus quite a lot of attention on it. But of course, if they come forward for testing on one thing, there is much more chance that if they have other, related needs, those needs are going to be identified and dealt with too.

Q208 John Austin: I am just curious. Despite the recommendations in our report, your White Paper does not mention abortion services at all. Is there a reason for that?

Miss Johnson: Our White Paper does not mention an awful lot of things actually. It was focused on the areas where we could principally change behaviour by a mixture of support, provision and education and information; an informed choice, as it were. There are obviously a whole lot of very difficult issues around abortion. There has been much

discussion of it. It has always been a matter for Parliament to decide what happens with the abortion laws, and a lot of the provision around it. We have certainly concentrated a lot more money on contraception, which I think is the right area to put a lot of extra investment in. We decided to leave many things out of the White Paper. It would have been a huge document had we included everything that technically belongs to public health.

Q209 John Austin: Abortion is clearly a key area within sexual health services. Will it feature in the implementation plan?

Miss Johnson: No. The implementation plan is focused on what is in the White Paper, so it will focus on sexual health, where we have already made announcements, so everything from contraception through to the national campaign for clinics, screening and Chlamydia and so forth. As far as I am aware, we are not planning to have any provision or any particular reference to delivery on abortion in there. We have focused on improving early access to abortion and we have succeeded in improving early access to abortion. It is a matter of personal view but I personally think it would be much better if we succeeded a lot more on contraception.

Q210 John Austin: Can I go on to a complete different area, charging for HIV services? There are many statements in the media, and I believe one of your colleagues in the Department has suggested that there is a high level of health tourism. In particular, there has been reference to HIV tourism, but I am not aware of any substantive research that has ever been carried out, and the evidence from organisations like Terrence Higgins that we have received would suggest that HIV tourism is a bit of a myth.

Miss Johnson: It is very difficult to produce figures. Historically, figures have not been collected by the Health Service, over decades—never, basically—about levels of people using the service who are not resident or normally resident in the UK. That is partly because, obviously, some of the people who use those services are genuine tourists—and I am not just talking about HIV/AIDS here; I am talking more generally, because it is quite difficult, again, to make distinctions between this and a number of other things for which people need treatment. It is impossible therefore to disaggregate data as to whether a tourist came over and broke their foot and received treatment through an A&E department or whether somebody came in and received another service as a so-called health tourist.

Q211 John Austin: The evidence seems to suggest that people who have come into the country with HIV actually seek treatment late, which seems to suggest they have not come here as HIV tourists.

Miss Johnson: Yes. I do not want to join in your conjecturing. I do not have any figures to supply you with on this. I concur with the point that it is difficult to measure it, and we do not have reliable information. What we are clear about is that there was some abuse going on of the existing rules, and

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that is why the rules review was undertaken, and a tightening up of the wording to deliver the same consequences that the rules had almost all been intended to deliver before. There has been very little change of substance on the rules, but what there has been is a tightening up of the wording so that they actually deliver the results that they were originally intended to deliver when they were first devised.

Q212 John Austin: I will come on to that in a moment, but you are really saying there is not any evidence that the UK is likely to become a magnet for HIV tourists?

Miss Johnson: What is clear is that if people think they can come in and, under any circumstances, remain here for free treatment, we would become such a magnet, and that was what we were concerned to deal with. We are a national health service; we are not a global health service. We are here for people who are resident, and residency is the basis of the entitlement here, as defined normally by many of us here, permanently resident, but there are a number of other categories of people who count as ordinarily resident here for these purposes, and we have made sure that those categories are very clear in the revision that has taken place, because we did not want the wrong messages to go out elsewhere.

Q213 John Austin: Let me come on to the rule changes and let us deal with the removal of the 12-month exemption. In the past, persons who have been here for 12 months, even if they no longer had proper authority to remain, were allowed treatment, and now that is not the case. That would include, of course, over-stayers and maybe failed asylum seekers, some of whom may well at some stage, through an appeal process, be regularised and be lawfully here. Has the Government any estimate of the numbers of people who are now no longer eligible for treatment as a result of the change in the 12-month exemption?

Miss Johnson: No, we do not. Let me be clear about a few things, because I think it is very easy in this area for people to get the wrong end of the stick on it. First of all, people who come here are entitled to free tests and, under any circumstances, somebody here, as they are entitled to free sexual health services, they are entitled to free diagnostic tests, and the initial response to that in terms of counselling, free on the NHS, and that includes anybody who thinks that they have HIV/AIDS. So there would be no reason in relation to any of these things why somebody should not come forward early; in fact, what we need to do is increase awareness so people do come forward as early as possible for testing. But when people are coming into the country, there is a lot of evidence that people do get tested. What we are doing is making sure that, when they are here illegally, they are not entitled to remain simply to get free treatment when they are illegal over-stayers. That goes back to the earlier point, that the basis of treatment has always been residency, and that means legal residency, and people who have simply over-stayed, however long they have over-stayed, do not become legally resident by over-staying. We did not

really change that, in a sense. We just went back to the fundamentals of it, that it is residency, and that means legal residency, and therefore, being here 12 months or more does not qualify you under those circumstances for free treatment. Can I just make one other point? There is still provision for easement by individual clinicians under individual circumstances, and at the end of the day, the decisions are the clinician's; they are not for ministers and they are not for politicians, or for any of the rest of us.

Q214 Chairman: You do not have an estimate of the numbers affected by this change? Have you access to anybody else's estimate as to the numbers affected? Have no voluntary organisations put to you the numbers that are affected? You have no knowledge whatsoever, no guesstimates?

Miss Johnson: No, no. Obviously, people who are being expelled are a matter for the Home Office as well, so that is not an issue for my Department.

Q215 Chairman: I appreciate that, but you are in contact with other government departments, obviously, and in conjunction with them, there has been no estimate from them as to the numbers that might be affected?

Miss Johnson: No.

Q216 John Austin: I want to come on to this question of testing. I acknowledge that HIV testing is free of charge to anyone, and obviously we encourage that, and most of the organisations working in the field are engaged in encouraging people to come forward for testing. But Terrence Higgins have suggested to us that, where we are talking about migrant communities, who may not be eligible for access to treatment, there is now therefore a reluctance to come forward for testing, and Terrence Higgins in their evidence suggested this was having a significant impact on their encouraging campaigns.

Miss Johnson: There obviously is a difference. The free bit of it is around the public health risk, and the public health risk if somebody has another sexually transmitted infection is that actually, if we treat them, that risk goes down to zero. Actually, treating somebody with HIV/AIDS, unfortunately, does not reduce their risk to the general population at all. It is only behaviour change that alters that risk.

Q217 John Austin: But it is part of the Government's policy to reduce the number of undiagnosed HIV infections in the UK.

Miss Johnson: Indeed, and we are actively trying to encourage people to come forward for diagnosis, because it is only upon diagnosis that people know that they need to change their behaviour definitively, and they can access treatment free, many categories of people, all those who fit the ordinary residency or who are applying for asylum whose applications are being considered. For those who are not legally resident here, obviously, there is not an ongoing entitlement to free treatment.

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Q218 John Austin: You are not concerned then about the evidence from Terrence Higgins that there is a resistance to come forward for testing where there is no eligibility for treatment?

Miss Johnson: We do not have any figures that show that. In fact, what I think the figures indicate is that there are more people coming forward for testing and for diagnosis, and that probably, as well, the improved health outcomes for people with HIV/AIDS as a result of the improved drug treatments are leading people to think it is more worthwhile making sure that they get tested early and they get put on treatment as early as possible because that is improving their life chances, despite having the disease.

Q219 John Austin: I might want to come back to that later. I understand that, in the correspondence between the Committee and your Department, the Department has made no assessment of the likely cost or cost savings of introducing the changes to charges for overseas visitors. Is that so?

Miss Johnson: I have already explained that there are no figures about the numbers of overseas visitors being treated.

Q220 Chairman: You must have an idea of what it would cost for a course of treatment. That is the point we are making. We appreciate you cannot add it up and say there are so many thousands, or whatever, but individually what would it cost or save? If *The Daily Mail* rang up your office and you had to argue with *The Daily Mail*, you could make an argument that it is in the interests of this nation financially to treat a particular person, so that it does not spread to others and cost the NHS more money.

Miss Johnson: Yes, but people who are here legally or who have started a course of treatment are actually entitled to continue with that treatment free of charge while they are here.

Q221 Chairman: I appreciate that, therefore you must know the cost of that course of treatment.

Miss Johnson: You mean the cost of an HIV course of treatment? It is an average of £14,000. It is somewhere between £10,000 and £18,000, depending on the patient, as I understand it, but the average that we use for costing purposes is £14,000 a year.

Q222 John Austin: On the risk issue as far as the general public health is concerned, in the evidence in a previous session, one of the witnesses, Dr Evans, in response to Dr Naysmith, was talking about the onward spread of HIV, and saying that they have reasonable data showing that the spread of HIV was strongly related to viral load, that viral load rises with the progression of the infection, etc, etc, and therefore saying that any delay in coming forward and being diagnosed is therefore likely to increase the spread of infection.

Miss Johnson: But there is no reason not to get a diagnosis, because the diagnosis is free.

Q223 John Austin: The diagnosis is free but the treatment is not available.

Miss Johnson: The treatment is available for all those who fit. We can have this debate but it is a balance at the end of the day. We do have to look at how we allocate the resources and what the balance is. To take a ridiculous example, if we were providing free treatment for anything for anybody, we could be providing a health service to the entire globe out of the UK. That is clearly not a sustainable position. Nonetheless, there is a balance to be struck on this, and the question is where do you draw the line in the sand? We have drawn the line on people ordinarily and legally resident in the UK, and they have to be legal residents here, or categories that fulfil that, such as an asylum seeker having their asylum application determined. Everybody is entitled to free diagnosis, but everybody in that category of legally resident is actually entitled to free treatment.

Chairman: I do not think anybody under-estimates the difficulties of decisions in this whole area. We are not in any way arguing that this is an easy area to address; I am sure it is not.

Q224 Dr Taylor: Going on with this theme, if I may, Minister, I think you said the decision to treat is always going to be the clinician's.

Miss Johnson: At the end of the day, yes, absolutely.

Q225 Dr Taylor: Even though the financial aspects for some people will have to be sorted out after the treatment has been started?

Miss Johnson: Yes, that is correct.

Q226 Dr Taylor: Have I got it straight that it is only illegal immigrants who will not be funded for treatment?

Miss Johnson: Yes. It is people who do not fulfil one of the legal residency requirements, and there are a number of categories; for example, if you are working here for a UK-based company, and there is a whole series—I do not want to run through the whole list because it is about a page of people who qualify under different categories—such as students here not for foreign language course purposes. There are lots of different categories of people who are entitled to use the NHS in this way, but what we have said is that people who are no longer legally entitled to be here . . . Actually, just on the point of appeal, while your appeal is being considered, you are still entitled to the free treatment, so if you appeal on an asylum case, for example.

Q227 Dr Taylor: But there could still be an appreciable number of people who are potentially infectious who are not getting treatment, and that must be a public health risk.

Miss Johnson: Yes. That is my point about the HIV/AIDS. People remain infectious. It does not matter how much treatment they get.

Q228 Dr Taylor: Although as soon as you begin to decrease the viral load, you begin to decrease the infectivity. Our attention has been drawn to . . .

Miss Johnson: Yes, but it is not like having another sexually transmitted infection where a course of antibiotics will remove the infection from the body. Let us just be clear. There is quite a difference here.

Q229 Chairman: Neither of your colleagues are medical experts, are they?

Miss Johnson: No, they are not.

Chairman: There are quite a few heads behind you shaking very vigorously. I do not think it is fair to press you on that. It is a very specific medical point.

Q230 Dr Taylor: I was only going to draw the Minister's attention to the paper we have been shown from Taiwan, which showed that the government policy of providing HIV-positive people with free treatment reduced the rate of HIV transmission by 53 per cent. That was in the *Journal of Infectious Diseases*. That is a fairly powerful bit of evidence that if there is an appreciable number of people around who are not being treated, there is a public health risk.

Miss Johnson: We obviously want to treat people because it improves their life chances and their quality of life and their life expectancy.

Q231 Dr Taylor: It protects other people.

Miss Johnson: That is not the main reason for treating people. The main reason for treating people is to improve their life chances and their life quality, and the question is, how far do our responsibilities as a government extend in this regard? I do not want to argue. I am very happy to get the Chief Medical Officer to write to you on the question of viral loads and all the rest of it. I have not seen this Taiwan paper. I have no idea where the research was done or what health service setting it was done in, nor what the circumstances of that are. The fact remains that you do not reduce to zero someone's infectivity by treating them when they have HIV/AIDS.

Dr Taylor: I think it is only fair to say we would like some of the medical background for that.

Q232 John Austin: I just want to go back to costs. You have said there is no estimate of numbers or likely cost savings of the changes, but what we do know is that the cost of treating someone with antiretroviral treatment is around £12,000 a year.

Miss Johnson: The average is £14,000 but I am not disagreeing with the broad, ball park figure.

Q233 John Austin: We understand that, without antiretroviral treatment, the chances are that that person will become seriously ill and may well need admission to hospital, possibly presenting at A&E, where of course A&E is free, but they may require treatment in hospital. If it is a matter of life and death, an emergency, that person will be treated but will presumably subsequently be billed for the services. I assume in most cases they are likely to be destitute, so the NHS is going to have to write that off at the end of the day. Has the Department done its sums on this, as to whether the cost of providing treatment might actually be a cost saving to the NHS rather than a cost liability?

Miss Johnson: It is probably lucky that none of us are the people actually treating the patients. It is up to clinicians to decide the circumstances under which they treat or continue to treat a patient. They are able to do so, and the easement provision in the regulations allows them to make those decisions and to continue to make those decisions. That was a very important part of the discussion around the regulations when they were revised.

Q234 John Austin: The clinician may admit the patient and treat the patient, but the cost of the treatment is likely to be twice the cost of the antiretroviral treatment they could have been given in the first place.

Miss Johnson: No, what I am saying is they can decide to treat the patient directly for HIV/AIDS if they decide to do so. That is a matter for them. The A&E attendances are free—of course, they are not free in one sense; they need to be paid for, but they are free to the patient and they are free whoever the patient is, under whatever circumstances.

Q235 John Austin: All I am saying is that the cost of treatment for someone who is denied antiretroviral treatment, who subsequently becomes seriously ill, is likely to be a bigger cost burden on the NHS than actually providing them with preventative treatment in the first place.

Miss Johnson: That is why it is a matter for the clinicians at the end of the day to decide, or it is one of the aspects why they should decide whether to treat or not.

Q236 Mr Bradley: Can I just be clear on this? What you are saying is that, with that clinical judgment and the fact that it would be half the cost to give the treatment in the first place, that is a decision that you would support because the cost to the NHS is much less than a person becoming ill and going into hospital through Accident & Emergency, and then receiving the treatment?

Miss Johnson: These decisions are made by clinicians.

Q237 Mr Bradley: You are happy for that to be the case?

Miss Johnson: I am happy for the clinicians to be making these decisions. I think it is right and proper that they make these decisions because they are in the best position to weigh these things up and to decide what the best course, the balance, is, taking into account both the patient's interests and wider interests in their decision-making.

Q238 Mr Bradley: And since it is cheaper to have the treatment in the first place, you would therefore, just in cost terms, recognise that that would be a beneficial decision by the clinician if they had the treatment at the earliest opportunity?

Miss Johnson: Every patient differs, every circumstance differs, and every clinician's judgment is for them to make. I cannot generalise about what is obviously a hugely diverse set of circumstances, and I am not a clinician.

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Q239 Mr Bradley: But you would want a consistent approach to this? As the Minister, you would want to ensure that each trust, each clinician, was dealing with people in this situation in a similar way?

Miss Johnson: The rules set out the overall framework and provide the arrangements under which people are treated free of charge or not. They will be treated with a charge whatever, but free-of-charge treatment provides the setting in which that takes place, provides the fundamental rules, the fundamental entitlements, and gives people advice about how those rules are to be operated. If a clinician wants to discuss something with the overseas patients manager in their trust, they are obviously at liberty to do so. They can seek advice from that person, but they are free to make their own decisions about things. I cannot generalise any more than I can generalise about what a GP should do for any other patient and for any other particular condition, because it is a matter for the doctor concerned.

Q240 Mr Bradley: But would you want to ensure that using the overseas patient officer is applying the test of eligibility consistently across the country? From your position, would you want to ensure that each trust, through that . . .

Miss Johnson: Yes.

Q241 Mr Bradley: You would?

Miss Johnson: Yes, but that is an application of the broad rules. You cannot argue about consistency in an easy way about individual clinician's decisions.

Q242 Mr Bradley: Do you monitor those decisions from the centre?

Miss Johnson: There are guidelines. There is a set of guidelines.

Q243 Mr Bradley: Do you monitor how they are being implemented?

Miss Johnson: There are obviously regular contacts. Elizabeth Ryan might want to comment on the contacts that are had between the Department and the managers, but clearly, there is regular contact between the Department and those involved with actually overseeing the implementation of the guidance.

Ms Ryan: As the Minister has said, we have issued very comprehensive guidance, which has gone to every trust, and which we know through our contacts with overseas visitors and managers is followed fairly closely. I and my team have regular contact with overseas visitors managers. We attend meetings of the overseas visitors support group that Pam Ward co-chairs. We have people telephoning us, seeking advice and so on, every day, so we do know what people are doing and we do know that, if a particular issue is coming up, we can be in a position to make sure that people understand what the correct procedure is.

Q244 Chairman: Would the kind of people ringing you be an individual GP or a PCT?

Ms Ryan: It is usually overseas visitors managers themselves, the people who are actually operating the procedure, but yes, we have telephone conversations with members of the public, and I have spoken to one or two GPs, yes. We will talk to anyone who wants to seek advice from us.

Q245 Dr Taylor: What bothers me, as an ex-clinician, is, with the clinical freedom, you start the treatment. Then the patient finds that they are one of the people who are not covered. Is there not a huge risk, when they discover the sort of bill they are footing, that they are going to just defect and not turn up and therefore stop treatment, and then they will be in an even worse state than before?

Miss Johnson: I am sorry. The circumstances were not clear to me. You say that they suddenly find out. I am not sure what that amounts to.

Q246 Dr Taylor: When the doctor starts them on treatment, does he say, because he has worked it out, "I am starting you on treatment but you are going to have to pay," or is that something that suddenly dawns on the patient later, so that when it dawns on them, they realise they are running up a huge bill that they can never ever afford, so they just stop the treatment and disappear, and then become another pool of infection?

Miss Johnson: If they are seeing the doctor in the first place, the doctor has presumably become aware of what their residency entitlement is, as it were, and therefore whether they are entitled or not in the first place. You are not talking about somebody coming in through an A&E clinic here. You are talking about somebody turning up for a booked appointment. I am assuming that the doctor may well know what the circumstances of that particular patient are in any case.

Ms Ryan: What would normally happen is that the patient will be told as soon as possible after first contact if they are likely to be chargeable. In an emergency, if somebody has turned up and they are clearly very ill and treatment needs to start straight away, then that treatment will happen, the treatment will start straight away, so there may be a day or two before it is possible to ascertain all the circumstances, to establish that they are chargeable, but you will not have somebody going weeks and weeks into treatment and running up a bill of thousands of pounds and then suddenly being told they have got to pay. That will not happen.

Q247 Dr Taylor: No, because as soon as they are told, they will defect, so they will not build up that bill.

Miss Johnson: One of the issues is, obviously, that some people do end up receiving charged treatment and are unable to pay, and so trusts do end up sometimes having to write off debts. That is not only in the HIV. We are only concentrating on this, but obviously these regulations cover a much wider area than HIV/AIDS. They cover the whole range of provision.

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Q248 John Austin: But with HIV, there is a major public health risk as well, which you, as a public health minister, must be concerned about.

Miss Johnson: Of course, and that is why we want people to come forward for diagnosis, and that is why we are encouraging them to come forward for diagnosis, and that is why diagnosis is free. For many of the people that we are talking about the treatment is also free. The question that you are raising is whether there is a public health advantage to free treatment for those for whom free treatment is not being provided, and what I am saying to you is that it is not like some of the other things for which we provide treatment, where there is a course of treatment and you are cured.

Q249 Dr Naysmith: We have evidence, Minister, that you will reduce the viral load by treatment, and that reduces infectivity, and that is known in HIV.

Miss Johnson: Yes, “reduces” is the imperative word, I fear, but this is a debate that I am sure the Chief Medical Officer will be very happy to engage in with you.

Q250 John Austin: The risk of transmission is very clearly linked to the viral load. The risk of transmission of infection is lower if the viral load is lower.

Miss Johnson: My point is that it is not zero. Somebody who has had a course of treatment for gonorrhoea and taken the course has a zero risk.

Q251 Chairman: We understand the point you are making. I am not sure everybody would agree with you, looking round the room. What I am interested in is, when we were looking at sex education—and we talked about this in the first part of this morning’s session—I have a vivid memory of lots of evidence 18 months ago about the continuing impact of section 28 on teachers’ views on what they could and could not say in the classroom, even though section 28 was withdrawn. Are you sure that clinicians understand exactly what they can and cannot do, or could we have an ongoing section 28-type situation, which could have serious public health consequences, because of a lack of clarity about what they can and cannot do, and a fear that what instinctively they want to do could have repercussions?

Miss Johnson: I am sure it is possible to produce some examples of confused clinicians with 1.3 million staff in the NHS, of whom quite a lot are doctors. Some of them may not be fully abreast of everything about everything. I cannot say that you are not going to produce some examples like this, but we would be concerned if people generally had some kind of misunderstandings about this, that there were myths of some kind out there. We would, of course, be very concerned about that. That is one reason why the regulations were revised to end up with fundamentally exactly the same basis that they had always had prior to 2004, but they were tightened in a way that made it clearer exactly who was eligible and who was not. I think the main change, which we have talked about at some length,

was the 12-month provision. It was never meant to cover those who had stayed illegally for 12 months; it was meant to cover those who were ordinarily resident; it was just that “ordinarily resident” had not been translated into “legally resident,” and we just made it clear that that was always the intention of it. So the whole purpose of doing this—and there is a discussion going on currently about primary care in the same way, with consultation—was to consult in a widespread consultation over this. It took a considerable period of time, and Elizabeth may want to say all the organisations that were involved in that. We have done our best to make sure that there is buy-in understanding and that this does clarify the situation considerably. That is not to say you will not find an example out there of somebody who does not understand.

Q252 Chairman: As far as Ms Ryan is concerned—and you mentioned earlier on that you do have contact with trust charging officers—you would feel that the Department has taken as many steps as it can do to ensure that the people who are in the front line, the clinicians who will meet the patients, fully understand what these regulations mean, and from a public health perspective, do not feel constrained?
Ms Ryan: Yes, I am very confident of that. The guidance is very clear that clinical priority comes first.

Q253 Dr Taylor: I am going on exploring that, because what we are missing is an actual clinician on that handle. If I can just pass on a comment that has been passed to me, it has been said by one of our experts that, because of the anonymity and the confidentiality and the open access of these sort of clinics, the doctors do not know every issue at the time when they have to start the treatment, and they are not really able to work it out, and there is no standard way that these people are assessed in clinics in practice, therefore people are being started on the treatment before they are aware at all of the costs, and so there is a huge risk of drop-out.

Miss Johnson: There is no reason why those who are managing the clinic should not be having a regular dialogue with the overseas visitors managers. If they are not doing so, obviously, they will necessarily be short of understanding and guidance, but there is no reason why that should not be taking place, and I am sure that the overseas visitors managers stand very ready to have a chat, either with clinics or with individual clinicians, whatever. As you know, people do not just turn up and get immediately put on a script for HIV/AIDS treatment, so it is not just going to happen overnight.

Dr Taylor: I can see a recommendation coming!

Q254 Dr Naysmith: Minister, this whole area has all sorts of potential ethical dilemmas between doctors and patients, and doctors and their employers, given what we have just been talking about, and doctors having the freedom to start a treatment, and then maybe a PCT deciding that they do not have enough money for it to continue, or whatever reason. We know from evidence that was given to us that

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doctors do not like this kind of gatekeeper role in this area. Have you had any discussions with the GMC about the implementation of this policy and what it means for the professionals who have to take these decisions?

Miss Johnson: Elizabeth may want to comment. It was before my time in the Department that a lot of the discussions were going on, and I am not the Minister who deals with this on a day-to-day basis either. What I would say is that people have had plenty of opportunity to be involved with the consultation. We did discuss the question of easement for clinical decision-making, and that easement was built into the new guidance that was issued. When you say people running out of money, I am not quite sure what you mean. I do not think people run out of money.

Q255 Dr Naysmith: I did not say “running out of money”.

Miss Johnson: I thought you did.

Q256 Dr Naysmith: I am sure the transcript will show. There are two primary care trusts in my area. Somebody in my constituency moved from one to the other recently, and they were receiving a treatment paid for by one, and when they moved into the next one, they were told they could not have it, until I intervened. There is room for that kind of

misunderstanding in this area, particular since I suspect in some parts of the country all PCTs do not have overseas visitors managers.

Miss Johnson: Overseas visitors managers. All the trusts do.

Q257 Dr Naysmith: I am sure they do, but in some places they will get a lot to do and in other places they will not get very much to do, and it is that kind of area where you can get problems arising because they just read a circular and think “This is what we do.”

Miss Johnson: I am sure their association also provides support and guidance as well, and I know that you had the opportunity of taking evidence from Pam Ward.

Q258 Dr Naysmith: We are quoting experts, and one of our experts passed me something that I should have known when I was talking about virus load. Basic epidemiology says quite clearly that you do not have to reduce a risk to zero; you only have to reduce it to less than one. Our experts win!

Miss Johnson: I note that. I think we shall have to get the experts to do battle. I nonetheless maintain the very firm understanding, which is that there is a zero risk for some things after treatment and there is not a zero risk with HIV/AIDS.

Dr Naysmith: I should have known that because of a basic immunology course I did many years ago. That was something I should have known.

Chairman: Minister, can I thank you and your colleagues for a very useful session. We are most grateful to you.

**Letter from Melaine Johnson MP, Parliamentary Under Secretary of State for Public Health,
Department of Health (SH 1A)**

During the evidence session on 10 February, undertaken as part of the Committee’s inquiry into sexual health and HIV, I agreed to write to you on a number of points and provide further information.

You spoke about your conversation with the Director of Yorkshire Mesmac, where he had expressed concern about the 48 hour waiting time target for GUM services (Q153). In particular it was alleged that at least one clinic in West Yorkshire achieved the target by not answering the telephone once all the following two days’ appointments were full.

Naturally, this is a cause for concern. I can assure you, however, that the procedures in place to monitor GUM waiting times, are designed to preclude any attempts to manipulate performance data. The survey data collected from patients attending GUM specifically asks when the first attempt was made to contact the clinic, including where the patient called but the clinic was closed, or the telephone was busy. Clinics will therefore, not be able to give the impression that they are meeting the target, when they are actually providing what is effectively a reduced service. I have asked my officials to share the relevant extract from the transcript of the evidence session with the sexual health lead of the Primary Care Trust in question, so that they are aware of this issue and can follow-up as appropriate.

On the question of when we received the data arising from the first phase of the GUM services review, currently being undertaken by MedFASH on behalf of the Department, I agreed to let you know when it was received(Q170). I understand that it was first received by officials in the Department in late December. As was stated at the evidence session, however, neither myself nor Geoff Dessent had sight of the document until early February, when you wrote and asked for it to be made available to the Committee.

Regarding payment by results for GPs providing contraception, and concerns that this could act as a disincentive to prescribing longer acting methods of contraception (Q200), a key element of the Government’s strategy in respect of contraception is to improve access to a wider range of methods. As you may be aware the National Institute for Clinical Excellence (NICE) is developing a clinical guideline on long acting methods of contraception. The guideline will provide recommendations for good practice that are

based on the best available evidence of clinical and cost effectiveness. This guideline together with the results of the national audit, backed by the £40 million additional investment from the public health White Paper 'Choosing Health', will help ensure that these issues are addressed.

I thought it might also be helpful to take this opportunity to clarify my comments about the new "easement clause" in the hospital charging regulations. Some of my remarks could, I think, have been taken as implying that it is a matter for clinicians to decide whether the easement clause should apply in any particular case. In fact the arrangements automatically apply where the required conditions are met. Thus, any overseas visitor who begins any course of hospital treatment free of charge must continue to receive that treatment free until it is completed, even if, for whatever reason, it is later established that they are no longer, or perhaps never were, eligible for free treatment. What is a matter for clinicians, of course, is when a particular course of treatment is complete. For HIV in many cases this will mean treatment will continue free of charge for a very long time.

28 February 2005

Written evidence

APPENDIX 1

Memorandum by the Medical Foundation for the Care of Victims of Torture (HA2)

NEW DEVELOPMENTS IN HIV/AIDS AND SEXUAL HEALTH POLICY

- The Medical Foundation for the Care of Victims of Torture (the “Medical Foundation”) is a human rights organisation that works with survivors of torture and organised violence, providing them with a range of psychological, medical and rehabilitative services.
- The majority of Medical Foundation clients are asylum seekers and refugees. However, increasingly the Medical Foundation is seeing its clients not being granted international protection, even though they are survivors of torture.
- A significant proportion of Medical Foundation clients (men and women) are survivors of rape and other forms of sexual violence. This year the Medical Foundation published “Rape as a Method of Torture”, a book written by a multidisciplinary team from the Medical Foundation, which reflects on significant clinical experience working with victims of persecution which has included rape. It includes a chapter on sexually transmitted infections as a consequence of rape.

THE CONSEQUENCES OF THE NEW AND PROPOSED CHANGES IN CHARGES FOR OVERSEAS PATIENTS WITH REGARD TO ACCESS TO HIV/AIDS SERVICES

1. In its response to the Department of Health Consultation on proposals to exclude overseas visitors from eligibility to free NHS primary medical services, Medical Foundation noted its concern that HIV/AIDS treatment was not exempt.

2. The Medical Foundation does not believe that restricting access to free HIV/AIDS treatment will reduce the number of people claiming asylum in the UK. There is no good evidence base to suggest that asylum seekers are “health tourists”; often they are fleeing civil war, political persecution, torture and other extreme stressors. The inclusion of asylum seekers of any category (including those whose claims have failed) is not a sensible step in combating “health tourism”, but rather will exacerbate the hardship for an already vulnerable group.

3. The Medical Foundation does not believe that a policy where patients can be tested, but not treated, for HIV/AIDS is an ethical, safe (in terms of public health) or logical one. Clients are unlikely to deem testing for HIV acceptable if there is no realistic hope of treatment (based on their experiences in their countries of origin where a diagnosis of HIV equates to a death sentence because of the lack of available treatment). Without knowledge of their HIV status they may not make changes in behaviour which would prevent onward transmission.

4. Medical Foundation believes that as far as possible the management of HIV, other sexually transmitted infections and TB must be integrated, accessible and delivered by methods designed to minimise stigmatisation of this patient group. It further believes that access to free primary care has a key role to play in identification and referral of patients at risk.

5. Medical Foundation regularly treats women who have conceived through rape, who may also be HIV positive (either through rape or otherwise). It is Medical Foundation’s strong belief that pregnant women must be offered free HIV care in order to minimise the risk of vertical transmission to the child.

RECOMMENDATION

6. Asylum seekers of any category should be entitled to free treatment for HIV/AIDS. The Medical Foundation does not believe that those who come to the UK to claim protection from persecution in their countries of origin are so called “health tourists”. As a group they already face significant barriers to accessing health care, and (by nature of government restrictions not allowing them to work in the UK) are without the means to pay for treatment.

APPENDIX 2

Memorandum by Children and Young People HIV Network (HA 3)

SUMMARY

This memorandum sets out the impact charging overseas patients will and is having on HIV positive children in the UK. It presents financial and ethical reasons for why HIV treatment such as highly active antiretroviral therapy (HAART), which has been so successful in preventing illness and prolonging life, should be excluded from this charging scheme. It presents how this goes against other government policies in regards to children. Also included is the progress to date of implementing some of the recommendations from the Health Select Committee within the children's HIV sector. The information provided reflects the views and experiences of both health and the voluntary sector in relation to children living with HIV in the UK.

Within this memorandum, the term "affected" refers to those children living in a family where one or more members are HIV infected.

THE CONSEQUENCES OF THE NEW AND PROPOSED CHANGES IN CHARGES FOR OVERSEAS PATIENTS WITH REGARD TO ACCESS TO HIV/AIDS SERVICES

The Network is concerned that the government is sending out conflicting messages. In the foreword of the NHS Improvement Plan, the Prime Minister stated in paragraph 1: "Despite past frustrations, the NHS and its values—healthcare for all according to need, not ability to pay—retain overwhelming public support. So, too, do its dedicated, skilled and compassionate staff".¹ Yet the proposed changes in charges will mean that NHS treatment will not be offered on the basis of need.

Case Study: A Doctor was informed by the Primary Care Trust (PCT) that funding was not available to treat an HIV positive child who did not at that time have leave to remain. This child was rapidly progressing to an AIDS related illness and had to be admitted to intensive care where the illness was treated, but still highly active antiretroviral therapy (HAART) was not permitted to be prescribed. The Doctor argued that one week in intensive care was the financial equivalent to nine months HAART, and that without HAART this child would have many periods in intensive care, with little hope of long-term survival.

We find the provisions to allow a child access to expensive intensive care treatment, yet not HAART, nonsensical. This procedure saves the PCT no money and causes unnecessary suffering to the child.

1. The Children Act 2004, section 11 gives a "duty to promote welfare" to all health bodies in regard to children's health and well-being and the Local Government Act 2000. Section 2, gives a duty for the "Promotion of well-being" to all local governments. In addition, the 1989 UN Convention on the Rights of the Child, ratified in the UK in 1991, states in article 6 that the child has the "right to survival and development"; continuing from this the Convention grants all children, amongst other things, the right to "the enjoyment of the highest attainable standard of health".² We believe that these new proposals contravene those valuable provisions to safeguard children's well-being.

2. "Overseas patients" includes those fleeing war torn countries to seek refuge in the UK. Many of these countries have high levels of HIV infection. Under these proposed changes, Clinicians will be expected to deny children essential medication (HAART) to prolong their lives because their families will have no way of paying for this.

3. Those working in Paediatric HIV Health, as with all health care workers, follow standards of medical ethics. Watching a child's health deteriorate when there are interventions available that could stop that child's suffering would seriously undermine that ethical practice and in turn affect workforce morale and eventually numbers.

4. Available data states that there are just over 850 children infected children (only including those born since 1989), a figure that has gradually risen since the pandemic began. Of these, approximately 45% were born abroad.³ But we do not know the figure for those who would not be entitled to NHS treatment under the new legislation.

5. When a pregnant woman is aware of her HIV status and takes appropriate interventions including anti-retroviral medication for herself and the baby, having a caesarean delivery and avoiding breast-feeding, the risk of the baby being infected is only 1%. Without interventions the risk of transmission is about 30%. If pregnant women were denied access to free care there would be many more babies infected with HIV, which is completely unacceptable.

¹ The NHS Improvement Plan: Putting People at the Heart of Public Services, June 2004.

² United Nations (1989) The Convention on the Rights of the Child. Adopted by the General Assembly of the United Nations on 20 November 1989. Geneva: Defence for Children International and the United Nations Children's Fund.

³ Royal College of Obstetricians & Gynaecologists; National Study of HIV in Pregnancy, Newsletter 60.

6. Children infected by HIV who are diagnosed and treated early live well for many years. Policies that result in exclusion and discrimination of people from accessing HIV health care are likely to counteract promoting HIV testing programs. This would undermine the Government's HIV testing campaign with the African communities and HIV testing in pregnancy. There is already evidence that some HIV positive children whose parents have been denied care after failed Asylum claims have disappeared from care services.

PROGRESS TO DATE IN IMPLEMENTING THE RECOMMENDATIONS OF THE COMMITTEE'S INQUIRY INTO SEXUAL HEALTH (THE COMMITTEE'S THIRD REPORT OF SESSION 2002–03)

7. The following information is in regard to Paediatric HIV service provision and voluntary sector service provision for HIV positive and affected children. Reference will be made to the numbered "Conclusions and recommendations" of the House of Commons Health Committee: Sexual Health.⁴

8. *Paragraph 2: patient involvement*

The Royal College of Paediatric and Child Health Infectious Diseases and the Children's HIV Association have striven to include the voices of HIV positive children in service development and delivery. HIV positive young people have been asked to present at events and voluntary sector organisations have been included in service development.

9. *Paragraph 11: single-handed consultants; Paragraph 20–21: adequate funding*

Following the London review of paediatric HIV services⁵ the specialised services commissioners group recommended a similar exercise for paediatric HIV services outside of London too, with an aim to develop national clinical networks for families with HIV.

10. CHINN (the Children's HIV National Network) was funded by the DoH and has brought together lead clinicians, commissioners and the voluntary sector to undertake a review of and support the development of regional clinical networks. These will work with the principle that all children and families with HIV have access to the same standard of care wherever they live in the UK.

11. There are now over 300 children with HIV living outside of London. It is impractical and inappropriate for all these families to travel to London for treatment and care. There are also increasing numbers of women with HIV giving birth and their family management is increasingly complex. It is essential that there are family centred services that can provide high quality HIV care, which is local to the family.

12. The CHINN review of services outside of London highlights the limited resources for Paediatric HIV services. Provision is often run from the good will of staff over and above their regular work. Specialist positions funded outside of Greater London consist of two part-time Consultants, two full-time and three part-time Nurses, one secretary and one day a week for a Pharmacist. This is clearly not sufficient to meet the needs of over 300 children and their families as described in the previous paragraph.

13. *Paragraph 24: voluntary sector resources*

There is limited work occurring to meet the support needs of both HIV infected and affected children through voluntary sector services. The actual number of affected children living in the UK is unknown, but an informed estimate is greater than 10,000. The Children and Young People Network will be working with Children with AIDS charity and the African HIV Policy Network to produce a toolkit to support voluntary and community sector organisations to work holistically with infected and affected children and their families.

14. *Paragraph 37–39: basic knowledge*

The Children and Young People Network has been working with the Department for Education and Skills (DfES) lead, and representatives from Local Authorities and the Health Development Agency to produce guidance for schools on supporting pupils living with and affected by HIV. This will be published in spring 2005 and will work towards raising the complex issues of stigma and discrimination in regards to HIV infection in the school setting.

⁴ House of Commons Health Committee: Sexual Health, Third Report of Session 2002–03 Volume 1 (pp 95–104).

⁵ Developing Clinical Networks for Paediatric HIV Treatment and Care in London (2004).

ADDITIONAL INFORMATION/RECOMMENDATIONS

15. "Overseas visitors" infected or affected by HIV or AIDS should not be charged for NHS treatment because:

- The system will be unmanageable. Will all patients be asked to prove they are entitled to treatment? Or will certain groups be targeted and discriminated against?
- The impact on NHS staff morale and ethical practice will be enormous; having to send ill children away without definitive treatment, knowing that they will return as emergency patients will be demoralising.
- Cost-benefit analyses suggest that providing definitive out-patient treatment (HAART) for those that meet the clinical criteria for starting therapy is a cheaper option than not giving HAART and treating life-threatening consequences of HIV infection with intensive or high-dependency in-patient care.
- The impact on individual children and breach of their human rights, "Convention on Human Rights" cannot be overstated. New Government legislation, such as the Children Act 2004 aims to protect children from harm and yet in this particular ruling, denial of medical care could cause harm.

APPENDIX 3

Memorandum by The British Association for Sexual Health and HIV (HA 4)

CONSEQUENCES OF THE NEW PROPOSED CHANGES IN CHARGES FOR OVERSEAS PATIENTS WITH REGARD TO ACCESS TO HIV/AIDS SERVICES

Summary

HIV positive patients in the UK irrespective of immigration status are of public health concern. Those that are seeking asylum or have undetermined status are often extremely vulnerable with complex needs requiring health care appropriate to their medical condition. The new and proposed changes in charging may result in increasing discrimination, discouraging people coming forward for testing at a time when the health agenda is to seek to identify those who are unaware of their status. Increasing barriers to individuals who do have entitlement to free treatment for other infectious diseases is an unwanted outcome. Other possible consequences include greater cost to the public purse through ongoing transmission of infection, including to unborn children and for emergency medical treatments due to complications. This raises questions about the public health implications of denying certain groups' access to health services and places clinicians in difficult ethical dilemmas. Charging for overseas patients is unlikely to deter people from seeking asylum, or encouraging those refused to return to their countries of origin. An opportunity to reconsider these changes is welcome.

1. There are humanitarian and human rights concerns in the application of changes to the regulations. A clinician asked to care for foreign national with a possible communicable disease ethically should treat everyone according to their assessed clinical need. Doctors recognise that providing antiretroviral therapy for HIV is expensive but whilst there maybe a short term cost reduction to local NHS budgets, in the longer term the overall cost to the public purse, public health and the individual may be greater. Several days in intensive care because of an emergency, life-threatening infection is more expensive than a year of antiretroviral therapy.

2. Reducing the risk of onward transmission of infection and the risk of progression of infection is paramount to using health care resources effectively. There is an irrefutable argument to prevent mother to child transmission of HIV to unborn children. This requires all HIV positive mothers to be offered antiretroviral treatment. After birth, free formula feed must be provided to avoid breast milk transmission.

3. The change in regulations may influence people within communities of high prevalence to come forward for testing if they are unable to obtain treatment. There is also the danger of misinterpretation of the regulations to refuse treatment to those who are entitled.

4. There are potential differences between clinics according to interpretations of the regulations that fuel health inequalities.

5. Those cases admitted as emergencies are not always made aware of possible subsequent charges. Many of these people are unable to pay. They have no legal means of employment and are effectively destitute which means that billing them is a waste of time and money. Further stress is placed upon already unwell individuals.

6. It is difficult ethically and clinically to separate HIV from other sexually transmitted infections, and other contagious diseases such as TB for which free treatment is provided.

7. Should the Home Office decide that the person is to be removed from the UK, even a short time on antiretroviral therapy may provide benefit. In such cases patients should have a detailed summary of their medical care and treatment in the UK that can be given to care providers in their destination country. Preferably medication should be provided for a minimum period of time from the date of their removal. Patients should be advised properly how to stop therapy if that is the outcome to reduce risk of viral resistance developing.

Conclusion

8. People with HIV who are unable to access antiretroviral treatment and other services will remain in the community and be more infectious than with treatment. There will be less opportunity to support safe sexual behaviour and avoidance of onward transmission.

9. Discussion of charging regulations may discourage people including some entitled to free NHS services from coming forward.

10. The effort and resource required to bill people for care and treatment, who are unlikely to be able to afford it is wasteful. This may also fuel fears of unfair discrimination, risking delayed presentation for testing and increased vertical and horizontal transmission of HIV in the UK.

11. Clinical failure to treat according to guidelines runs the risk of patients requiring expensive emergency treatments repeated many times, which is not cost saving.

12. The immigration status of migrants is the responsibility of the Home Office. HIV status should not be a sole factor in deciding immigration status of individuals, nor should the need for antiretroviral treatment ensure granting right of residency.

PROGRESS TO DATE IN IMPLEMENTING THE RECOMMENDATIONS OF THE COMMITTEE'S INQUIRY INTO SEXUAL HEALTH (THE COMMITTEE'S THIRD REPORT OF SESSION 2002–03)

Summary

The Committee's report raised the profile of sexual health and made this a higher priority. The result of increased resources has had some impact on GUM service delivery. However, there are major concerns from GUM physicians with the continuing deterioration of service access that has marked regional variation. There is increased demand, rising STI and HIV rates with insufficient capacity within GUM to deal with the demand. There is little capacity across other providers who require training and support to deliver sexual health care. Further resources are needed without delay, which must reach the services for which they are intended. This requires either ring fencing or robust performance management. "Choosing Health" is welcomed but the implementation plan and resource distribution are key to alleviating the deterioration in GUM services since the publication of Health Select Committee Report. Manpower, estates and space requirements are immediate priorities for all clinics. Provision of training budgets is necessary to build capacity amongst the plurality of sexual health providers.

Introduction

1. The National Sexual Health and HIV Strategy published in 2001 set out a framework for improvement of sexual health services. GUM services were identified as key stakeholders as major service providers for sexually transmitted infection (STI) and HIV diagnosis, treatment and care across a range of providers. GUM services are central to clinical governance.

2. The House of Commons Health Committee Sexual Health Report published in 2003 was crucial to raising the profile of sexual health and getting this onto the political agenda where professional and voluntary care organisations had failed to get their concerns acted upon. The resultant increase in resource was welcomed but the £8 million recurrent resource received by GUM services was less than a third of the £22–30 million estimated in 2001 to address capacity issues. This lack of recurrent resource has been a major factor in continuing deterioration of services.

3. The recent publication of the White Paper—"Choosing Health: Making Healthy Choices Easier" has started to address many of the issues raised by the committee. Sexual health has been recognised as a major public health problem. There is now political leadership with central direction. The £130 million allocated to "modernisation of genitourinary medicine services" would impact on service.

4. Concerns persist that BASHH wishes to draw to the Health Select Committee attention.

Recent Epidemiological data (Ref 1)

5. The numbers of newly diagnosed HIV accelerate year on year. There are an estimated 53,000 cases of HIV (HPA data 2003). Between 2001–02 and 2002–03 there was a 20% and 19% increase respectively of reported new cases. Of the 7,000 new cases in 2003 over half were infected abroad from high prevalence areas. This increases the burden on services disproportionately as these patients are often complex cases, presenting late with many other social and health care needs.

6. Co-infection with other sexually transmitted infection is increasingly common. Hepatitis C in HIV positive patients is an additional burden requiring more complex management and expensive medication

7. Since the publication of the National Sexual Health and HIV Strategy in 2001, overall STI diagnoses have risen by 11% (Table 1). There is geographical variation, with the Northern and Eastern regions showing the most marked increases.

- (a) Syphilis outbreaks have continued with an increase of 112%. The epidemic now affects heterosexuals in addition to men having sex with men (MSM). Cases of congenital syphilis are being seen. However, there is no national surveillance system for congenital syphilis at present.
- (b) Gonorrhoea cases diagnosed in GUM clinics have increased by 5% from 2001. Whilst between 2002–03 there was an apparent reduction in gonorrhoea of –2% through GUM surveillance, laboratory reports increased by 11%. From 2002–03, there was an increase of 11% of gonorrhoea in MSM indicating continuing high-risk behaviour in this group.
- (c) Diagnosed cases of Chlamydia have increased by 25% from 2001–03. This may in part be due to Chlamydia screening activity in other settings generating higher levels of awareness within the young sexually active population and more coming forward for testing.

GUM response to National Sexual Health and HIV Strategy

8. All clinics have changed their clinical practice and protocols to increase capacity since the publication of the national strategy. With increased resource of 8% over the baseline cost for GUM Clinics of about £114 million, workload figures increased by at least 15% in 2003.

9. Virtually all now offer HIV testing to all new patients and almost half have moved to an opt-out policy for testing. The targets set in the Sexual Health and HIV Strategy to reduce undiagnosed HIV have been surpassed. Tests offered to MSM are now more than 64% (2007 target 60%). For heterosexual attenders the offer rate is over 56% (2004 target 40%).

10. The proportion leaving the clinic with an undiagnosed HIV infection has fallen from 55% to 45% for MSM and for heterosexuals from 48% to 41% between 1998 and 2003.

11. For Hepatitis B vaccination, 85% received the first dose (2004 Target of first dose uptake of 80% in 2004).

Access to GUM services

12. The ability for patients to be seen has deteriorated since 2001 with the increased demands of patients wishing to access the services. In 2001 the mean waiting time was 11 days for men and 12 days for women.

13. The joint BASHH/HPA monitoring of access in May 2004 showed that overall in England only 38% of patients were seen within 48 hours and 30% wait more than two weeks to get an appointment.

14. There is regional variation with worst access outside London. In Northern region 50% of the patients wait more than two weeks to be seen with only 21% seen within 48 hours; in Yorkshire and Humberside and Eastern 45% have to wait over two weeks with only 28% able to access a service within 48 hours.

15. The regional data for GUM waiting times for clinics compared with the number of cases diagnosed show increasing diagnoses of Chlamydia, gonorrhoea and syphilis in association with increased waiting times. (Table 2). These data do not necessary prove a causal link but the argument that increased delay to diagnosis and treatment provides greater opportunity for onward transmission of infection is compelling.

Allocation of resources

16. Although sexual health services were deemed a priority, with “Shifting the balance of power” the lack of a star rating for STIs and HIV within Performance and Planning frameworks 2001–04 resulted in inability to ensure investment in sexual health.

17. The 2004 DH figure for investment and modernising in GUM services is £26 million; In January 2003, 90% of £5 million allocated direct to GUM clinics was received. £10 million was allocated as recurrent funding in 2003–04 of which £8 million was distributed to PCTs by July 2003. Only 64% received their full allocation clinics. Of a further £5 million of non-recurrent money given for GUM services in January 2004, approximately 50% of the money reached its intended destination.

18. BASHH has received further reports that some Trusts who agree to carry over the money to 2004–05 have used money for more pressing priorities. One example serves to illustrate the difficulties faced by front line clinicians. A GUM consultant negotiated that £58,000 was carried over from 2003–04 to 2004–05. Job descriptions were ready, an advertisement placed when she was informed by her immediate manager that this money was no longer available. It was required for an overspend elsewhere. She raised this with the PCT Sexual Health Commissioner, Strategic Health Authority Public Health Lead having failed to influence the Chief Executive. She has been told to keep quiet and stop making a fuss. This bullying behaviour is unjustifiable.

19. £1.1 million was released in 2004–05 to the 10 successful pilot sites identified through the Joint DH/BASHH Working Group. This is short of £2 million promised for 2003–04.

Current Issues

Demand for GUM services is not being met. Manpower and space are major issues.

20. The Health Select Committee was informed of a shortfall of 90% in consultant numbers against the recommendations of the Royal College of Physicians (paragraph 8, page 95). Consultant numbers have increased by 4% between 2002–03. Nearly 16% consultants still work single-handedly compared with 19% in 2002.

21. Increased numbers of nurses, health advisers and laboratory technicians are needed to cope with demand.

22. The poor condition of many GUM premises was noted by the Health Select Committee (recommendation 14). Around 40% clinics do not have dedicated premises.

23. More than eight out of 10 clinics regard shortage of space to be a major limiting factor inhibiting service development and modernisation

24. The DH/BASHH Group reviewed more than 70 tenders amounting to £100 million. £15 million of capital monies provided in 2003 have now been allocated but mainly to those in unsafe accommodation and portakabins. This capital money is welcome but is insufficient to address the sub-standard accommodation resulting from years of under-investment.

25. Information campaigns although targeted to change sexual behaviour, inevitably raise awareness around STI which fuels demand for services especially those emphasizing asymptomatic nature of many infections

26. Delaying health information campaigns until more capacity exists would avoid difficulties in meeting public expectations.

Chlamydia Screening

27. The goal of national coverage for Chlamydia screening by March 2007 indicated in “Choosing Health” is welcomed.

28. Almost half of all GUM clinics still do not have Nat’s Chlamydia testing available for all men and women attending as patients.

29. There should be equity of access to NAATs irrespective of age. In practice there is a postcode lottery. For example an area which has financial support for Chlamydia screening programme has NAATs for under-25s presenting in community and other screening settings whereas the GUM Department has EIAs.

30. In 2004, 45% of laboratories are still using EIA test methodology and 45% of all Chlamydia tests are undertaken using EIA. The £7 million allocated to change test methodology will not impact until the financial year 2005–06.

Costs of HIV treatment and care

31. Increase in detection of new HIV cases means an increase of costs of HIV antiretroviral therapy The cost of provision for newly diagnosed patients in 2003 will be in the region of £35–50 million (50–70% of 7000 needing treatment at £10,000 per year)

32. The laudable aim of reducing undetected HIV infection will increase the number of people requiring HIV treatment and care. Overspend on drug budgets this year is inevitable in London. It is unlikely that the financial impact has been fully appreciated or can be catered for by PCTs across England.

Training and Clinical Governance

33. There is little capacity outside GUM services at present. It will take time for capacity to build up amongst the plurality of sexual health providers.

34. Training programmes supported by GUM are required. There is no training budget allocation for this. Whilst GUM physicians are committed to provide theoretical training through the STI infection foundation course devised by BASHH in collaboration with other providers, providing practical training will require additional funding over that required for increasing service capacity.

35. The speciality recognises its key role in clinical governance of sexual health service provision to ensure standards are maintained across service providers and quality of care for patients through clinical networks. Time is needed to fulfil these roles and to increase collaboration between the statutory and voluntary care sector to better utilise resource.

Implementation of “Choosing Health”

36. BASHH welcomes the public health white paper and looks forward to supporting its implementation

37. The resource allocation and distribution of £130 million for modernising GUM services is key to achieving the 48-hour access goal. Delay until 2006–07 will give little chance of success. There is some concern that this money is unlikely to be sufficient to cover both recurrent resources and the capital expenditure needed to modernise clinics to be fit for the 21st Century.

38. Robust performance monitoring by Strategic Health Authorities is clearly a requirement to ensure that resources directed to PCTs reach the services for which they are intended.

Conclusion

39. An increase in GUM service capacity is essential. This requires increase in manpower, space and improvement of facilities

40. This needs immediate action with no delay in provision of some resource to incrementally move towards the 48-hour access target. This should be clearly defined as a target for “next available appointment” and not emergency walk in.

41. Community provision requires incentives to engage primary care. Specific Quality and Outcome Framework points are needed within the nGMS GP contract to achieve this.

42. GUM services have a responsibility to facilitate training and support other health care workers who will be expected to provide STI diagnosis and care. GUM services need a training budget need to increase their training capacity. It is important that PCTs recognise the key role of GUM in terms of Clinical Governance. Training and responsibilities for diagnosis and management of STIs and HIV should be overseen by those who are accredited in the speciality of GUM/HIV.

REFERENCES

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2. Kinghorn GR, Abbott M, Robinson AJ, Ahmed-Jushuf. BASHH survey of additional Genitourinary medicine-targeted allocations in 2003 and 2004. *Int J STD AIDS*. 2004 Oct 15: 650–2.

Table 1

STI DIAGNOSES IN ENGLAND 1995–2003

	<i>Number of annual cases</i>			<i>% increase</i>		
	<i>1995</i>	<i>2001</i>	<i>2003</i>	<i>1995–2003</i>	<i>2001–03</i>	
All STI diagnoses	428,575	608,636	674,827	1.574583	57%	11%
Syphilis	102	717	1,519	14.89216	1,389%	112%
Chlamydia	29,241	68,256	85,550	2.925687	193%	25%
Gonorrhoea	9,950	22,418	23,584	2.370251	137%	5%
Genital warts	51,236	62,551	65,414	1.276719	28%	5%
Genital Herpes	15,021	17,076	17,173	1.143266	14%	1%

**CHANGES IN NUMBERS OF CASES OF BACTERIAL SEXUALLY TRANSMITTED
INFECTIONS IN GUM CLINICS**

Chlamydia change 2001–03

<i>Region</i>	<i>Numbers of cases diagnosed in GUM</i>						<i>Waiting times for GUM clinics</i>	
	<i>ct male</i>			<i>ct female</i>			<i>% patients seen within</i>	
	<i>2001</i>	<i>2003</i>	<i>% change</i>	<i>2001</i>	<i>2003</i>	<i>% change</i>	<i>48 hrs</i>	<i>2 weeks</i>
South West	2,314	2,626	13%	2,799	3,218	15%	42	70
London	8,594	9,850	15%	9,364	10,170	9%	54	85
East Midlands	2,371	2,826	19%	3,429	3,848	12%	42	73
West Midlands	3,070	3,764	23%	3,594	4,648	29%	28	60
Eastern	2,060	2,751	34%	3,471	4,450	28%	28	55
South East	3,046	4,119	35%	4,112	5,703	39%	37	76
Yorks & Humber	3,292	4,575	39%	4,557	5,800	27%	27	65
North West	4,005	6,145	53%	5,844	7,677	31%	28	65
North East	852	1,404	65%	1,502	1,976	32%	21	50
England	29,604	38,060	29%	38,652	47,490	23%	38	71

Gonorrhoea change 2001–03

<i>Region</i>	<i>Numbers of cases diagnosed in GUM</i>						<i>Waiting times for GUM clinics</i>	
	<i>ct male</i>			<i>ct female</i>			<i>% patients seen within</i>	
	<i>2001</i>	<i>2003</i>	<i>% change</i>	<i>2001</i>	<i>2003</i>	<i>% change</i>	<i>48 hrs</i>	<i>2 weeks</i>
London	6,765	6,184	–9%	2,740	2,632	–4%	54	85
West Midlands	1,838	1,842	0%	952	912	–4%	28	60
North West	1,981	2,096	6%	756	776	3%	28	65
East Midlands	897	961	7%	485	504	4%	28	60
South East	1,347	1,485	10%	469	595	27%	37	76
South West	808	958	19%	310	439	42%	42	70
Eastern	643	807	26%	358	432	21%	28	55
North East	371	468	26%	174	226	30%	21	50
Yorks & Humber	1,019	1,519	49%	585	748	28%	27	65
England	15,669	16,320	4%	6,749	7,264	8%	38	71

Syphilis change 2001–03

<i>Region</i>	<i>Numbers of cases diagnosed in GUM</i>						<i>Waiting times for GUM clinics</i>	
	<i>ct male</i>			<i>ct female</i>			<i>% patients seen within</i>	
	<i>2001</i>	<i>2003</i>	<i>% change</i>	<i>2001</i>	<i>2003</i>	<i>% change</i>	<i>48 hrs</i>	<i>2 weeks</i>
North West	272	196	–28%	113	132	17%	28	65
Yorks & Humber	28	51	82%	10	21	110%	27	65
London	299	619	107%	178	364	104%	54	85
West Midlands	40	88	120%	14	37	164%	28	60
East Midlands	15	56	273%	5	14	180%	28	55
Eastern	16	65	306%	3	14	367%	37	76
South East	36	153	325%	15	92	513%	37	76
South West	10	52	420%	6	14	133%	42	70
North East	2	60	2,900%	1	47	4,600%	21	50
England	618	1,340	117%	351	749	113%	38	71

APPENDIX 4

Memorandum by Migration Watch (HA 5)

SUMMARY

1. One of the Targets identified in the Strategy of the Committee's Third Report of Session 2002–03 was "to reduce by 25% the number of newly acquired HIV infections . . . by 2007" (see para 77). Progress towards this target will be virtually impossible as long as the government refuses to test immigrants for HIV when they apply for visas.

2. The Committee stated in its Conclusions and Recommendations, at para 18:

"We are concerned by the trends in HIV and support the Government in its aim to reduce the prevalence of undiagnosed HIV and in turn to safeguard public health. Early diagnosis of HIV not only reduces the chances of it spreading within the community but it also greatly improves outcomes for those infected. On the basis of evidence we have heard, however, we do not believe mandatory testing of asylum seekers, refugees, immigrants, visitors newly arrived in this country, and returning residents, to be an effective way of achieving the Government's aim."

It is the submission of MigrationwatchUK that testing on arrival is a "straw man" and that the Committee is evading the real issue, namely mandatory HIV testing overseas of persons applying to immigrate to the UK, by a doctor approved by the British government. Such testing should be confined, initially, to countries of high HIV incidence.

3. This would provide immigration authorities with information, relevant to public health and public finances, to consider in their evaluation of each case. Refusal would not be automatic but there would have to be strong reasons to grant the visa. Such a policy would substantially reduce newly acquired HIV infections in the UK. It would also assist in restoring public confidence in the immigration system.

DETAIL

4. Whilst the number of diagnoses of homosexually acquired HIV infections has been fairly stable for around 10 years, the number of heterosexually transmitted infections diagnosed in the UK continues to rise. The increase has been particularly sharp since 1999. In its Third Report of Session 2002–03 ("The Report"), the Committee said of HIV diagnoses made in the UK, at para 59:

"Most of those people diagnosed in the UK who have acquired infection heterosexually were not infected in this country. In answering our questions on heterosexual infection abroad, Dr Vicki King, a microbiologist in the Communicable Diseases branch of the Department of Health, confirmed this. In the late 1980s and early 1990s the majority of the African infections were acquired in East Africa but more recently the impact of the HIV epidemic in South Eastern Africa has been greater."

5. According to statistics produced by the Health Protection Agency, 90% of diagnoses of heterosexually transmitted HIV in 2003 were of cases thought to have been acquired overseas, largely from Africa. There is currently no mandatory testing for HIV of persons applying to immigrate to the UK. There is, however, such testing for applicants to immigrate to any of 47 other countries, including the USA, Canada, Australia and New Zealand.

6. According to Professor Pat Troop, Chief Executive of the Health Protection Agency, "Each HIV infection prevented can save between £500,000 and £1 million in treatment and lost productivity . . .". Taking the lower figure gives the cost of infection, from Malawi, Zambia and Zimbabwe alone, as £750 million per year. The Government's response so far is to increase funding for all Sexually Transmitted Diseases by £100 million a year for three years. As the Report states, at 58:

"... specialist HIV service providers . . . have been struggling to meet increasing demand for counselling, testing and treatment . . . Our recommendations draw attention to serious concerns that the spiralling cost of HIV drugs will continue to deplete the resources needed by clinical and support services for sexual health . . ."

CONCLUSIONS

7. The sexual health crisis in the UK is being exacerbated by the unnecessary and avoidable importation of cases of HIV. This is also having the effect of taking up a disproportionate share of badly needed resources for tackling the existing domestic crisis. Whilst the Government may not be willing to consider a policy of refusing admission to immigrants on the basis of their HIV-positive status, we submit that this information should be available for immigration authorities to take into account when making decisions in individual cases, as is the case in 47 other countries across the world.

8. Rather than making testing for HIV compulsory on arrival in the UK—an option that the Committee has already (and rightly) ruled out—testing should be made compulsory as part of an application to immigrate to the UK. Tests could be carried out overseas by a doctor accredited for the purpose by the General Medical Council.

9. As a recent poll in *The Economist* showed, public hostility to immigration in Britain has grown considerably since 1997, and has done so across the board. If immigration policy is to enjoy public support, it must be and be seen to be in the national interest. The current levels of immigration by HIV sufferers and the cost of their treatment to the public purse is undermining public confidence in the immigration system, and must be effectively addressed.

APPENDIX 5

Memorandum by the Royal College of Physicians of Edinburgh (HA 6)

The Royal College of Physicians of Edinburgh welcomes the opportunity to offer evidence to the Health Committee on its “Inquiry into new developments in HIV/AIDS and Sexual Health Policy” and offers the following brief comments to inform their discussions:

1. The campaign by the Terence Higgins Trust and the All Parliament Group on AIDS to exempt all sexually transmitted infections (STIs) from overseas patient charges should be supported. There are strong public health, economic and humanitarian reasons for this including the reduction of HIV infections and associated conditions and the containment of costs by avoiding emergency inpatient care and expensive antiretroviral drug treatments.

2. There is a need for a national strategy to promote initiatives designed to reduce the onward transmission rates for HIV and STIs. Such initiatives should include compulsory education in schools, targeted public health campaigns, UK wide chlamydia screening and improved access to diagnostic testing in the community.

3. A recent article in the *International Journal of STD and AIDS*, reporting a study by Kinghorn, suggests that previously targeted funds for GUM services in England may not be getting through to front line teams. The infrastructure and staffing levels in GUM are not improving despite previous reports of a crisis in the service. This must be investigated.

4. Although the Health Committee is primarily concerned with England, there is no finalised Sexual Health Strategy in Scotland or Northern Ireland and efforts through clinical and political networks to address this would be welcome and mutually supportive.

5. The trend indicators for sexual health continue to show rising infection rates, increasing pregnancy and reduction in the age of coitarche. This is a public health crisis that results in significant spending across the health services in infertility, cervical neoplasia, and infectious obstetric/paediatric complications and antiretroviral therapy. An integrated approach to improving accessible diagnostic services, prevention measures, treatment and contact tracing are essential if these trends are to be reversed.

APPENDIX 6

Memorandum by SSL International plc (HA 7)

INTRODUCTION TO SSL INTERNATIONAL PLC

SSL International plc is a multinational healthcare business, manufacturing well-known brands including the world’s leading condom brand—Durex.

Durex has been manufacturing condoms for 75 years and our research shows Durex is the world’s most popular condom with four out of five people in the UK choosing it as their favoured brand.

Durex would welcome the Health Committee’s inquiry into “New developments in HIV/AIDS and sexual health policy.”

We see this as being a positive step in tackling the increase of STIs in the UK and raising awareness of the need to promote safer sex, especially among at risk groups.

Durex is committed to reducing the incidence of STIs by encouraging condom usage through new and innovative products specially formulated for maximum pleasure and enjoyment. Each year we invest in excess of £12 million per annum in R&D and have an active programme of contact with universities and research establishments.

For example, in response to consumer insight which indicated condoms were difficult to put on and uncomfortable, we carried out a scientific penis size survey of 3,000 men and used the research to develop the first anatomically shaped condom. This means that most Durex condoms are now in an “easy on” shape, making them easier and quicker to put on and more comfortable to wear.

We have also produced the first commercially available ultra thin condom, Fetherlite, the first benzocaine condom, Performa and the first commercial polyurethane condom for men, Avanti.

Durex also actively supports safer sex and AIDS awareness initiatives throughout the world.

In the UK, we are an established supporter of government-led public health campaigns, supplying high quality condoms to ensure that health and population programmes are successful in reducing the transmission of HIV and other sexually transmitted infections (STIs) and reducing unplanned pregnancies.

For example, we recently teamed up with APPG AIDS to raise awareness of the World AIDS Day message by sending condom cards to 600 MPs. The cards highlight increasing rates of HIV/AIDS in the UK and contain a Durex Extra Safe condom.

We have also recently produced a new range of educational leaflets and posters giving the facts about condoms which our brand managers will be distributing to healthcare professionals.

Our work in the international arena includes the annual Durex Global Sex Survey—which this year had 350,000 respondents—twice as many as 2003.

The survey asks questions including what measures people take to protect themselves against STIs and HIV and at what age they lost their virginity.

The research findings help to ensure we are fully aware of changing sexual attitudes, behaviour and lifestyles.

Durex also involves itself in major social marketing projects such as Program H in Brazil. This was established with the aim of educating groups of young men—many of them prone to promiscuous sexual behaviour and violence towards women—to change their attitude and build awareness of their own health needs, particularly in relation to HIV/AIDS.

RESPONSE TO THE HEALTH COMMITTEE'S REQUEST FOR PROGRESS TO DATE IN IMPLEMENTING THE RECOMMENDATIONS OF THE COMMITTEE'S 2003 ENQUIRY INTO SEXUAL HEALTH

Response to Section 5

5.1 Durex agrees the monitoring service of the HPA is excellent and the data provided is invaluable.

5.2 Durex's own research into the sexual behaviour and attitudes of people in the UK complements the findings of the HPA. The Global Sex Survey has been running since 1994 and researches sexual attitudes and behaviours of people around the world. In 2004 more than 350,000 people from 41 countries took part. The portfolio of Global Sex Surveys demonstrates how sexual attitudes and behaviours have changed across the world, over the last 10 years. The 2004 survey revealed people in the UK lose their virginity at an average age of 16.7 years old. Previous Durex Global Sex Survey data reveal a trend to losing your virginity earlier, the average age in 2001 was 16.9 and in 2000 it was 17.1. It also reveals that 48% of people in the UK have had unprotected sex, Durex data shows this is a 14% increase on 2003 demonstrating a need for further education and 46% of respondents in the UK believe sex education should be taught by parents/guardians. The full results of the 2004 Global Sex survey can be seen as an appendix to this document.

Response to Section 16

16.1 The Durex-run Innovation in Sexual Health Award invites healthcare professionals across the UK to submit details of their sexual health projects. Entries need to demonstrate their project is successful in targeting at risk groups, flexible, innovative and effective. The award scheme is run through Sexual Health News, Durex's quarterly publication for sexual health professionals.

The winner of the 2004 competition was the MESMEN project based in Lichfield, Staffordshire. The campaign targeted men, encouraging them to have “sexual health MOTs” and used posters, postcards and the Haynes Sex Manual to promote the check-ups. Each year the winner receives £1,000 to further their project.

If the Government was to endorse this award, examples of excellent practice could be further highlighted to a wider audience. This form of support would motivate healthcare professionals in educating young people about the benefits of good sexual health. Alternatively, the Government could initiate and fund a scheme that would replicate the winning projects across the country, as a result there would be a decrease in rates of STIs.

16.2 National Condom Week is an annual initiative run by Durex to promote safer sex to all sexually active people, and 16–24 year olds in particular. The initiative has been successfully run in schools for the past eight years, and in 2005, Durex is looking to run a number of high profile activities to send the safer sex message to an even wider audience. As part of National Condom Week, Durex also works closely with

healthcare professionals, educators, retailers and pharmacists to communicate the importance of good sexual health and is supported by the media, celebrities and leading politicians. Active support of National Condom Week by the Government—either financially, or through endorsement, would allow us to reach an even greater audience.

16.3 Durex is working closely with *Nursing Times* in 2005, to add a specific award for excellence in sexual health to the portfolio of Nursing Times Awards. This is the first year a sexual health award will be given, demonstrating further support and commitment to those working at grassroots level. We believe that this award will act as a positive support mechanism allowing nurses in the field of sexual health to achieve their objectives more effectively.

Response to Section 35

35.1 Durex agrees the promotion of sexual health is an important method of helping to raise awareness of STIs and is effective in tackling sexual health problems.

35.2 See 16.2.

35.3 See 16.1.

35.4 Durex produces a quarterly newsletter, “Sexual Health News”, for sexual health professionals. It is distributed to a database of more than 3,500 healthcare professionals, key opinion formers and MPs throughout the UK to update them on Durex initiatives and news in the arena of sexual health.

35.5 In January 2004 Durex launched durexchange.co.uk, a website designed for sexual health professionals. It provides a facility for people to post details about their work and exchange ideas and information with other people in the field of sexual health. It also offers a best practice framework for professionals to learn from. The site was designed as part of Durex’s ongoing investment in supporting sexual health professionals to help promote good practice across the UK to the sexual healthcare industry.

With Government endorsement and funding, this site could be further developed to offer an extensive service to healthcare professionals and anyone working in the field of sexual health across the country to aid in their work. Durex believes the Government needs to invest heavily in support healthcare professionals at grass roots level and durexchange.co.uk offers a good opportunity for this.

35.6 Durex carries out sampling activity at selected events. In the past Durex has provided products to be distributed at Glastonbury, Reading and Leeds festivals, charity fundraising events, and the MOBO awards. To date, in 2004, Durex has given almost 250,000 condoms, including 80,000 at Glastonbury and 40,000 at the Oxegen Festival in Dublin.

35.7 Throughout summer 2004, Durex worked with the Department of Health’s “Sex Lottery” campaign to distribute 35,000 condoms in 10 popular holiday resorts, to promote safer sex to young people. The condoms were distributed to 18–24 year olds through youth holiday company Escapades. A total of 30,000 door hangers were produced which said “Do not enter—Don’t play the sex lottery” along with 50,000 Sex Lottery scratch cards.

Response to Section 37

37.1 Durex agrees that sex education programmes are an essential way of helping to improve sexual health.

37.2 See 16.2.

37.3 Durex has produced an interactive sex education CD ROM as a resource for schools to support SRE programmes. It is distributed to teachers and healthcare professionals to educate young people about safer sex and includes information on sex education, contraception, STIs, HIV/AIDS and pregnancy and parenting. There is also a special sex and relationships quiz to assess the pupils’ understanding of modules and identify any areas that need to be re-addressed.

Response to Section 39

39.1 See 37.3.

CONCLUSION

Durex is delighted the Health Committee has decided to undertake this inquiry into recent policy development surrounding HIV/AIDS and sexual health services, specifically with regard to progress to date in implementing the recommendations of the committee’s 2003 inquiry into sexual health.

Durex believes there are numerous examples of great practice happening across the UK at grassroots level. These schemes could be utilised to help the Government meet its targets of reducing rates of STIs from 2006. The Government could invest in these schemes, enabling them to be promoted nationwide.

Durex is committed to helping to promote good sexual health practice through its broad range of initiatives detailed above.

As a result we would be happy to share our experience with all relevant parties to work to improve the sexual health of the nation.

APPENDIX 7

Memorandum by Barnardo's (HA 9)

1. BARNARDO'S WORK

Barnardo's works directly with more than 100,000 children, young people and their families in 361 services across the UK. These services are located in some of the most disadvantaged neighbourhoods where child poverty and social exclusion are common features. We work with children affected by today's most urgent issues: poverty, homelessness, disability, bereavement and abuse. Some of our services have sexual health as a special focus; others include this perspective in their overall approach to children and young people. We support families affected by HIV and Aids, encouraging safer lifestyles, and we have a number of projects for young people who are sexually exploited.

This evidence addresses the second of the terms of reference of this inquiry—ie progress to date in implementing the recommendations of the Committee's inquiry into Sexual Health (the Committee's Third Report of Session 2002–03).

2. MAKING SEXUAL HEALTH A PRIORITY

Many of the children and young people we see are isolated within their families and schools and have few links with the health services. Their self confidence is low and they are at risk of developing partial or abusive understandings of their own sexuality and sexual relationships with others. So it is encouraging that sexual health is now a priority on national and local government agendas and that major initiatives have been launched in the last few months, taking up many of the Committee's earlier recommendations.

For example, *Choosing Health* (the Public Health White Paper) identifies improving sexual health as one of government's overarching priorities. Three developments are particularly welcome:

- The new national campaign targeted at younger men and women about the real risk of unprotected sex, and the benefits of using condoms to avoid the risk of sexually transmitted infections (STIs) or unplanned pregnancies.
- Piloting, from 2006, health services dedicated to young people designed around their needs, including sexual health.
- Provision of targeted material for specific groups such as disabled children, young people in public care and care leavers.

The National Service Framework for Children, Young People and Maternity states:

“Health promotion for young people is targeted to meet their needs, and in particular, to reduce teenage pregnancy; smoking, substance misuse, sexually transmitted infections and suicide. Young people are actively involved in planning and implementing health promotion services and initiatives.”

3. TIMESCALE AND RESOURCES

Barnardo's supports the aims of both the White Paper and the NSF. However practical progress will depend on whether the resources and staff are available to implement the proposals, and on how quickly this can be achieved. We know that the planning and setting up of the right kinds of services takes time. Nevertheless the issue is increasingly urgent and some of the timescales proposed in the White Paper seem to us worryingly slow. For example, the White Paper sets out the goal that by 2008 everyone referred to a GUM clinic should be able to have an appointment within 48 hours. Three years is a long time to wait for such a basic service to be available. All delays place young people—and others—at risk; in boroughs where a high number of young people are vulnerable, every effort should be made to achieve this goal well before 2008. We urge the Select Committee to use its influence to speed up the planned changes.

4. THE LINK TO SEXUAL EXPLOITATION

The evidence from our work with children abused through prostitution is that the sexual exploitation of children can only be reduced if sexual health services are readily available and user-friendly. Young people tell us that:

- They value Barnardo's non judgmental, confidential and young person centred services. When they need sexual health services they want to talk to a worker whom they have already checked out, whom they know and trust and who approaches them as a whole person.
- They think that services should be where they feel most comfortable to access them. They do not want to sit in waiting rooms where they feel judged and made to feel guilty that they have sex.
- They want multi-agency partnerships to work for them and provision not to be random. This means that local strategic partnerships have to make sure their services are joined up on the ground; multi-agency services to young people must be properly resourced and there must be services for the young people as well as their babies.
- They want the advice and information services that they use regularly to be holistic and able to respond to connected issues such as substance misuse. They do not want to have to go from service to service repeatedly asking for help.
- They want to have a say through their focus groups or committees on how those services should improve.

In our local partnerships Barnardo's is already taking forward the principles outlined in the National Plan for Safeguarding Children from Commercial Sexual Exploitation. We are committed to the multi-agency working emphasised by standard 5 of the National Service Framework.

5. SEX AND RELATIONSHIPS EDUCATION [SRE]

Barnardo's is a member of the Sex Education Forum, which has argued for many years that SRE should be statutory. The Public Health White Paper recognises the importance of SRE but disappointingly keeps it at the level of guidance. This affects the status of the subject in schools and the confidence of staff responsible for teaching it. Some schools deliver SRE very competently. They encourage students to look at sexual health in its widest sense, covering sexual boundaries, respect for others, keeping safe and the risk of STIs. Other schools treat the subject in a nervous and limited way; they confine SRE to the physical, biological and reproductive elements in science lessons and fail to address wider relationship aspects.

6. SUPPORT FOR PARENTS

The Committee report emphasised the need to support parents in this area and to help them feel confident in talking to their children. Again this recommendation is taken up in the proposals of the White Paper. Our experience is that in a highly sexualised culture it is increasingly important that young people learn how to draw sexual boundaries between themselves and others, and are helped to become more assertive about what they want and need. Professionals do have a role here, but parents clearly have a large part to play in helping their children develop healthy approaches to sexuality and relationships.

7. OPPORTUNITIES FOR MULTI-AGENCY WORKING

The provisions of the Children Act 2004 and the Change for Children programme offer many opportunities to bridge the traditional divides between health, social care and education. The link between health and education is crucial. Many young people would be greatly helped by being able to get confidential advice from sexual health professionals visiting or based in their schools.

We also notice that the young people we work with often been excluded from school or have poor attendance records; they have therefore missed out on SRE. For them preventive multi-agency work in the community can be crucial. For example Barnardo's and Brook Advisory Centre have jointly run a weekly drop-in sexual health session in a homelessness hostel in London for 10 years. The session is well attended. Led by the young people themselves, it has enabled many of them to talk about sex and relationships, and make up for what they missed at school.

8. THE INTERNET AND SEXUAL HEALTH

One of the most troubling developments since the Committee last reported on this issue in 2002–03 is the growing threat to children's and young people's sexual health posed by the internet. Barnardo's report *Just One Click* (2004) demonstrated the risks that internet and mobile phone technology can pose. Although the internet can be a source of useful information and advice for children and young people, it can also be used by adults for abusive purposes. The evidence is that the children involved in this form of abuse are getting younger, the abuse more severe and the settings more everyday.

9. FUNDING

The Committee in its report described sexual health in this country as being “in crisis” and identified it as a major public health issue. Despite the recommendations at the time, funding remains precarious for many sexual health services, including our own. Some of our services receive money from the Teenage Pregnancy Unit but this does not cover the important work with young men, especially young gay men. Small but important matters make the work more difficult. For example one of our projects used to be given free condoms so that young women who wished could be to some extent protected from unsafe sexual activity. Now the condoms have to be purchased by the service itself, thus using up valuable resources.

Finally, we record our experience that sexual health policies and provision still vary considerably from one part of the country to another.

APPENDIX 8

Memorandum by the Faculty of Family Planning and Reproductive Health Care (HA 10)

INTRODUCTION

The Faculty of Family Planning and Reproductive Health Care of the Royal College of Obstetricians and Gynecologists (FFPRHC) oversees Postgraduate Medical and Specialist training in the field of Sexual and Reproductive Health Care. The Faculty has over 11,000 members which represents a significant proportion of doctors providing contraceptive care in the UK in both Primary Care and Specialist Services.

PROGRESS TO DATE IN IMPLEMENTING RECOMMENDATION OF COMMITTEES ENQUIRIES INTO SEXUAL HEALTH

Recommendation 8—Lack of consultant training positions

We note there does not appear to have been any substantial investment in consultant posts either in Family Planning/Contraceptive or Genitourinary Medicine (GUM). There have only been an additional four National Training Numbers awarded to Family Planning in the last two years. This is not adequate even to maintain the current workforce, let alone train doctors to lead services where there is no medical need. Without specialist leadership, innovative approaches, prevention and treatment of sexually transmitted infections (STIs), abortion and contraceptive services within the community will not be possible. Family Planning/Community Sexual and Reproductive Health Services have the capacity to train more consultants, but not the resources or National Training Numbers. It should be noted that the majority of consultants leading Family Planning/Contraceptive services are single-handed. This is far from ideal. They need to work alongside consultant colleagues in Family Planning/Contraception or a GUM consultant.

Recommendation 9—Lack of resource

The Faculty welcomes the additional resources recently released to support Sexual and Reproductive Health. We believe however, better value for money would be obtained by distributing a much greater proportion of the extra funding to community Family Planning and Sexual Health services who would be able to most effectively relieve pressure on GUM services by diagnosing, treating and supporting a large proportion of patients who would otherwise need to travel to a central GUM clinic. By working in partnership in this way with specialist GUM clinics, Family Planning and other community services would encourage innovation which should improve access for “hard to reach groups” and help address inequalities seen within Sexual Health. For those still needing or choosing access to GUM clinics, waiting times would fall dramatically.

Recommendation 10—Lack of development of nurse role and long distance learning initiatives

The Faculty strongly supports the important role of nurses in the provision of Sexual Health. Nurses have traditionally played a major role in the provision of contraception and amply demonstrated their ability to screen, diagnose and treat sexually transmitted infection. Specific targeting of resources to allow more nurses who work in the community to access prescribing of courses and further develop their role, would greatly improve sexual health service capacity. To date, this has not occurred in a systematic manner and there has been no clear demonstration to Primary Care Trusts of potential development of nurses working within community services.

The Faculty however is most supportive of the intention by the Department of Health to develop long distance learning initiatives for all clinicians.

Recommendation 12—Clinical networks

The further development of clinical networks would be supported by the Faculty, but in order for this to happen, a greater proportion of funding must be directed at training community specialists and improving the infrastructure in community based contraceptive services.

The Faculty welcomes the Department of Health intended survey of contraceptive provision within Primary Care Trusts—but notes funding must be set aside to help address deficiencies as they are identified.

Recommendation 13—Waiting times

The Faculty welcomes improved access to Genitourinary Medicine that should be achieved through increased investment. We note however the tradition within contraceptive clinics that provide walk-in services, means the pressure of increased demand cannot be monitored this way.

Recommendation 14—Infrastructure

We welcome the Department of Health initiative to visit GUM premises within England—we are concerned this has not been extended to other specialist contraceptive and sexual health clinics.

Recommendation 15—Chlamydia screening

The Faculty notes with approval, substantial progress being made to introduce systematic chlamydia screening for the under 25 year olds.

Recommendation 29—Contraceptive services

The Committee recommended the Government took “immediate steps to rectify priority in balance” (Para 211) regarding the investment in contraceptive services. This has not happened. It is vital funding is secured to act on deficiencies identified in a survey performed by the Faculty of Family Planning and Reproductive Health Care in November 2004.

Recommendation 32—Abortion services

No progress made to date in re-modeling services to improve choice and access.

Recommendation 49—National service framework

Progress has been made within the last 18 months, but it is patchy. A national service framework does not appear to have been seriously considered. The Faculty is in complete agreement with the Committee, that it is required to ensure a systematic approach to improving Sexual Health through sexual relationships, education and Health Promotion as well as clinical services.

The Faculty welcomes the work of the House of Commons Health Committee on Sexual Health and believes it is essential to ensuring continued focused efforts of the National Health Service on Sexual Health. Excellent Service Standards have recently been developed by MEDFASH. Standards alone however, will not improve sexual health. It is essential that all Primary Care Trusts focus on monitoring and improving their services against these national standards.

APPENDIX 9

Memorandum by Brook (HA 11)

1. INTRODUCTION

Brook, a registered charity, is the country's leading sexual health organisation for young people, offering young women and men up to the age of 25 free and confidential sexual health advice and services.

2. PROGRESS TO DATE IN IMPLEMENTING THE RECOMMENDATIONS OF THE COMMITTEE'S INQUIRY INTO SEXUAL HEALTH

2.1 *Access target for GUM services*

Brook welcomes the goal set by the White Paper *Choosing Health* for everyone referred to GUM clinics to have access within 48 hours. However, in light of the annual increases in STI diagnoses, especially amongst younger people, it is of some concern that the date for achieving this target is 2008.

Brook believes that more integration between contraceptive and GUM services which enables STI testing and treatment to take place in community settings would make services more accessible to young people and reduce the risk of transmission caused by long waiting times at GUM clinics. This model is already in place in many Brook centres across the country. The announcement in the White Paper that testing and screening for STIs will be increasingly delivered in the community is therefore welcome but we believe treatment should also be available in these settings if transmission is to be reduced.

2.2 *Planning framework*

We welcome the Government's commitment in *Choosing Health* to issue a "supplementary technical note" to ensure that NHS Local Delivery Plans address inequalities in sexual health. However, we regret that sexual health was not more explicitly included in the original planning framework for 2005–08 as recommended by the Committee. The positive impact that specific inclusion in the planning framework can have is clear from a survey of Strategic Health Authorities in England carried out by Brook, fpa, Medical Foundation for AIDS and Sexual Health, National AIDS Trust and Terrence Higgins Trust in 2003. This found that plans for improving sexual health were included in only 10 out of 28 Local Delivery Plans. This is in contrast to teenage pregnancy which was addressed in all the plans as a result of its inclusion in the priorities and planning framework and the Department of Health's Public Service Agreement. Without ring fencing or a strong focus on sexual health within the planning framework, there must be concern as to how far local organisations will use the additional funding earmarked for sexual health for its intended purpose.

2.3 *Sex and relationships education*

We are particularly disappointed that the Government has not implemented the Committee's recommendation that Sex and Relationships Education become a core part of the National Curriculum.

Brook believes that the most effective way to ensure that the current and future generations of young people are enabled to make informed choices about their sexual health is to make Sex and Relationships Education a statutory entitlement for all children within the PSHE curriculum.

There have been welcome improvements in SRE as a result of the teenage pregnancy strategy but consistency and quality would be further improved by a statutory curriculum instead of leaving it to the discretion of individual schools to define within their SRE policy what is taught, if anything.

Brook believes that age-appropriate sex and relationships education should begin in primary school and be built on as children progress through school, continuing into colleges and further education institutions.

The Sex and Relationships curriculum should not just focus on information-giving but should help young people to develop the skills to act on the information they have been given and help them clarify their values and attitudes. Young people need to be specifically helped to develop the ability to recognise and resist pressure so that they can delay intercourse until they are ready for it; to develop healthy relationships; and to negotiate and practise safer sex.

The needs of young people who attend school irregularly or who are excluded from schools should not be forgotten. It is all too easy for these particularly vulnerable young people to miss out on SRE altogether. Brook has found that outreach education work in youth and community centres, peer education and detached work are all effective methods of reaching young people. Youth workers, with appropriate training, would be in an ideal position to deliver sex and relationships education to young people who may not have received education in mainstream settings. SRE must also be delivered within Pupil Referral Units.

We strongly recommend the development of links between schools and clinical services. International research has shown that good and comprehensive sex education combined with easy access to contraceptive services leads young people to delay first intercourse and results in them being more likely to use

contraception when they do become sexually active. Brook Centres have found it particularly effective to use outreach education workers to deliver information sessions about Brook services in schools, or to host visits from classes of local school pupils to introduce them to the services available so that they will feel comfortable to use them when they need to.

2.4 *Abortion services*

We agree that waiting times for abortion should be reduced. However, this alone will not address the difficulties women may experience in getting a referral in the first place. Callers to Brook's Young People's Information Service still report problems obtaining referrals from GPs some of whom are clearly not following guidance to refer women to other doctors if they have a conscientious objection to termination of pregnancy.

Experience from Brook Centres suggests that the development of self-referral systems locally has done much to improve early access to termination services. Brook would like to see these systems evaluated and rolled out nationally if appropriate.

We welcome the committee's recommendation to improve the availability of medical abortion. However, one Brook Centre has experienced its local hospital deciding to provide only medical abortions. This results in women who do not want a medical abortion or who are more than nine weeks pregnant having to be referred to clinics in other areas. This can be particularly problematic for younger women. A choice of appropriate methods should be made available to all women.

2.5 *Young people's sexual health services*

There have been welcome increases in the number of services for young people as a result of the Teenage Pregnancy Strategy with around 85% of local authorities having at least one service for young people. However, not all of these provide a full range of services, often resulting in young women having to be referred back into mainstream services if they require a termination referral for instance. It is to be hoped, therefore, that the prospectus for extended schools, which is expected shortly, will encourage the provision of comprehensive sexual health services for young people.

Brook is concerned that the information sharing proposals in the Children Act, could compromise young people's right to confidentiality and put them off using services at a time when they are most vulnerable. Research has consistently demonstrated that confidentiality is of paramount importance for young people using contraceptive and sexual health services as has been acknowledged by government guidance. Any measures to record young people's use of sexual health provision would undermine their belief in the confidentiality of services. This could act as major deterrent to their seeking help at a time when England and Wales continue to have the highest rate of teenage pregnancy in Western Europe and rates of sexually transmitted infection amongst young people are increasing.

APPENDIX 10

Memorandum by Positively Women (HA 12)

In response to the enquiry into the consequences of the new and proposed charges for overseas patients with regard to access to HIV/AIDS services I wish to submit the following evidence. Positively Women would also be prepared to submit oral evidence.

INTRODUCTION

Positively Women (PW)

Positively Women is the only national charity working to improve the quality of life of women and families affected by HIV:

- Providing specialist support by women living with HIV.
- Enabling women to make informed choices.
- Challenging stigma and discrimination.

Central to Positively Women's work is the ethos of "peer support", that is support for women living with HIV by women living with HIV. Services to women and families include:

- Immigration advice.
- One-to-one and group support.
- Treatment information.
- Drug and alcohol work.

- Volunteering and work opportunities.
- Specialist work with parents and young people.
- Outreach in clinics, hospitals and women's prison.

Nationally, PW provides expertise to other organisations in developing services to meet the needs of women and families. The quarterly newsletter, written and edited by women living HIV, is a vital resource for those who are isolated. To ensure the voices of women living with HIV are heard, the Taking Part project trains women with HIV to lobby and inform policy at all levels.

PW works collaboratively with a range of organisations including Asylum Aid, THT and The UK Coalition of People Living with HIV and AIDS, and is a founding and leading member of the Positive Futures Partnership.

Positively Women (PW) recognises the issue of applying limited NHS resources accurately to improve health and treat disease and illness. This response results from direct contact with people living with HIV who use PW services.

Positively Women believes the results of the charges to overseas visitors is to create a situation that endangers the health of individuals and will lead to the increase in onward transmission of HIV.

The failure to include HIV in the exemptions for free treatment has serious consequences in causing individual hardship and constitutes a public health danger. As such this regulation is likely to have high cost implications.

The widespread perception at grassroots level that treatment will be refused is preventing people with HIV from accessing health and support services.

Anti-retrovirals act to suppress HIV, which breaks down an individual's immune system. Without this treatment HIV will resume the destruction of the immune system, opportunistic infections will then be able to take a hold, resulting in increased use of emergency services and long use of hospital beds. Failure to treat the cause of illness is not good clinical practice.

The cost in health terms to women, who are still in the main the carers of the family's health, is particularly high.

The ethos of the National Strategy for Sexual Health and HIV/AIDS is to promote testing in at risk communities, to identify early those with HIV, in order to treat, promote health and prevent transmission.

There is evidence that many migrants have been diagnosed as HIV positive after entering the country for purposes other than health benefits. To refuse treatment for people in this situation is at odds with the commitment of the National Sexual and HIV/AIDS strategy to reduce transmission of HIV by 25%.

Refusing treatment will further fuel the stigma of HIV, which the strategy is committed to reducing. It is also likely to lead to lower levels of diagnosis of other sexually transmitted infections and TB both of which have public health implications. A number of migrants with HIV have also proved to be co-infected with TB.

In PW's experience, which is borne out by research by Sigma Research, most migrants with HIV do not have the means to pay for treatment, and HIV takes a back seat to housing and food needs.

Since September 2004, PW's full-time team of HIV positive women peer mentors report the following:

- eight women reported that their doctors have asked them for proof of immigration status so they can be able to access ARV treatment;
- three women on treatment reported have been threatened with withdrawal of treatment if they do not confirm their immigration status; and
- one woman has been denied treatment.

On a day-to-day basis this team is now seeing women who are facing withdrawal of life saving medication.

CONCLUSIONS

PW recommends that treatment for HIV should be exempt from charges.

- The amendment to remove treatment rights for migrants who have been resident in the UK for more than 12 months will lead to increased onward transmission of HIV, including that from mother to child.
- The charges will ultimately be costly in personal health and emergency treatment terms.
- The amendment is contrary to the commitment of the National Sexual Health and HIV strategy
- HIV should be included with other STI's and TB for eligibility for NHS treatment on public health grounds.

APPENDIX 11

Memorandum by Family Education Trust (HA 16)

1. The Family Education Trust was founded in 1971 to carry out research into the causes and consequences of family breakdown, and to publicise the findings of such research.

2. The Trust has always made the welfare of young people its special concern, and adopted the operating title of Family and Youth Concern to express this. We are therefore particularly concerned that the rapid spread of sexually transmitted infections is concentrated amongst those in the younger age groups, where such infections can result in maximum harm.

3. We note with regret that since the Committee report of 11 June 2003, the sexual health crisis has worsened:

- (a) The overall conception rates for under 16s have remained at much the same level since 1975⁶ and the latest figures show a small rise in conceptions in under-18s in England and Wales from 42.7 to 42.8 per 1,000.⁷
- (b) In 2003, for women resident in England and Wales, the total number of abortions was 181,600, compared with 175,900 in 2002, (a rise of 3.2% and the highest ever annual total) and the under-16 abortion rate was 3.9 per 1,000 compared with 3.7 per 1,000 in 2002.⁸
- (c) In 2003, the total number of new HIV diagnoses was 6,606—more than twice the number in 1998.⁹
- (d) Many non-HIV STIs continue to rise. Chlamydia is now the commonest STI diagnosed in England, Wales and Northern Ireland, rising by 8% from 82,558 to 89,431 from 2002 to 2003. Syphilis is of particular concern because of the rate of increase (28% in men 32% in women) from 2002–03.¹⁰

A. PROPOSED CHARGES FOR OVERSEAS PATIENTS WITH HIV/AIDS

4. We are opposed to anything that would act as a disincentive to overseas patients accessing services for the detection, control and treatment of STIs, including HIV. We note the HPA report of December 2004¹¹ which focuses on migration from high-risk areas such as sub-Saharan Africa as a major factor in the heterosexual spread of HIV in the UK.

B. PROGRESS IN IMPLEMENTATION

5. The report (p 25) identifies the primary causes of the deterioration in sexual health but gives no recommendations as to how these primary factors may be modified. No country in the world including Thailand has seen its HIV rates decline without a decrease in promiscuous sexual partnerships.¹² There is an increasing recognition that condoms, even when used consistently and correctly, cannot, in isolation from other behavioural change, lead to improved sexual health as the following quotations show:

*“The past decade has seen substantial increases in high-risk sexual behaviours in the British population. Although condom use has also increased, this is likely to have been offset by greater increases in unsafe sex.”*¹³

*“The possibility that presenting casual sex using a condom as socially acceptable, enjoyable and safe might increase sexual risk behaviour in the general public cannot be dismissed. Condom promotion need not increase sexual activity to produce a negative effect.”*¹⁴

⁶ Paton D The economics of abortion, family planning and underage conceptions *J Health Econ* 2002 21 207–25.

⁷ www.statistics.gov.uk/pdfdir/hsq1104.pdf

⁸ www.publications.doh.gov.uk/public/sb0414.htm

⁹ www.hpa.org.uk/infections/topics_az/hiv_and_sti/publications/annual2004/fop_3_hiv.pdf

¹⁰ http://www.hpa.org.uk/infections/topics_az/hiv_and_sti/publications/annual2004/fop_4_sti.pdf

¹¹ www.hpa.org.uk/hpa/news/articles/press_releases/2004/041124_hiv_annual_report.htm

¹² Wilson D Partner reduction and the prevention of HIV/AIDS *BMJ* 2004 328 848-9.

¹³ www.hpa.org.uk/infections/topics_az/hiv_and_sti/publications/sexual_health.pdf

¹⁴ Hearst N Chen S Condom promotion for AIDS prevention in the developing world: is it working? *Studies in Fam Planning* 2004 35 39–45.

¹⁵ Stoneburner RL Low-Ber D Population-level HIV declines and behavioural risk avoidance in Uganda *Science* 2004 304 714–8.

¹⁶ Hogle J, Green EC, Nantulya R, Stoneburner J *et al* *Whatever Happened in Uganda? Declining HIV prevalence, behaviours change and the national response* USAID-Washington and The Synergy Project TvT Associates, Washington DC 2002 www.usaid.gov/pop_health/aids/Countries/africa/uganda_report.pdf

¹⁷ Shelton JD, Halperin DT, Nantulya Vinand *et al* Partner reduction is crucial for balanced “ABC” approach to HIV prevention *BMJ* 2004 328 891–3.

¹⁸ Halperin D *et al* The time has come for common ground on preventing sexual transmission of HIV *Lancet* 2004 364 1913–4.

¹⁹ Low-Ber D, Stoneburner RL Behaviour and communication change in reducing HIV: is Uganda unique? *African J of AIDS Research* 2003 2 9–21.

6. The report (p.78) states that the committee sees “no benefit in preventative approaches based primarily around promoting abstinence”. Since the report was published however the evidence showing that abstinence has had a major part to play in the dramatic reduction of HIV incidence and prevalence in Uganda has continued to grow.^{15, 16, 17} There have been several authorities recommending that the lessons learned from the Ugandan success be applied in other countries.^{18, 19}

7. The experience of the USA is particularly impressive. The conception rate in 15–19 year-olds fell by over 28% from 120.2 to 85.6 per 1,000 from 1990–2000. The comparable figures for the UK were a fall of 7% from 68 to 62.8 per 1,000. Abortion figures for this age group showed a 41% fall in the USA from 42 to 24.8 per 1,000 whereas in the UK the fall was 2.6% from 26 to 25.3 per 1,000. The teenage abortion rate is now lower in the USA than in the UK.^{20, 21}

8. The only peer reviewed published evidence of which we are aware that examines the reasons for these trends in the USA from 1990–95, attributes two-thirds of the decline in conceptions to single teenagers to increased abstinence.²²

9. The latest figures show that teenage abstinence is still increasing in the USA. The proportion of never-married females at 15–17 years of age who had ever had sexual intercourse dropped significantly from 38% in 1995 to 30% in 2002. For males the comparable figures fell from 43% to 31%.²³ Though contraceptive use also increased at first intercourse, there can be little doubt that such a large increase in teenagers abstaining from intercourse will have made a substantial contribution to the reduction in teenage conceptions to single mothers from 1995–2002 as it did in 1990–95.

10. One of our trustees predicted in 2001²⁴ that the increased availability of emergency pills from pharmacies would be accompanied by an increase in STIs because the opportunity to counsel and advise on, screen for and treat STIs, would be lost without the encounter with a doctor or nurse. This prediction has proved correct, though the link has not been proved to be causal. We strongly recommend it would help improve sexual health if the manufacturers of emergency pills were to place a warning on the packet or product leaflet, that the user is at risk of an STI as well as pregnancy, and listing contact details for further help.

APPENDIX 12

Memorandum by Dr A Menon-Johnsson (HA 17)

“ACCESS FOR ALL”

REASONS WHY THE NHS SHOULD PAY FOR ALL INDIVIDUALS WITH ADVANCED HIV DISEASE

Those not eligible for full NHS treatment:

- Students on courses for < 6 months.
- Those who have not yet submitted an asylum or refugee application to the home office.
- Those who have had an asylum application turned down and exhausted the appeals process.
- Illegal immigrants.

Pollard and Savulescu, BMJ 2004;329:346–9

Care available to those who are ineligible to full NHS care:

- Emergency treatment.
- Services provided by A&E.
- Notifiable infectious diseases/STIs.

¹⁵ Stoneburner RL Low-Ber D Population-level HIV declines and behavioural risk avoidance in Uganda *Science* 2004 304 714–8.

¹⁶ Hogle J, Green EC, Nantulya R, Stoneburner J *et al* *Whatever Happened in Uganda? Declining HIV prevalence, behaviours change and the national response* USAID-Washington and The Synergy Project TvT Associates, Washington DC 2002 www.usaid.gov/pop_health/aids/Countries/africa/uganda_report.pdf

¹⁷ Shelton JD, Halperin DT, Nantulya Vinand *et al* Partner reduction is crucial for balanced “ABC” approach to HIV prevention *BMJ* 2004 328 891–3.

¹⁸ Halperin D *et al* The time has come for common ground on preventing sexual transmission of HIV *Lancet* 2004 364 1913–4.

¹⁹ Low-Ber D, Stoneburner RL Behaviour and communication change in reducing HIV: is Uganda unique? *African J of AIDS Research* 2003 2 9–21.

²⁰ www.guttmacher.org/presentations/trends.pdf for USA figures.

²¹ www.nationalstatistics.gov.uk for UK figures.

²² Mohn JK Tingle LR Finger R An analysis of the causes of the decline in non-marital birth and pregnancy rates for teens from 1991–95 *Adoles and Fam Health* 2003 3 39–47. www.afhjjournal.org

²³ www.cdc.gov/nchs/data/series/sr_23/sr23_024.pdf

²⁴ Stammers T Emergency contraception from pharmacists misses opportunity *BMJ* 2001 322 1245.

- HIV excluded.
- Family planning.
- Compulsory psychiatric treatment.

Adapted from Pollard and Savulescu, BMJ 2004; 329:346–9

Key arguments why all HIV patients should be treated are:

- Economic.
- Public Health.
- Duties/Ethics.
- Human rights.

Spending money to save money:

- Primary care is cheaper than secondary care which is cheaper than tertiary care.
- Estimated cost to care for one HIV positive person per year in London = £10,000.
- Inpatient “hotel” charges = £300/night.
- “Hotel” costs alone for admission with an OI.
 - PCP $2/52 = £4,200$
 - Tuberculosis $4/52 = £8,400$
 - Toxoplasmosis $6/52 = £12,600$

These “Hotel” costs do not include cost of treatment for the above conditions. All patients who present with AIDS defining illnesses need to start HIV treatment too.

HIV treatment costs:

- Drug costs/month (NHS)
 - AZT,3TC,EFV = £666 (as Combivir)
 - d4T, ddI, NVP = £606
 - TDF, 3TC, EFV = £755
 - TDF, 3TC, LOP/r = £882
- Drug price discounts based on time the drug is on the market, certain combinations and size of cohort.
- WHO estimated cost of generic first line Rx = £12/month.

Public Health reasons:

- Transmission.
 - Voluntary Counselling and Testing (VCT) uptake.
- Mother to Child Transmission (MTCT).
- Tuberculosis (TB).

Barriers to HIV testing:

- For all patients:
 - Stigma.
 - Not aware of risk.
 - Not aware of treatment.
- Additional barriers to the overseas visitor:
 - Lack of knowledge of the healthcare system.
 - Language barrier.
 - Cost.
 - Fear of disclosure.

Voluntary Counselling and Testing (VCT):

- Patients are more likely to test if something can be done:
 - Note experience of HIV testing in the UK prior to anti-retroviral treatment (ART).
- The NHS currently only provides HIV testing and counselling to those ineligible to full NHS care.

VCT uptake:

- Experience of the NGO Partners for Health in the resource poor setting = www.pih.org
- VCT uptake initially poor and limited to those:
 - Who are sick.
 - Or sexual partners of the sick.

- VCT uptake rose significantly when offered:
 - Primary care.
 - TB screening.
 - Antenatal services.
 - Sexual Health screening.
 - Free Anti-Retroviral Treatment.

Mother To Child Transmission (MTCT):

- A number of trials have shown benefit of:
- Anti-retroviral treatment (ART):
 - Zidovudine.
 - Nevirapine.
 - Stavudine.
 - Didanosine.
- Caesarean section.
- Bottle-feeding.
- Reduce MTCT from 33% to 1%.
- Opt-out antenatal services now exist.

TB: HIVs' most constant companion:

- Progression to AIDS and death is more rapid when an individual is co-infected with TB.
- HIV patients 100x more susceptible to develop active TB.
- HIV-positive persons are more susceptible to develop active TB after exogenous re-infection.
- Risk of poor response to TB treatment—including mortality and rates of relapse—is greater among HIV-positive individuals.
- ART, when indicated, can improve survival and decrease risk of progression to AIDS.
- In 2002: ~6,900 new cases of TB were diagnosed in the UK:
 - 3,000 of these new TB cases were in London.
 - 200 cases of TB in HIV infected persons per year.
- HIV screening is part of TB management:

Duties/Ethics:

- Duties of a doctor (General Medical Council):
 - Make the care of your patient your first concern.
 - Respect patients' dignity and privacy.
 - Work with colleagues in the ways that best serve patients' interests.
- Moral principles:
 - Principle of temporal neutrality.
 - Duty of easy rescue.

Human Rights:

- The relationship between human rights and HIV/AIDS prevention and control has proceeded through three phases:
 1. Application of public health measures.
 2. Recognition that discrimination against PLWHA reduced the effectiveness of public health prevention methods.
 3. Vulnerability to HIV infection:
 - (PLWHA = people living with HIV and AIDS).
- Vulnerability addressed through a Human Rights framework

Universal Declaration of Human Rights (Key articles):

- Article 2:
 - Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.
 - Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which the person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

-
- Article 25:
 - Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.
 - Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same protection.

Data from the FXB Center for Health and Human Rights at Harvard School of Public Health (1994) shows that the quality of public health delivery is directly related to human rights quality.

Other important strategies in addition to HIV treatment include:

- Focus on improving home situation.
 - Development funding:
 - Hypothecated to the Healthcare sector.
 - Including supply of affordable (free) treatment.
 - Women's Rights.
 - Support to civil society.
 - Arms embargo when internal conflict /civil war.

Summary:

- HIV is cheaper to treat in primary/secondary care.
- HIV treatment facilitates the uptake of testing + has significant public health benefits.
- Failure to treat a patient with advanced HIV disease is in conflict with duties of the doctor and moral principles.
- Health is a basic human right.

APPENDIX 13

Memorandum by Dr Colm O'Mahony (HA 18)

ONGOING PROBLEMS

1. Small amounts of money dribbled out over the last three years has been a bit of a help, but has meant that Trusts and PCTs have said "well, there's your money" and you can't have any more. The DoH continually says there is money in baseline funding for development of GUM services—the PCTs say categorically there isn't, so nothing other than the small amounts of money assigned by the DoH have come through.

2. Allocations of the new money should not simply reward poor practice and failing clinics. PCTs and Trusts that have not invested in the GUM services over the last 10 years should not be rewarded now by large amounts of money to bail them out. Trusts that have done their best to support these services like, for example, mine here in Chester with a cohort of patients from all around the place with minimal funding, and it's about time that the work was recognised with additional funding. Please make sure that significant amounts of money goes to clinics that have actually modernised and are doing the business or this will just simply engender further disillusionment.

APPENDIX 14

Memorandum by Royal College of Nursing (HA 19)

TERMS OF REFERENCE OF THE INQUIRY

The Committee will undertake a short inquiry into recent policy developments surrounding HIV/AIDS and sexual health services—specifically, it will address:

- The consequences of the new and proposed changes in charges for overseas patients with regard to access to HIV/AIDS services.
- Progress to date in implementing the recommendations of the Committee's inquiry into Sexual Health (the Committee's Third Report of Session 2002–03).

1. INTRODUCTION

1.1 With a membership of over 370,000 registered nurses, midwives, health visitors, nursing students, health care assistants and nurse cadets, the Royal College of Nursing (RCN) is the voice of nursing across the UK and the largest professional union of nursing staff in the world. RCN members work in a variety of hospital and community settings in the NHS and the independent sector, including the workplace. The RCN promotes patient and nursing interests on a wide range of issues by working closely with the Government, the UK parliaments and other national and European political institutions, trade unions, professional bodies and voluntary organisations.

1.2 The RCN has worked in partnership with the Teenage Pregnancy Unit (DfES) and Sexual Health and HIV Strategy Team (DH England) to establish a Sexual Health Skills distance learning programme. It is a 15 week course, with two experiential learning and assessment days at RCN centres across the UK and Northern Ireland. It operates as a foundation in sexual health care, and its intended learning outcomes focus upon improving sexual health assessment skills, detailed knowledge on all methods of safe sexual contraceptive techniques and sexual health infections, and referral methods for Genito-Urinary (GU) services. The course aims to work towards Patient Group Directions, or similar protocols.

2. CONSEQUENCES OF THE NEW AND PROPOSED CHANGES IN CHARGES FOR OVERSEAS PATIENTS WITH REGARD TO ACCESS TO HIV/AIDS SERVICES

2.1 Our members have made it clear that they are still unclear about the specifics of these changes. In particular there are concerns around poor dissemination of information.

2.2 Many nurses consider it would be a dereliction in the duty to care if a person—no matter what their politico-legal status—if, on clinical grounds, needs Highly Active Anti-Retroviral Therapy (HAART) or other HIV medications/treatments, and were denied these simply because of their status. Similarly, many feel they would be put in a dreadful situation if they were party to refusing necessary medications to a person, because of the client's politico-legal status. Our members do not want to be put in the position of policing what treatments patients are entitled to. Indeed, for those working in Genito-Urinary services, issues of confidentiality are prescribed in the Venereal Diseases Regulations.

2.3 The RCN is wary of public and media misconceptions of “asylum seekers” and overseas patients. Given the exceptionally small numbers of people this policy refers to, and the fact that good sexual health provision helps prevent further escalation in the UK's sexual ill-health statistics, the RCN believes that it would be inequitable to charge overseas asylum seekers requiring sexual health assistance.

3. PROGRESS TO DATE IN IMPLEMENTING THE RECOMMENDATIONS OF THE COMMITTEE'S INQUIRY INTO SEXUAL HEALTH

3.1 *Recommendation No 6—Sexual Health Provision*

Initial indicators are that practices are slowly improving. However, the lack of commensurate resources for clinical service provision is still a major barrier to care. In addition sexual health remains a limited area of care and is therefore not seen as part of good holistic care.

It might be a useful model to consider, however the RCN has now implemented the UK's first nation-wide professional and academically validated distance learning course in Sexual health Skills (www.rcn.org.uk/sexualhealthlearning). This course has already been accessed by over 300 nurses, midwives and health visitors across the UK and Northern Ireland. The current curriculum is validated for three years and is credit rated at academic levels II and III, by the University of Greenwich. According to course evaluations, the participants have been able to increase service provision around aspects of sexual health prevention and care.

3.2 *Recommendation No 8—Expansion of Consultancy Posts*

There is still a lack of resources to maximize the great potential of various nurse-led initiatives, especially Nurse Consultants. Our members have pivotal roles in various programmes and services of prevention, assessment, treatment and management of people affected by the poor consequences of sexual ill-health. Nursing roles have developed in response to client needs, as well as specialist academic study to enable better qualifications. In all of these initiatives, a lack of facilities (including funding) for nursing development and career enhancement is a key factor in poor recruitment and retention in key areas and important posts.

3.3 *Recommendation No 11—Diversion of funding*

Feedback from our members indicates that diversion of funds does still occur. Many sexual health clinics have had to significantly cut condom budgets due to the cost of HIV drugs, which are still currently around £10,000 per person per annum. It is imperative that designated sexual health funding is allocated appropriately. This should also include monies for prevention, for no matter how much the costs of treatment spiral, prevention is not only less economically expensive, but in total human terms, is ultra beneficial too. Greater resources should be allocated to significantly raising the awareness of safer sex and condoms as contra-infection, and not simply contraception alone.

3.4 Recommendation No 13—Waiting times indicator

The RCN has not seen any evidence of reduced waiting times since the publication of the Health Committee's report. Increasing the number of nurses trained across sexual health specialities would greatly improve access to care, and help diminish long waiting times. In looking at waiting times, special regard should also be paid to specialist clinics, such as those based on individual gender and sexual orientation, as these are often in shorter supply than mainstream GUM and sexual health services.

3.5 Recommendation No 15—Chlamydia Screening Programme

The National Chlamydia Screening programme is gradually being implemented across the UK with full roll out due by 2008 and the *RCN's Sexual Health Skills* distance learning course supports this programme. It enables far more nurses, especially in Primary Care, to be able to talk about sexual health, make sexual health and risk assessments of clients, and be prepared to contribute towards Chlamydia screening. Greater resources are required to improve wider availability of testing.

The Royal College of Nursing is about to publish *the RCN Chlamydia educational initiative*, a learning resource aimed at improving the knowledge and skills of nurses in Primary Care settings around Chlamydia prevention, screening and treatment. This important initiative will ensure nursing staff have the appropriate skill set to be able to test-screen, treat and or refer patients, which will enable fast tracking.

3.6 Recommendation No 16—Male sexual health outside traditional settings

The RCN Sexual Health Skills distance learning course has a wealth of material looking at specific issues for male sexual health needs, and encourages nurses, in line with the Health Select Committee's 2003 Report of the Inquiry into Sexual Health, to think "outside the box" of traditional services, especially for males and other hard-to-reach populations. For example, the homeless, the prison population and providing services in pubs, clubs and health centres.

3.7 Recommendation No 18—HIV statistics

2003 saw the highest numbers of newly diagnosed cases of HIV since testing first began in the 1980s. This figure also showed the overwhelmingly high percentage of UK endogenous new infections to continue among under 24 year old gay, bisexual and other men-who-have-sex-with-men. This can be attributed in part to the almost complete invisibility of HIV prevention strategies outside of the SRE arena, particularly in schools to all young non-heterosexuals.

3.8 Recommendation No 28—Primary Care service provision

As sexual health does not have a National Service Framework (NSF) it does not gain the priority it deserves.

The large percentage of nurses in Primary Care, including GP services, who are undertaking the *RCN Sexual Health Skills* distance learning course are laying the foundations for improving sexual health services across the care setting. A number of nurses in NHS Direct have also accessed this course, and report that it meets the demands for their learning, as sexual health questions can crop up on a daily basis. PCT Sexual Health Leads, prison nurses, school nurses, A&E, mental health care nurses—in fact, nurses across the spectrum of care—can benefit from undertaking this course.

Negotiations are currently underway with the Faculty of Family Planning and Reproductive Health Care (FFPRHC), British Association of Sexual Health and HIV (BASHH), the Department of Health and the National Association of Nurses for Contraception and Sexual Health (NANCSH) looking at ways of enabling or supporting the primary care team to deliver on sexual health. The Medical Foundation for Aids and Sexual Health (MEDFASH, a charity supported by the British Medical Association) is also currently drafting standards around sexual health to be launched in the spring.

3.9 Recommendation 35—Sexual health promotion

Nurses in all areas of care could have the potential opportunity for promoting good sexual health, especially messages of prevention appropriate to individual clients, their abilities and skills. At this moment in time, nurses are still being underused in this way.

3.10 Recommendation 41–51—SRE Education and the National Curriculum

The fact that young people's sexual health is still such a cause for concern in the UK, compared to many other western European nations, shows that much work still needs to be done. This is especially true for nurses working with children and young people in schools, Young Offender's Institutions and in various outreach services. Many of these nurses highlight how they need specific learning on sexual health to empower them to deliver customised messages effectively. The optional nature of SRE in schools is a key stumbling block, and a lack of joined-up collaborative work across all young people's services continues to hinder the full and equitable teaching of sexual health appropriate and available to all.

APPENDIX 15

Memorandum by Joint Council for the Welfare of Immigrants (HA 21)

This Memorandum is submitted in respect of part one of the terms of reference: the consequences of the proposed changes in charges for overseas patients with regard to access to HIV/AIDS services.

REASONS FOR SUBMITTING THIS MEMORANDUM

The JCWI (Joint Council for the Welfare of Immigrants) is an independent national organisation which has been providing legal representation to individuals and families affected by immigration, nationality and refugee law and policy since 1967.

We actively lobby and campaign for changes in law and practice and our mission is to eliminate discrimination in this sphere. Access to services including healthcare for those individuals affected by immigration laws and policies is therefore of central importance to JCWI. This is why we offer this statement to the Health Select Committee in respect of the proposals to exclude overseas visitors from free primary care and their consequences for persons with HIV/AIDS.

CONCERNS

We feel the Department of Health's consultation document on the proposals to restrict free primary care is misleading in its continual reference to "overseas visitors" whereas those potentially affected include:

- Failed asylum seekers—including those from countries which the Government deems too insecure to return people to;
- Undocumented migrants; and
- Overstayers.

The above categories of people are already prone to exploitation in the unregulated economy and have progressively become devoid of civic and social rights. Consequently their health needs may be greater. We are opposed to restricting eligibility to primary medical services to these groups for a variety of reasons but view HIV/AIDS sufferers as among those particularly vulnerable. We raise three issues in respect of them:

1. Pregnant women are usually routinely tested for the HIV virus. If a mother is HIV + the disease may be passed on to their unborn child. The risk of transferring the virus can be reduced through for example treatment during pregnancy, opting for a caesarean section birth, avoiding breastfeeding and ability to take informed decision about health. Although HIV diagnostic testing is not excluded in the proposals put in this consultation, even assuming that a pregnant woman would approach an STD clinic for testing, this will be of very limited value if no treatment is available to the woman and if the mother has to pay thousands of pounds for a caesarean section birth. Preventing mothers with HIV from accessing ante-natal and HIV treatment could impact on the number of babies born with the virus. The incidence of HIV/AIDS could increase further among the immigrant population.

2. Persons with HIV may incur a delay in obtaining treatment as a consequence of perceived restrictions on access to treatment. Research from the US suggests that, for individuals with tuberculosis, a perception that restrictions may apply, delays in seeking care are likely to result and consequently the period of transmission be prolonged.

3. Non-, or delayed, treatment could contribute to development of drug resistance. Barriers, whether real or perceived, to care for chronic communicable diseases may result in erratic, delayed, or intermittent treatment. These promote the development of drug resistant strains of disease. The public health challenge that results from drug resistant communicable diseases may be substantial and very costly both in financial and human terms.

The proposals, if implemented, not only jeopardise the government's overall preventative approach to health, including in regard to HIV/AIDS, but also puts at risk those who are already on the margins of society and deserve the protection of a basic safety net of health care which will not be provided by "emergency or immediately necessary treatment".

There is a perception that because some migrant persons are not documented they present a burden on services paid for by UK nationals through taxation. Whether migrant workers are documented or not, they pay VAT on goods, and are generally ineligible for social security benefits, tax credits or full employment rights that UK nationals draw on. As both the former Home Secretary David Blunkett and the Immigration Minister Des Browne have publicly acknowledged the functioning of the UK's dynamic and flexible economy depends on their participation across a range of sectors. It contributes to the reasons for their presence here before they may realise they have any need to access primary health care services.

JCWI is concerned that the Government is making these proposals without concrete evidence of figures in relation to the cost of so-called "health tourism" and without an analysis of the impact of recent changes in eligibility to secondary care that came about on 1 April 2004. There does not appear to be any concrete

evidence to show that these proposals will bring about a reduction in costs to the NHS. The Government needs to differentiate between so called “Health Tourism” and the vulnerable groups discussed in this document.

We are also worried about the impact these proposals are likely to have on immigrant communities. It is feared that while there is not a discriminatory intention behind these proposals nevertheless the changes could make people feel that they are being discriminated against, if for example eligibility checks are made on people with foreign-sounding names.

APPENDIX 16

Memorandum by Dr Jane Anderson (HA 22)

1. This memorandum has been written by Dr Jane Anderson, PhD, FRCP, an HIV specialist physician in East London based at Homerton University Hospital Foundation Trust, Hackney. I am currently the Director for the Centre for the Study of Sexual Health and HIV at Homerton University Hospital NHS Foundation Trust. I also hold positions as co-chair of the African HIV Research Forum and as Honorary Secretary of the British HIV Association. Having worked in the field of HIV medicine since 1984 and at consultant level since 1990 I have direct experience of the impact and management of HIV both before and after the availability of effective therapy. My comments to the committee are based on my direct clinical experience and my research work and have been formulated within wider discussions with colleagues in both statutory and voluntary sector organisations.

2. Our clinic serves a cohort of 450 HIV infected people a majority of whom are from overseas, particularly from African backgrounds and many either have been or currently are involved in the immigration process within the UK. My work also encompasses research and I have been involved in large studies on the experiences of African people living with HIV in London.

3. The policy changes that have been enacted require that long stay visitors, those refused asylum or leave to remain (but not yet removed from the UK) and all undocumented people should be charged for every NHS hospital service other than those carried out for emergencies or for those listed as exempted conditions. It is my opinion that most Individuals who will attract charges are those who are least likely to be able to pay and this will impact on their access to care.

4. All sexually transmitted infections (STIs) other than HIV remain exempted from the new charges, as is treatment for tuberculosis. Putting HIV outside the regulations for all other STIs and tuberculosis is inconsistent not only with good clinical practice but also with the government’s other policies concerning the proper diagnosis, management and containment of sexually transmitted infections and HIV.

5. Although no cure exists for HIV there is now effective suppressive therapy. Since 1997 the evidence that Highly Active Antiretroviral Therapy (HAART) reduces mortality and morbidity in people with HIV infection has been substantial. Based on published scientific evidence the British HIV Association (BHIVA) produces clinical guidelines for the appropriate treatment of people with HIV infection. These guidelines are now considered by the medical profession and those who commission health care to define the proper standard of clinical care for people with HIV in the UK and are the benchmark for my own clinical practice.

6. There is now agreement that the outcomes of therapy are improved in those patients who start treatment before their immune system is too profoundly damaged. In consequence the numbers of people dying from HIV or progressing to AIDS have fallen dramatically in the UK in recent years. However, those who are still dying of HIV and its complications are frequently people presenting for the first time with advanced infection. In the main they have been unaware of their HIV status and thus failed to access appropriate therapy. National data from the Health Protection Agency (HPA) and from a BHIVA audit reveal that a high proportion of late presenters are from African backgrounds. This is certainly true of the situation in East London and many of the people who attend our service have very advanced HIV infection, are frequently very sick and need immediate therapy.

7. HIV infection results in progressive loss of immune competence which lays the infected individual open to a range of serious and potentially life threatening complications. Such complications present as emergencies and frequently require prolonged and complex in-patient hospital stays which may necessitate the use of intensive care facilities. Some, once established, are incurable.

8. For as long as the individual remains severely immunocompromised such emergency complications can occur repeatedly, necessitating sequential hospital stays. In my experience these admissions can last for many weeks at a time and patients may need to be managed within the intensive care unit. There is substantial evidence to demonstrate the role played by HAART in allowing immune restoration and a subsequent fall in the complication rate which in turn reduces the impact of HIV on inpatient beds.

9. Treatment of emergencies only with no consideration given to reversing the underlying cause of the immune compromise is not only inconsistent but also poor clinical practice. This is particularly the case in an environment where effective preventative therapy is readily available. To manage HIV infection in this

way would be in breach of the BHIVA guidelines and would place individual clinicians in a very difficult position in terms of proper clinical practice, and is likely to use significantly more resources than would be the case if the HIV itself were appropriately treated.

10. Tuberculosis and HIV co infection is common in non UK born HIV infected people. The appropriate standard of care for HIV/TB co infected patients includes antiretroviral therapy. Tuberculosis is included in the list of exempted conditions whilst HIV is not. A consequence of this legislation is that some HIV/TB co infected patients (often within the same treatment centre under the care of the same medical team) will receive optimum treatment under current guidelines and others will not, based entirely on their immigration status. There are significant ethical issues that are raised for clinical staff working in this situation.

11. High rates of psychological distress resulting from past life experiences are observed in migrants' especially in those fleeing conflict. Many have seen the consequences of untreated HIV in close family members. Uncertainty and complexity of the asylum process fuels levels of anxiety and depression in psychologically vulnerable individuals. The further burden that charging for care will place upon an already psychologically vulnerable population might be expected to result in additional psychological morbidity. In my opinion the psychological impact of denying care to such a population has not been documented but might be expected to be substantial.

12. HIV and pregnancy poses particular issues. The introduction of antiretroviral therapy in pregnancy, delivery by caesarean section and avoidance of breast feeding can reduce the risk of transmission of HIV from mother to baby from 25–30% to less than 1%. In consequence government guidance has been issued to recommend HIV testing to all pregnant women to allow them to take advantage of these medical interventions. To make a diagnosis of HIV in pregnancy and then to deny therapy which is readily available within the UK on the basis of immigration status is not only illogical on the basis of current government health strategy but also ethically unacceptable.

13. If lack of treatment of a pregnant HIV infected woman results in a baby being infected with HIV it is possible that the baby would then receive treatment (for a largely avoidable infection). At the same time the untreated mother's health would be expected to deteriorate over time with a resultant reduction in her ability to care for her child.

14. Withholding antiretroviral therapy has a potential impact for onward transmission. A major determinant of HIV transmission is the plasma viral load which is substantially reduced when HIV infected individuals are taking effective antiretroviral therapy. The Department of Health estimates that preventing one new HIV infection saves between £0.5 million and £1 million.

15. Current government strategy seeks to reduce the rate of undiagnosed HIV infection in the community. This has led to the promotion of widespread of HIV testing campaigns. Early diagnosis allows for timely treatment interventions and a negative test allows for safer sex messages to be promulgated. Acceptance of testing is likely to be reduced for those patients for whom no therapy will be forthcoming in the event of a positive result. If therapy is unavailable to a proportion of the most vulnerable people in the community, who are already hard to reach it, is unlikely that they will elect to test. This will undermine both treatment and prevention initiatives which underpin the current government strategy.

In conclusion it is my opinion that the imposition of charges for HIV for certain sections of the UK dwelling population will have deleterious effects on the health, wellbeing and longevity of some individuals and at the same time will potentially have an impact on the wider HIV epidemic in the UK. It will place an increased burden on the emergency services and on in patient hospital beds. In addition clinicians will be asked to treat patients in a way that is contrary to national recommendations and standards. This will pose ethical problems for medical practitioners.

I would like to suggest that the committee recommends that HIV be incorporated with, and treated in the same way as, all other sexually transmitted infections and be exempt from charges whilst individuals are in the UK.

APPENDIX 17

Memorandum by PACT (HA 23)

Please accept the contribution of the Providers Association for AIDS Care and Treatment (PACT) to the "New Inquiry—New Developments in HIV/AIDS and Sexual Health". PACT is an independent subscription based organisation made up of HIV provider units from across the United Kingdom representing the views of clinicians, health professionals and managers.

CHARGING FOR OVERSEAS PATIENTS

1. Support the campaign of the Terrence Higgins Trust and the All Parliamentary Group on Aids to add HIV infection to those sexually transmitted infections exempt from the Overseas Patient charges. This support is based upon Public Health (reduce infectiousness from HIV and associated conditions eg

MDRTB) and economic (ie less cost to treat with Antiretroviral drugs in outpatient setting, than wait until patient develops an infection such as PCP or CMV and requires expensive emergency inpatient admission) grounds, as well as humanitarian.

IMPLEMENTATION OF SEXUAL HEALTH RECOMMENDATIONS

2. Reinforce the need to concentrate resources on preventing onward transmission of HIV and STI infection, through compulsory PSHE in schools, targeted Public Health campaigns, Chlamydia screening across the whole of the United Kingdom and increased access to “Rapid Testing” and “Point of Care Testing” diagnostics in the community (especially HIV antibody testing in primary care).

3. Increased screening in the community, utilising new diagnostic technologies, will identify and separate “Asymptomatic” and “Symptomatic” patients at the earliest point of access. Early diagnosis will improve referral patterns and access to main GU Centres of Symptomatic patients, develop integration of primary care and acute services and increase overall efficiency of capital and human resources.

4. The Health Committee recommended increasing access to GUM clinics and described the crisis in their funding, their fabric and their staffing levels. The governments own figures suggest the situation is worsening, there has been no targeted improvement of the buildings and consultant expansion has not increased. A study by Kinghorn *et al* in *Int J STD AIDS* in October demonstrated the failure of DoH monies to reach frontline services in England because of the failure of PCTs to pass on the targeted funding.

5. There is no published Sexual Health strategy in Scotland or N Ireland and this is unacceptable.

6. STI epidemiology is rising alongside teenage pregnancy and a falling age for Coitarche. If the governing bodies of each nation accept that this constitutes a Public Health crisis with major economic effects on NHS expenditure (eg from Infertility, Cervical Neoplasia, infectious Obstetric/Paediatric complications and the costs of Anti-retroviral Therapy) then surely an integrated and coordinated Public Health approach, based on accessible medical services, prevention and treatment and contact tracing are the keystones that history teaches us will work in reducing sexual ill health.

7. Where has been the promised impetus to funding the increased delivery of contraceptive care and STI asymptomatic screening in primary care? The lack of development of networks, including GUM and contraceptive specialist services alongside community screening facilities was much promised in the English strategy and much talked up elsewhere-the health committee should highlight the failure to develop this pivotal aspect of modernisation of integrated services.

8. Consistent flaws are emerging in the structure and process of commissioning Sexual Health and HIV services across the UK. The fragmentation of the commissioning base into small locally focused PCT’s is failing to address the challenges of delivering national Public Health based Sexual Health and HIV services. Local cost pressures and a failure to identify the activity and disease drivers for Sexual Health and HIV within mainstream contracts is contributing to the restriction of funding and a lack of strategic thinking and vision around these services. These pressures are creating ever greater tensions between Commissioners and Provider Units, which are leading to the break down of the Public Health ethos that underpins “Open Access” services, a restriction on access to services and the development of a “postcode lottery” for treatment and care. Managed clinical networks and the integration of Sexual Health and HIV commissioning is now an urgent priority if we are ever to achieve the recommendations set out by the Committee.

APPENDIX 18

Memorandum by Dr Paul Williams (HA 24)

INTRODUCTION

1. I am a principal in General Practice in Stockton-on-Tees in North East England. All of the 600 patients in my Primary Medical Services (PMS) practice are seeking asylum, have been given refugee status (or other forms of protection) or are failed asylum seekers. I have been the general practitioner to more than 1,000 people seeking asylum since my practice opened in April 2002.

2. I have taken testimony, as an independent medical expert, from more than two hundred people seeking asylum regarding physical and psychological health problems resulting from injury, imprisonment, rape and torture. I have received training and appraisal from the Medical Foundation for the Care of Victims of Torture.

3. I am a member of the Royal College of General Practitioners and have diplomas in tropical medicine, child health, family planning and obstetrics and gynaecology. I have a Masters degree in Public Health from the University of Newcastle upon Tyne.

4. I am an Honorary Lecturer in the school for health at the University of Durham.

HEALTH TOURISM

5. There is a perceived problem of “health tourists”; people whose primary purpose in coming to the UK is to make free use of the NHS. Asylum seekers, by definition, are seeking protection in the UK from persecution in their countries of origin; their motivation in coming to the UK has never been proved to be linked to accessing NHS health care. If people were coming to this country and using the asylum process as a way of accessing free health care, I and other GP colleagues working in asylum health would be the main people noticing this phenomenon.

6. Of the one thousand people seeking asylum that I have provided primary care to in the last two years, I have only seen one case where I suspect “health tourism” was a factor in the decision to come to the UK. The family, from Iran, had a daughter with kidney disease. They suspected that she was getting inferior care in Iran, and had been in conflict with the authorities over their daughter’s medical care. This conflict had resulted in the detention of the father prior to their decision to leave the country. I have seen no other cases where the decision to leave the country of origin, or the decision to come to the UK, has been influenced by the availability of health care in the UK. When I meet with colleagues who work in asylum and refugee health none of them talk about “health tourism” being a problem.

7. The existing and proposed changes to entitlement legislation will probably be successful in reducing health tourism, but would also have the damaging effect of denying necessary health care to many thousands of failed asylum seekers and other adults and children whose primary purpose in coming to the UK was to seek asylum not to get free NHS care.

FAILED ASYLUM SEEKERS AND ACCESS TO PRIMARY CARE

8. The Home Office is making it much more difficult for people who apply for asylum in the UK to be granted permission to stay. According to Home Office statistics, in 2002 10% of people coming to the UK were granted refugee status by the Home Office, and a further 24% were granted exceptional leave to remain. In the first nine months of 2004, of the 37,575 people who claimed asylum only 1,195 (3%) were granted refugee status and 2,940 (8%) were given other forms of protection.

9. The proportion of successful appeals to the Immigration Appellant Authority (IAA) fell slightly from 22% in 2002 to 20% in the first nine months of 2004.

10. Home Office Research Study 243 examined the decision-making of asylum seekers by interviewing 65 asylum seekers. It found that most people were fleeing violence, persecution or threats of violence. These asylum seekers had very little knowledge of entitlement to benefits in the UK.

11. Most people who come to the UK to seek asylum will become “failed asylum seekers”. Failed asylum seekers are not “bogus” asylum seekers. The burden of proof in an asylum application lies with the applicant to show that there is a reasonable degree of likelihood that they would suffer persecution (on the grounds of race, religion, nationality, political opinion or membership of a social group) if returned to their country of origin.

12. Many barriers to access to health care for people seeking asylum exist. These include difficulty in communicating in English, a poor understanding of the health care system in the UK, prejudice and racism towards asylum seekers from health service staff and fears about confidentiality and the possible cost of treatment. The existing and proposed changes will only increase barriers to access for those entitled to treatment, do nothing to support the inequality policy agenda and will result in large numbers of people living in the UK who do not get access to healthcare.

13. Access to all types of health care begins in primary care. The antenatal care provided in the UK ensures that maternal and perinatal mortality rates are low, vertical transmission of HIV reduces from more than 30% to less than 1% and babies are born in a safe environment. Denying access to care will only result in more vertical transmission of HIV, higher maternal mortality rates and higher perinatal mortality.

AUDIT AND RESEARCH DATA FROM THE ARRIVAL PRACTICE, STOCKTON-ON-TEES

14. A cohort of 288 adults seeking asylum, who had been “dispersed” to Stockton-on-Tees in 2003, were followed for six months. 47% of people were from Africa, 40% from Asia and 6% were from Europe.

15. 43% of adults presented with mental health problems after dispersal. The prevalence of Post Traumatic Stress Disorder was 7%, Depression 15% and Anxiety 3%.

16. Altogether the prevalence of HIV was 4%. All of the people with HIV were born in Africa, so the prevalence of HIV in Africans was 8%. On arrival at the practice only 25% of African adults knew their HIV status, and after six months of health promotion and encouragement of HIV testing 51% knew their HIV status. This still left 49% of African adults who did not know their HIV status. The prevalence of HIV in African adults who had ever had an HIV test was 16%. The audit concluded that there was likely to be undiagnosed HIV in African patients.

17. I have asked all of my patients with HIV, in clinical consultations, if they knew that they had HIV when they were in Africa. All of them were diagnosed in the UK. All of them have said that they did not know that they had HIV until they were tested in the UK. I have no way of knowing how truthful these responses were, but I have been given no reason ever to suspect that any of my patients with HIV had come to the UK to seek treatment.

18. 46% of people with HIV disclosed rape or sexual assault during the six months of the study. The overall prevalence of rape or sexual assault was 17% in African people (43% in African women). People with HIV were significantly more likely to have disclosed rape than people without HIV.

19. There are significant barriers to HIV testing in African people. People are afraid of a positive result as they associate HIV with death from their own experiences in Africa. They have difficulty in building up trusting relationships with health professionals, fear that their HIV status will be disclosed to the Home Office and this will affect their asylum claims, and fear the huge stigma that a positive diagnosis brings in African communities. None of my patients with HIV are openly positive—I asked for a volunteer recently to speak at a community event about HIV that I had organized. Everyone was too afraid of persecution to let others know their status, and we had to get a speaker with HIV to come up from London. More work needs to be done to break down barriers to accessing voluntary counseling and testing services in the community, and to attempt to dismantle the prejudice and stigma surrounding HIV that exists in African communities.

20. If I thought that any of my patients who were diagnosed with HIV would be denied treatment if their asylum claims failed, I would have to tell them this when counseling them for HIV testing. At the moment, I can counsel them that “it is better to know” if they have HIV, because of the potential benefits to them of accessing treatment if they have the disease. If they might not be able to get free treatment, the benefit to the individual of knowing their HIV status would be minimal.

UNINTENDED OR UNDESIRABLE CONSEQUENCES OF CHANGES AND PROPOSED CHANGES TO LEGISLATION

21. The proposals allow general practitioners to give “immediately necessary” treatment to failed asylum seekers. The notion of health problems falling neatly into those that are “immediately necessary” and those that are not is a false one. Many non-urgent problems may, if not managed correctly, result in serious illness. For example, steroid inhalers are not “immediately necessary” for someone with asthma, but without them an individual may become dangerously unwell. The correct management of a pregnant woman with HIV reduces the risk of transmission from mother to child from 30% to less than 1%. The phrase “immediately necessary” was coined by general practitioners as a way of getting payment for seeing a patient registered elsewhere, not as a way of deciding which healthcare was essential and which was not.

22. It is difficult to tell when an asylum claim has “failed”, as some cases may be subject to appeal or to judicial review. NHS staff have already reported people who are not failed asylum seekers being refused NHS treatment. Members of ethnic minorities or people seeking asylum (who are entitled to free NHS care) will be disproportionately affected.

23. The proposals will lead to confusion and prejudice amongst health service staff, undermining other important initiatives to improve social cohesion, redress inequality and facilitate access to health care for disadvantaged groups.

24. Doctors and nurses have an ethical duty to provide care for their patients, based on assessments of medical need and no other criteria. They are not trained, or professionally inclined, to deny treatment to those in need of it. These proposals conflict with ethical codes of conduct governing health professionals, including the GMC’s “duties of a doctor”.

25. It is only possible to determine whether or not someone has an “immediately necessary or life-threatening” problem or an infectious disease (categories that would be entitled to free treatment under the new legislation) by performing a medical assessment. Reception staff are unqualified and do not have the skills to make this determination, but are most likely to be the people turning away patients.

26. It is economically nonsensical to deny simple illness prevention, but allow expensive emergency care when a condition becomes life-threatening. Preventative medicine and early identification and treatment of illness reduces suffering and comes at a lower financial cost.

27. Asylum seekers move from lawful residency to an “illegal” status if they fail to secure the right to refuge. Withdrawal of health care eligibility for such a vulnerable group without enforcing their leaving the UK demonstrates a failure to take responsibility.

Case study 1 (KH has given his full consent for the disclosure of this information)

28. KH is a 36 year old former policeman from Zimbabwe. As the chief of his police station he took a stand against juniors who were facilitating farm occupations by “war veterans”. His superiors heard about this, and put verbal pressure on him. K fled Zimbabwe after his family home was burnt down by Zanu-PF

supporters in reprisal. He was diagnosed with HIV several months after arrival in the UK. He has been married for 14 years, but did have one extra-marital affair about six years ago, from which he thinks he caught HIV. He had no idea of his HIV status prior to his arrival in the UK. His lowest CD4 count was 47 and he is currently on antiretroviral treatment, provided free of charge by a local hospital. He is now a failed asylum seeker. He was not able to convince the Home Office or the IAA that there was “a reasonable degree of likelihood” that he would suffer persecution if returned to Zimbabwe as there was no evidence that he could put forward to substantiate his story, and the burden of proof in an asylum case lies with the applicant. He is terrified of returning to Zimbabwe, not because of the lack of HIV treatment (he says he would work to pay for treatment) but because he still reads about attacks by Zanu-PF supporters on people like him. As a failed asylum seeker he is not allowed to work (but he does earn a bit of money by doing work on friends cars), gets no benefits and has no housing provision (he lives on the floor of a friends house).

Case study 2 (KD has given his full consent for the disclosure of this information)

29. KD is the son of a doctor from West Africa. He is well-educated and articulate. Some time after his asylum claim failed he disclosed to me that he has been detained by the authorities in his country in 1999. During this time he was raped anally and a lime was inserted into his rectum. He says that he had never disclosed this to anyone before as he was too ashamed. “Late disclosure” of rape or torture is a common phenomenon described by the Medical Foundation for the Care of Victims of Torture. There are no legal avenues still open to him. After this disclosure we decided that an HIV test was sensible, and he was found to be positive. In fact his CD4 count was less than 50 and soon afterwards he was diagnosed with TB pericarditis and underwent heart surgery. Under the new entitlement arrangements for failed asylum seekers he would have been entitled to the urgent heart surgery and treatment for TB (but would have been presented with a bill for it afterwards), but would not have received antiretroviral treatment. By now he would be dead. Fortunately the local hospital is not aware of his “failed” status and is giving him free treatment. K is terrified of returning to his country, and is currently living in a house funded by donations from a church group.

Case study 3 (SO has given her full consent for the disclosure of this information)

30. SO is from Uganda. She was abducted from her home and kept in a cage by a rebel group. During this time she was multiply raped vaginally and anally. Her asylum claim failed after the medical evidence provided by me was rejected as being “inconclusive”. It is very unusual for anyone to have “conclusive” medical evidence months after being raped. A further submission by her solicitor and by me explaining this was rejected by the IAT. She has children in her country being looked after by a relative, but is terrified to return. She was diagnosed with HIV in Dover and began antiretroviral treatment last year when her CD4 count was 144 and she developed TB. At the time she was gaunt and depressed. Now she is lively, well and is an active member of her church group. This church provides her with accommodation. Without antiretroviral treatment it is likely that she would now be dead.

RECOMMENDATIONS

31. Before framing new legislation, an evidence-based impact assessment of both the new proposals for primary care and those recently introduced for hospital care should be performed. This should include consideration of the likely impact on personal and public health and an economic analysis of the status quo and of proposed changes. HIV and AIDS should not be considered separately from other illnesses or health problems that affect this group.

32. Any link between immigration status and health care entitlement should be removed. Free primary and secondary medical care should continue to be provided until someone is removed from the UK.

33. If the proposals are enacted, everyone should be entitled to a free health assessment by a health professional in order to establish their degree of need. When establishing entitlement to free care, the means to pay should be taken into account. The consequences of denying free NHS care to a wealthy Texan are very different from denying care to an HIV positive Zimbabwean.

APPENDIX 19

Memorandum by the Royal College of Paediatrics and Child Health (HA 25)

BACKGROUND

Prior to 1998 the UK was lagging behind comparable countries in making HIV testing available for pregnant women. A national Intercollegiate Working Party issued recommendations for action designed to reduce mother to child transmission in the UK by making an offer and recommendation of voluntary confidential HIV testing a routine part of all antenatal care (*Intercollegiate Working Party Recommendations for enhancing voluntary confidential HIV testing in pregnancy: reducing mother to child transmission in the United Kingdom. Royal College of Paediatrics and Child Health Publications. 1998*).

In 2002 the Working Party reconvened to review progress against its recommendations and against the instructions in a Health Service Circular issued by the DH in 1999 (*Department of Health. Reducing mother to baby transmission of HIV. Health Services Circular 1999/183*). The offer and recommendation of HIV testing to all pregnant women as a routine part of antenatal care has been established nationwide, and there is good evidence that uptake rates are high. An updated report which reviews progress made to date and highlights challenges for the future is at the stage of going for final approval to the participating bodies prior to publication in 2005.

The evidence presented here is drawn from those parts of the report that are relevant to the Terms of Reference of the inquiry.

TERMS OF REFERENCE

1. *The consequences of new and proposed changes for overseas patients with regard to access to HIV/AIDS*

In 1997 only around one third of HIV infected women giving birth in the UK were diagnosed prior to delivery. This figure has risen dramatically to a predicted 89% in London and 92% in the rest of England and Scotland in 2003. The estimated proportion of UK children exposed to vertical HIV transmission likely to have been infected was around 6% (and 4% in 2003). This compares to around 20% in 1997 when the majority of women were not diagnosed prior to delivery. (These estimates are based on transmission rates of 26.5% for infants born to undiagnosed women and 2.2% for infants born to diagnosed mothers⁵) (data from: *UK Collaborative Group for HIV and STI surveillance. Focus on Prevention. HIV and other Sexually Transmitted Infections in the UK in 2003. Health Protection Agency Centre for Infections. November 2004.*)

The mainstay of management for preventing HIV transmission in women identified as being HIV positive has been Zidovudine (AZT) therapy for mother and infant, elective Caesarean section and avoidance of breast-feeding for all women regardless of whether they had early or more advanced disease. The table below shows the relative contributions of these interventions. Guidelines for the best management of HIV in pregnancy have been drawn up by the British HIV Association (BHIVA) and are currently being updated (www.bhiva.org). Some women require highly active antiretroviral therapy (HAART) in pregnancy for their own health, but this also enables delivery of the infant with an undetectable viral load in the mother's blood. The use of combinations of antiretroviral drugs in pregnancy is being closely monitored, as there are concerns over potential long-term, as yet unknown, effects of intra uterine exposure.

We are concerned that these changes in charges for overseas patients may reduce the uptake of antenatal testing for HIV and consequently implementation of interventions to prevent mother to child transmission. We understand that under the Children Act treatment for the child will be free of charge but that this is not the case for the pregnant mother. All the preventative interventions are dependent on the mother agreeing to be tested and most are implemented prior to delivery. If required to pay for these interventions women who cannot afford the costs may be deprived of appropriate antenatal care and risk producing HIV infected children. In the long term costs of care and support for such children would greatly outweigh the costs of providing care to the mother in pregnancy.

TABLE OF INTERVENTIONS TO REDUCE TRANSMISSION OF HIV
FROM MOTHER TO CHILD

<i>Intervention</i>	<i>Transmission rate (approx)</i>	<i>References</i>
None	25–30%	1
Avoidance of breast feeding	12–15%	2
AZT mono-therapy	6–8%	3, 4, 5, 6, 7
Pre labour CS (+/- ART)	2%	8, 9
Pre labour CS + AZT mono-therapy	< 2%	8
Combination anti-retroviral therapy +/- CS (delivery VL < 400 copies/ml)	1%	10
(delivery VL < 50)	no published data yet	

Key: AZT—Zidovudine; ART—antiretroviral therapy; CS—Caesarean Section; VL—Viral Load

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2. *Progress to date in Implementing the recommendations of the Committee's inquiry into Sexual Health (the Committee's Third Report of the Session 2002–03)*

Despite the great improvement in antenatal HIV testing and uptake of appropriate care for HIV infected women, there remain situations where management of HIV in pregnancy is still complex/problematic. As part of the deliberations of the Intercollegiate Working Party, four main areas have been identified where future challenges will need to be met in order to maintain the progress achieved so far. In summary these include:

(A) Development of networks for the management of HIV in pregnancy

1. The need for units to have a regular multi-disciplinary forum for managing HIV in pregnancy with a recognised process for the development of individual birth plans.
2. The need to encourage women to allow disclosure of their diagnosis to the primary care team so as to avoid conflicting advice being for instance in regard to breast feeding or infant immunisations.
3. The need to develop a regional network across the country for managing children with HIV. The Children's HIV National Network (CHINN) have recently conducted a review (available shortly at www.bhiva.org/chiva) and one of the main recommendations is the development of such a paediatric HIV network to manage paediatric cases but also contribute to the multidisciplinary input on perinatal care and, importantly, to follow up all children both infected and non-infected, who have been exposed to antiretroviral treatment pre- or post-natally.

(B) Case Management

1. The need for units to have a policy on how to revisit sympathetically the offer of HIV testing at a later stage in pregnancy for women who initially refuse the test and, for those women who are positive but refuse interventions in pregnancy a system for pre-birth planning of postnatal interventions in the infant to reduce the risks of transmission.
2. The Department of Health has produced national standards for Antenatal Screening for Infectious Diseases (*Screening For Infectious Diseases in Pregnancy*, www.doh.gov.uk/antenatalscreening). It should be standard practice that units audit their performance against these standards.
3. The consideration that a national confidential enquiry programme for investigating cases in which mother to child transmission of HIV occurs should be established in the UK to identify possible systems failures.

(C) Evolution of the management of HIV disease

1. In view of the rapidly increasing complexity of treatments for HIV infection generally, there is a major need for continuing surveillance and analysis of the results of different interventions for preventing HIV transmission so as to enable mothers to receive the best evidence based management.

(D) Long term follow-up of antiretroviral exposure *in utero*

1. The necessity that robust mechanisms for very long term follow up of antiretroviral drug exposed infants to be continued and enhanced.

2. The requirement that all pregnancies in HIV infected women be reported prospectively to the National Study of HIV in Pregnancy and Childhood (NSHPC) and to the international drug registry (www.apregistry.com), and all infants born to mother to the NSHPC (co-ordinator of the NSHPC: *Dr Pat Tookey 0207 829 8686, email p.tookey@ich.ucl.ac.uk*). The Children's HIV National Network (CHINN) could be involved in collecting the paediatric data.

3. The need to continue the current funding arrangements for Paediatric HIV services which are dependent on the reporting of outcomes for infected and non-infected infants.

4. The need to keep families and voluntary sector organisations fully informed with up to date evidence.

APPENDIX 20

Memorandum by the Association of Directors of Social Services (ADSS) (HA26)

1.1 The Association of Directors of Social Services (ADSS) is pleased to be invited to submit evidence to the Parliamentary Hearings, and welcomes a new developments in HIV/AIDS and sexual health policy.

1.2 The ADSS continues to be concerned that the new developments addresses the social and health care needs of a very diverse population in England and that the changes are sensitively managed. There is considerable emphasis on measures to improve the health and well-being of children and young people, including their mental health and the new measures and publicity campaign needs to be age appropriate with emphasis on promoting healthy schools and prioritising SRE guidance in schools and community settings. A “youth offer” that will be the subject of a forthcoming Green paper will include proposals to improve health and provide alternatives to risk taking behaviour. Targeted information and services aimed at young people will need to involve young people in the planning, development and evaluation of this important initiative.

1.3 All this is adding to an environment already experiencing rapid change and uncertainty. It is also important that the implementation of the new developments takes full account of the successes and lessons learnt since the start of the HIV pandemic 19 years ago. The key role of social care and support services in enabling people living with HIV/AIDS to live longer and healthier lives in the community needs to be recognised and built on. It is also vital to engage with disadvantaged communities such as teenage parents in the tackling of teenage pregnancy.

1.4 The Government has introduced a wide range national initiatives, which Councils and, in particular, Social Services have lead responsibility for implementing. They bring with them significant challenges, including the recruitment and retention of skilled professionals. Demographic changes also impact heavily on social care services, and resources must be set aside for us to respond effectively. Discharging patients with an AIDS diagnosis without the right support structures in place defeats the objective of responding to the crisis in waiting lists in the NHS and good patient care. The impact of reduced funding to Social Services for promoting independence to provide support has ceased and there are ongoing financial pressures leading to overspends of several millions last year which are largely due to increase in the number of children coming into care—some of whom are children of teenage parents and children affected by HIV/AIDS.

1.5 The personal social care aspects of current policies are missing and with little reference to the role of Local Authorities and Social Services in particular. Nor do they address the community leadership and regeneration roles that Social Services carries with partners. Our role is to know the needs of diverse communities and to respond often not on our own but in a range of ways and in partnership. This starts with individuals, for example a mother living with AIDS presenting with a range of cross cutting themes—an asylum seeker from a war-torn East African country, often isolated and excluded from the wider community, may experience racial discrimination and harassment and may be in need of housing for herself and her family. Social care professionals work in partnership with many cases such as this and staff use a range of skills to find solutions. These solutions are often outside the Health domain and require corporate working with other parts of Councils.

1.6 Social care professionals play a pivotal role in the prevention of HIV and other STIs yet the funding for this work is patchy throughout the country. Whilst nationally, there is encouraging news about a small decline in teenage pregnancy rates, we would caution against complacency as the rates of new conceptions in Inner-London and other metropolitan areas are rising.

1.7 We would urge wider promotion of evidence based models and work with a range of communities and strongly support the targeting of HIV related work amongst East African communities and vulnerable children and young people. The development of good practice guidelines for working with African communities is necessary.

1.8 The AIDS Support Grant has led to effective service responses in England and future funding must be guaranteed as developments for communities previously not included are underway. The Local Implementation Grant for tackling teenage pregnancy is crucial and funding beyond the next two years must be guaranteed.

1.9 We are hopeful that the policies implemented at a local level will tackle the spread of STIs including HIV. However, the reduction in stigma (especially to those communities already experiencing discrimination and marginalisation) is also important, and leadership at a number including Government is necessary to achieve this. Despite the reservations expressed above, it must be said that there is more public and policy interest in sexual health than there has been for decades but policy must be genuinely holistic.

APPENDIX 21

Memorandum by the Medical Foundation for AIDS and Sexual Health (HA 27)

1. *Medical Foundation for AIDS & Sexual Health*

1.1 The Medical Foundation for AIDS & Sexual Health (MedFASH), a charity supported by the British Medical Association, aims to promote excellence in the prevention and management of HIV and other sexually transmitted infections. We work by informing and advising health professionals on excellence in practice, and by briefing policy-makers. We welcome the opportunity to submit evidence to the Health Select Committee's inquiry into new developments in HIV/AIDS and sexual health policy.

1.2 We would be happy to provide more information or give oral evidence to the Committee. Copies of MedFASH publications mentioned in this evidence can be supplied on request. Our full contact details are at the end of this memorandum.

2. *Summary*

2.1 Our evidence is in two parts, addressing each of the Committee's areas of inquiry in turn.

2.2 MedFASH believes there are strong public health and economic arguments for allowing access to HIV treatment and care for those who are clearly unable to pay. In our view, restricting access for those ineligible for NHS care is a false economy in relation to individual care, and a major risk to public health. Access to antiretroviral treatment avoids the cost of expensive emergency care, supports HIV prevention interventions both among those who are infected and in the wider community, encourages uptake of HIV testing thus reducing rates of undiagnosed infection, and can radically reduce rates of mother-to-child transmission of HIV.

2.3 We welcome the White Paper, *Choosing Health*, and the sexual health Public Service Agreement (PSA) target. These represent a prioritisation of sexual health that is necessary to address the sexual health "crisis" identified by the Health Committee in 2003. Since the Committee's report HIV and STI diagnoses have continued to rise and the ability of services to meet demand has worsened. Our evidence focuses on the learning from, and potential benefit to be gained from, our recent and current projects: developing recommended standards for NHS HIV services and for sexual health services, undertaking a national review of GUM services, and producing a resource by and for GPs on HIV in primary care. All of these should support service modernisation as proposed in the *National strategy for sexual health and HIV* and in *Choosing Health*. We remain convinced of the need for increased local investment to expand capacity in sustainable way across a range of settings.

THE CONSEQUENCES OF THE NEW AND PROPOSED CHANGES IN CHARGES FOR OVERSEAS PATIENTS WITH REGARD TO ACCESS TO HIV/AIDS SERVICES

3. *Introduction*

3.1 There are humanitarian, public health, economic and ethical arguments for enabling access to NHS care for those overseas patients with HIV who have no means to pay. We are concerned about any measures which mean refusing treatment and care to vulnerable individuals with HIV.

4. *Is restricting access cost-effective?*

4.1 While the proposed changes to limit access to NHS treatment for overseas patients might appear to be a money-saving measure for the NHS, we query the cost-effectiveness of restricting care to situations defined as emergencies. Timely investment in treatment prevents expensive management of acute illness and repeated emergencies in those infected. According to current UK clinical guidelines, antiretroviral therapy (ART) should be prescribed early enough to prevent a deterioration in health which may not be reversible. Such a deterioration would eventually result in emergency care and inpatient admission. We understand that an average inpatient stay for someone with HIV disease would probably last about 10 days, at a likely cost to the NHS of about £7,500–10,000, and that the average patient with severe HIV disease might be expected to spend a month in hospital during a 12-month period—ie two to three such inpatient stays. With the annual cost of antiretroviral therapy in the region of £10,000, the benefit to the public purse of providing such therapy in a timely way to those with HIV, rather than waiting to deal with emergencies, is clear.

4.2 Enabling access to treatment should provide further significant economic benefit by reducing transmission of HIV infection to others. Preventing one new HIV infection saves between £0.5 million and £1 million (*Department of Health, National Strategy for Sexual Health and HIV, 2001*).

5. *How access to treatment and care supports HIV prevention*

5.1 Preventing new infections clearly also has a major public health benefit. People living with HIV can play a major role in prevention. Those receiving treatment and in regular contact with health professionals can be supported to avoid activities which might transmit HIV. In addition, by radically reducing viral load, it is likely that the treatment itself will reduce the risk of transmission if such activities do occur. Hard evidence for this effect of ART has been hard to obtain (apart from mother-to-child transmission), but a case-control analysis of 386 serodiscordant heterosexual partners, presented at the XV International AIDS Conference in Bangkok (July 2004), concluded that when HAART became widely available, a reduction of about 80% in heterosexual transmission of HIV was observed, irrespective of changes in other factors that affect transmission. (Castilla, J *et al. Decline in sexual transmission of HIV in heterosexual couples attributable to HAART*. eJIAS. 2004 Jul 11;1(1):ThOrB1410, available at <http://www.iasociety.org/ejias/show.asp?abstract—id=2171493>)

6. *Impact of restricted access on health promotion and uptake of testing*

6.1 To prevent HIV, health promotion initiatives are important among communities most at risk, and this is rightly a key part of the *National Strategy for Sexual Health and HIV*. There is international evidence that HIV prevention programmes are more effective when complemented by the availability of social support and medical care for those infected, reducing fear and stigma. If some individuals from the migrant communities most affected by HIV in the UK do not have access to medical care and social support, those communities may be less receptive to prevention messages, less willing to seek HIV testing, and more likely to engage in activities which transmit HIV.

6.2 Yet it is among these communities that uptake of HIV testing most needs to be encouraged. Of the main population groups in the UK affected by HIV, people from sub-Saharan Africa are least likely to have had their infection diagnosed. Because late diagnosis is associated with ill-health and death, and because it potentially increases the risks of ongoing transmission, the *National Strategy* aims to broaden access to HIV testing and encourage uptake in this population group. However, for those at risk, there may be little perceived advantage in taking up the option of being diagnosed with a progressive, fatal and highly stigmatised disease if there is no opportunity (or no perceived opportunity) to obtain the treatment which would radically improve quality and length of life.

6.3 It cannot be assumed that this disincentive to testing would apply only to those individuals who would not be eligible for free NHS care. Migrant communities will include many individuals who are fully eligible, but unaware of the eligibility regulations and aware of the experiences of others in their community, and thus nervous of seeking testing or other healthcare. This may be particularly marked among asylum seekers, who often have a background of persecution and abuse before coming to this country, resulting in fear of interaction with “the authorities”. A requirement to prove eligibility on presentation at a healthcare setting could exacerbate such reluctance and put off both those who are, and those who are not, eligible from presenting at all. Thus, a lack of access to treatment for some members of the migrant communities most affected by HIV risks directly undermining the objective of increasing uptake of HIV testing, set out in the *National Strategy for Sexual Health and HIV* and highlighted more recently as a priority in the Annual Report of the Chief Medical Officer 2003 (Department of Health, 2004).

6.4 It is appropriate that HIV testing, along with testing and treatment for other STIs, is currently free to all in GUM services, regardless of NHS eligibility. To increase rates of uptake, the availability of HIV testing should be expanded in a range of settings. We believe the principle of universal free access to HIV testing should apply in all these settings, including primary care.

7. *Prevention of mother-to-child transmission*

7.1 A large proportion of HIV infections in pregnant women in the UK occurs among those from overseas, primarily sub-Saharan Africa. Appropriate interventions before, during and after birth can reduce the risk of HIV transmission from mother to child from 25–35% to under 2%, but in order to achieve this, ongoing medical care and social support is crucial. This support should include access to free formula feed (not currently available to those ineligible for NHS care), to enable HIV-infected mothers to avoid breastfeeding and the associated risk of HIV transmission. The public health rationale for such interventions is very strong, and there are clearly major economic benefits in reducing the numbers of children born in the UK needing lifelong monitoring and treatment for HIV. MedFASH does not believe that any woman in the UK should be denied this treatment or the necessary associated support, regardless of her immigration status.

8. *Access to primary care*

8.1 In most cases, it is hospital services which provide antiretroviral therapy. However, primary care can play an important role in complementing specialist care and the *National Strategy for Sexual Health and HIV* states the government's intention to expand the role of primary care in relation to HIV and sexual health. More detail on how primary care can complement specialist care in the management of people with HIV is contained in *Recommended standards for NHS HIV services (MedFASH, 2003)* and in *HIV in primary care (MedFASH, 2004)*. Primary care professionals can provide psychological and practical support to improve patients' adherence to difficult antiretroviral drug regimens, and they can act as a first port of call for those with symptoms which may or may not be related to their HIV or its treatment. This primary care role can help ensure that HIV specialist services are dedicated to the aspects of treatment and care which are truly specialist, making the most cost-effective use of their expertise and pressured resources. We would therefore argue that entitlement to free NHS treatment and care for people with HIV should apply not only in acute hospital settings but also in primary care.

9. *The ethics of restricting access*

9.1 In addition to the public health and economic arguments presented above, there are serious ethical concerns for health professionals. Doctors have a duty of care, and MedFASH would query whether it is ethical (or even in some cases whether it is clinically negligent) to:

- withhold treatment and support from a pregnant women which could almost eliminate the risk of her transmitting HIV to her baby;
- offer and provide such treatment to a pregnant woman but withhold ongoing treatment for the woman herself and her family;
- fail to offer an HIV test to someone presenting with symptoms and seeking to know what is wrong with them;
- offer a test for HIV, then withhold treatment which could prevent serious illness and death;
- withdraw treatment from an individual (eg if their immigration status changes, reducing their legal entitlement to free care) when their need for it is still as great, especially as their future treatment options would be reduced by cessation of current medication (because of drug resistance); and
- provide emergency care but withhold ongoing treatment which could prevent a likely repeat emergency and possible death.

PROGRESS TO DATE IN IMPLEMENTING THE RECOMMENDATIONS OF THE COMMITTEE'S INQUIRY INTO SEXUAL HEALTH (THE COMMITTEE'S THIRD REPORT OF SESSION 2002–03)

10. *Introduction*

10.1 MedFASH welcomed the report of the Committee's inquiry in 2002–03. We believe that the "crisis" in sexual health continues and, in many ways, has worsened. New diagnoses of HIV and other STIs are still rising, and services are struggling as much, if not more, to meet demand. In partnership with other national organisations, we have continued to argue for sexual health and HIV to have higher priority for planning and funding at national and local level.

10.2 The publication of the White Paper, *Choosing Health*, marks a significant change on this front. We very much welcome its prioritisation of sexual health, along with the £300 million additional funding announced to support implementation in relation to sexual health. We believe the guidance to strategic health authorities, issued in November 2004, on the sexual health Public Service Agreement (PSA) target should prove a valuable lever for prioritisation and investment at local level. With the devolution of decision-making and funding to local level in the wake of *Shifting the balance of power*, such levers are essential. Reversing the current trends in epidemiology and service provision in order to meet the three goals within the guidance is likely to prove a major challenge for PCTs and services.

10.3 Since the Committee's inquiry, MedFASH has managed a number of major projects. Our evidence is structured around, and draws on the learning from, these projects to make recommendations of relevance for the Committee's new inquiry.

11. *Service standards for HIV*

11.1 Since Committee's last report, which mentioned the standards then in development by MedFASH, the *Recommended standards for NHS HIV services* have been published and gained the endorsement of the Department of Health, the British HIV Association (BHIVA) and the National Association of NHS Providers of AIDS Treatment and Care (PACT). The standards focus on the patient pathway and delivery of multidisciplinary care through service networks. We have received feedback that they are being used in different ways by service providers, PCTs, SHAs, voluntary organisations and service users groups and we know that in some places they have been used to support local discussions between providers and commissioners about the planning and resourcing of services.

11.2 However, because of the low priority accorded to HIV in NHS policy, we fear that in many places scant attention will have been paid to the standards, and their use as a tool for service commissioning and improvement is likely to have been limited to those areas where there are local enthusiasts or where HIV is identified as a local priority.

11.3 It would be valuable to undertake a review of how the recommended standards are being implemented around the country. The learning from this could provide support to SHAs in their performance management of sexual health and HIV, as well as to commissioners and service providers. The intelligence gathered through such a review could also be used to inform an eventual revision and updating of the standards.

12. *HIV prevalence and costs*

12.1 We believe the need for HIV service standards can only intensify. The annual number of new HIV diagnoses has been rising rapidly, reflecting both new infections and some improvement in the rate of diagnosis. The annual numbers of HIV tests performed in GUM clinics increased from 150,000 to 400,000 between 2001–03. We expect this upward trend to continue, especially if there is success in meeting the objective of reducing the rate of undiagnosed infection, as set out in the *National strategy for sexual health and HIV* and in the CMO's annual report for 2003.

12.2 With the rise in numbers, total HIV treatment costs are continuing to increase, treatment budgets are under increasing pressure and overspends are not infrequent. There are threats to cap HIV treatment budgets, but we cannot see how such a cap can work for an open access service where the numbers needing treatment are rising rapidly, unless a commitment to provide the optimum treatment (in line with BHIVA guidelines) is abandoned. Open access should not be abandoned, as it encourages the take-up of services in the context of the fear and stigma associated with HIV. There is also a serious risk that these budget pressures will result in disinvestment from other aspects of HIV care which complement and support drug treatments (as set out in the recommended standards) and from local HIV prevention. We hear anecdotally that this is already happening.

13. *HIV service networks*

13.1 The Select Committee, in its report on sexual health, supported the development of HIV service networks and our project work has aimed to facilitate this. In the face of the challenges described above, we think networks are ever more needed. While welcoming the progress that has been made in some parts of the country on network development, we would argue that more support is needed for this.

13.2 Our more recent work (see below) on standards and networks for sexual health services raises questions about the options for integrated or overlapping networks for HIV and sexual health services. Different solutions may be found to this in different parts of the country, but a co-ordinated approach is important, especially in view of the close links between HIV and some other STIs.

14. *HIV and national sexual health priorities*

14.1 We regret that HIV did not feature more prominently in *Choosing Health*, nor in the associated announcement of new funding nor the LDP guidance on the PSA target. We hope there will be a recognition at national, SHA and PCT levels that effective implementation of the White Paper, in relation to improving sexual health and reducing health inequalities, must include adequate investment in HIV service provision, including prevention. The *Recommended standards for NHS HIV services* should support this, along with the forthcoming recommended standards for sexual health services (see below).

15. *Service standards for sexual health*

15.1 Commissioned by the Department of Health, MedFASH has been developing recommended standards for sexual health services, to be published in 2005. These address sexually transmitted infections, contraception, abortion, sexual health promotion and access to psychosexual services, and are organised around how to meet the needs of service users. They are not setting-specific, applying to both primary care and specialist sexual health services, as well as other settings where sexual health needs may be identified or met. They promote an integrated approach to sexual health service provision, and delivery through sexual health networks.

15.2 In the face of the challenges outlined above, particularly the new LDP guidance requiring 48-hour access for GUM services, a reduction in new diagnoses of gonorrhoea and an increase in uptake of chlamydia testing, the standards should be a valuable tool for providers, commissioners and SHAs. We hope that they will be strongly endorsed and embedded in relevant national guidance and frameworks from the Department of Health, the Healthcare Commission and other relevant bodies.

15.3 As with the HIV standards, we believe it will be valuable in time to review how the standards are being implemented at local level. With their focus on integrated service provision they should drive modernisation across local health economies, involving a plurality of providers as advocated in *Choosing Health*.

16. *National review of GUM services*

16.1 Prompted by concerns about the challenges facing GUM services and their capacity to respond effectively, as highlighted in the Select Committee's report, MedFASH has been commissioned by the Department of Health to undertake a two-year national review of GUM services. The review will:

- undertake a multidisciplinary assessment of each GUM service in England, highlighting factors both facilitating and obstructing their ability to offer a prompt and high quality service; and
- offer recommendations for service improvement and modernisation arising from the assessment, to GUM clinics, PCTs and SHAs; and
- provide findings and recommendations from the review to the DH.

16.2 The first phase of the review was a written questionnaire, sent to all GUM clinics in England in September, about issues to be covered in more depth during review visits. A quantitative analysis of responses from the first 72% of clinics gives the most up-to-date snapshot available of the state of GUM around the country. See Appendix A for a list of topics covered. We have submitted this analysis to the Department of Health, which owns the data, and MedFASH would be happy for it to be shared with the Select Committee.

17. *Primary healthcare*

17.1 Primary care is expected to play a key role in implementing the *National strategy for sexual health and HIV* and *Choosing Health*. We agree that the active involvement of primary care is vital to increase capacity and plurality of provision, making services accessible to a broader range of people. The new GMS contract provided an opportunity to increase the provision of sexual health services in general practice but it has become clear that local budgets and priorities do not currently permit much, if any, local commissioning of the contract's national enhanced service for more specialised sexual health services, and few PCTs are even commissioning locally enhanced services for sexual health. We hope that the priorities set out in *Choosing Health*, and the imperative of meeting the sexual health PSA target, will serve as drivers for a review of the contract and how it can support an enhanced and wider role for GPs in the management of sexual health and HIV.

17.2 The forthcoming *Recommended standards for sexual health services* (see above) are explicitly inclusive of primary care, which is a leading provider of contraception and an important provider of other sexual health services. The *Recommended standards for NHS HIV services* highlight the role of GPs in reducing rates of undiagnosed HIV infection and in dealing with the day-to-day healthcare needs of people with HIV. We hope that commissioners will recognise the relevance of these when planning integrated local services for sexual health, including their contracts for primary care.

17.3 GPs and primary care professionals have historically been nervous of addressing some aspects of sexual health, especially HIV. However, they may not recognise how transferable many of their existing skills are for dealing with this long-term chronic disease. Building on those skills, they need practical support to improve their ability to undertake a clinical diagnosis of HIV (recognising signs and symptoms), offer HIV testing with confidence, recognise the side-effects of antiretroviral therapy (ART) and understand the implications of a patient's HIV infection or ART for their day-to-day healthcare (such as immunisation, cervical screening, contraception). MedFASH has just published *HIV in primary care—an essential guide to HIV for GPs, practice nurses and other members of the primary healthcare team* (2003), which is written by GPs to address these needs, in a format appropriate for use in busy primary care settings. It should help primary care providers to implement the recommended HIV service standards.

18. Service capacity

18.1 We share the concern about service capacity expressed in the Committee's 2003 report. Despite initiatives in many places to modernise services, it is clear that capacity is still very far from adequate to meet current demand and in many places the mismatch has worsened. From our project work and our contacts with health professionals, it is clear that improving the sexual health of the nation requires a significant increase in service capacity. Increasing the numbers of staff in traditional and in innovative community-based services, as well as changing job roles as part of modernisation, will require significant investment in training. The currently overstretched services need to play a key role in training, and planning for increases in service capacity needs to include provision for this.

18.2 We welcome the plans for a national public education campaign, as set out in *Choosing Health*. We believe that, like previous campaigns, this is bound to increase the demand for services, whether to obtain contraception including condoms, for information and reassurance about the risk of STIs or to seek testing for suspected infection. This increased demand will put a further strain on capacity. National campaigns and local initiatives should be synergistic for maximum effectiveness, and as both public education and capacity increases are needed urgently, we hope that they will be planned and resourced in an integrated way at national and local level.

APPENDIX A

National review of GUM services—questionnaire topics

Host organisation (District General Hospital, PCT, Foundation Trust, etc)

Dedicated GUM or shared premises

Whether shortage of space is adversely affecting modernisation

Dedicated space for HIV patients

Separate male and female sessions

Average time spent in the clinic for new patients with an appointment

Average time spent in the clinic for new walk-in patients

Number of formal complaints received

Change in practice or protocols in last three years to increase capacity

Contract category of service level agreement

Whether priorities relating to STIs appear in PCT local delivery plan

Number of clinics with increase in new patients in 2004

Number of clinics with increase in follow-up patients in 2004

Whether NAAT chlamydia tests are routinely available

Whether HIV testing is offered to all patients attending for STI screening.

APPENDIX 22

Memorandum by the National Study of HIV in Pregnancy and Childhood (HA 29)

ABOUT THE NSHPC

Surveillance of obstetric and paediatric HIV in the UK is carried out through the National Study of HIV in Pregnancy and Childhood (NSHPC) at the Institute of Child Health, University College, London. The NSHPC provides the paediatric data for the overall national surveillance of HIV: summary data are forwarded to the Health Protection Agency Centre for Infections and Health Protection Scotland four times a year for integration with adult data.

1. Anonymised demographic, laboratory and clinical information on pregnant women is available; this includes country of origin, timing of maternal diagnosis, uptake of interventions to reduce the risk of mother to child transmission of infection (antiretroviral therapy and mode of delivery), outcome of pregnancy and the subsequent infection status of the child.

2. In the UK it is estimated that about 25% of HIV positive women who remain undiagnosed at delivery will transmit infection to their baby. Antiretroviral therapy in pregnancy, caesarean section delivery, and avoiding breast feeding substantially reduce the risk of transmission, and most diagnosed women take up these interventions. As a result, less than 2% of infants born to diagnosed women in the UK are themselves infected.

3. Since the introduction of the routine offer and recommendation of HIV testing to all pregnant women as an integral part of antenatal care (in England in 2000, and subsequently elsewhere in the UK), a steadily increasing proportion of HIV infected pregnant women have been diagnosed before delivery. In 2003 nearly 900 HIV infected women gave birth in the UK, of whom over 90% were diagnosed before delivery. Nevertheless, about 170 infected children are believed to have been born in the UK between 2000 and 2003, 80% of them to women who were undiagnosed at the time of their child's birth. About two-thirds of these infected children have been diagnosed and reported to the NSHPC so far, including 13 who have died.

4. A majority of HIV infected pregnant women giving birth in the UK were themselves born overseas. Any developments which discourage women from accessing antenatal care, or restrict their access to interventions, could result in avoidable transmission of HIV from mother to baby.

APPENDIX 23

Memorandum by Dr Mayura Nathan (HA 30)

1. This memorandum is written by Dr Mayura Nathan, in his capacity as Lead GUM Physician at the Homerton University Hospital Foundation Trust in Hackney (East London) and as the Chairman of the North East Sector (London) GUM (Sexual Health) Group. I have been working in the field of Sexual Health and HIV for over 20 years. This memorandum reflects the changes perceived locally and sector-wide in the last two years.

2. A Service Network has been established in North East London for HIV and Sexual Health, to enable improved standards of care and service provision. The GUM Group has recently met and identified priorities for the network.

3. Some improvement has been noted in patient access to Sexual Health Services since the recent injection of one off monies and revenue funding to GUM services by the Department of Health. There remains however, examples of two week wait for an appointment to a GUM service as well as people turning up to open access services and being turned away due to capacity problems. While the involvement of General practices in the provision sexual health is welcome and will improve accessibility to a wider public, it is felt that this will not solve the problems of capacity and access to people seeking GUM services.

4. Department of Health has recently commissioned the proposal of a National Standards for Sexual Health Services. It is felt that setting standards will enable a more equitable service provision across the UK. While issues relating to access, care standards and referral pathways and some prevention work could be addressed through national standards, it will not address other issues facing sexual health services such as burden of disease or local variation in disease spread. In 2004, we identified an outbreak of infectious syphilis amongst commercial sex workers in Hackney. The capacity problems do not allow a robust diversion of resources to study the outbreak in detail.

5. Service network arrangements are likely to help with access to full range of sexual health services, through care pathways and explicit referral arrangements. There are limits however, in terms of distance people are willing to travel or prepared to wait for specialist services. Locally some specialist services have a waiting time of five to six months and this may have an impact on the disease complexity.

6. Service networks should help ensure collection of unified data from services and thus make better comparison of disease pattern and management. However, the type of data collection in general practices or family planning clinics is different to the data collected by GUM services. The use of READ codes by general practices and KC60 codes by GUM services will make it difficult to pool the data, to help ensure common standards.

7. The setting up of a two year programme of GUM Clinic Review is welcome and timely. However, unlike some past initiatives, we need to make sure sufficient monies follow recommendations by the review bodies. Capital allocation and space has been a continued problem in many GUM services including those in North East London.

8. Many sexually transmitted diseases show an upward trend in numbers affected in the last few years. Behavioral change in populations, for example, adopting safer sexual practices, are slower to evolve than one would like, and therefore a realistic approach to dealing with disease burden is needed.

9. We recommend that a thorough review of GUM clinic premises and services are undertaken and standards are laid down based on activity both current and future projected levels. In our local example, we opened new clinic premises in 1998 based on attendance figures of 1996 (12,000 patient visits). The anticipated attendance level was 17,000 per annum. Currently we are seeing 26,000 attendances with some being turned away. We allowed for 75 HIV patients to attend for care in 1998. Our HIV patient population currently stands at 450.

10. We recommend that no patient/client motivated to attend a service should be turned away and that sufficient capacity should be available based on demand.

11. We recommend that sufficient flexibility in services should be available to deal with outbreaks or variable demand. At the least, some pooled resources sector-wide should be available to respond swiftly to increased demand in individual services.

In conclusion, it is my opinion, that several good initiatives are being planned to improve access and care for people seeking sexual health services, but we need to ensure that sufficient resources are targeted to enable the implementation of the recommendations. We also need to respond to higher demands that are placed in some parts of the country.

APPENDIX 24

Memorandum by the Royal College of General Practitioners (HA 31)

1. The College welcomes the opportunity to submit written evidence to the Inquiry by the Health Committee into new developments in HIV/AIDS and sexual health policy.

2. The Royal College of General Practitioners is the largest membership organisation in the United Kingdom solely for GPs. It aims to encourage and maintain the highest standards of general medical practice and to act as the “voice” of GPs on issues concerned with education; training; research; and clinical standards. Founded in 1952, the RCGP has over 22,000 members who are committed to improving patient care, developing their own skills and promoting general practice as a discipline.

3. The context of the debate about sexual health policy includes the following information which notes the worsening of the sexual health crisis since the Health Committee reported on 11 June 2003:

- In 2003, the total number of new HIV diagnosis was 6,606—more than twice the number in 1998 (1).
- Non-HIV Sexually Transmitted Infections continue to rise overall—Chlamydia is now the commonest STI diagnosed in England, Wales and NI having risen by 8% from 82,558 to 89,431 from 2002 to 2003 while Syphilis is also of particular concern because of the rate of increase (28% in men, 32% in women) from 2002–03 (2).
- The overall conception rates for under 16s have remained at much the same level since 1975 and the latest figures show a small rise in conceptions in under-18s in England and Wales from 42.7 to 42.8 per 1,000 (3).
- In 2003, for women resident in England and Wales, the total number of abortions was 181,600, compared with 175,900 in 2002, (a rise of 3.2% and the highest ever annual total) and the under-16 abortion rate was 3.9 compared with 3.7 in 2002 (4).

THE CONSEQUENCES OF THE NEW AND PROPOSED CHANGES IN CHARGES FOR OVERSEAS PATIENTS WITH REGARD TO ACCESS TO HIV/AIDS SERVICES

4. The concept of charging overseas patients for medical care services raises a number of difficult and complex issues. The College discussed these in its response to the Department of Health consultation of May to July 2004 which set out proposals to exclude overseas visitors from free NHS Primary Medical Services. A copy of the College’s response is attached and forms part of our evidence.

5. The key issues for us about the proposed changes in charges as far as they affect overseas patients seeking access to HIV/AIDS services are:

- This is a public health issue of protecting the population at large as well as the effect on particular individuals and the additional barrier of cost should not be put in the way of mitigating the spread of HIV/AIDS among the general public: we note that the Health Protection Agency singles out “the migration of people from areas of the world where there is a high prevalence of HIV, such as sub-Saharan Africa” as a major factor in the increase in heterosexual spread of HIV in the UK (5).
- General Practitioners and their staff should not be required to police patients between those eligible for free access to HIV/AIDS services and those not.
- We currently see HIV Positive patients being denied treatment when they are well. When a crisis point is reached, these patients are then admitted to Accident and Emergency departments with AIDS defining conditions only partially to recover, be discharged in remission and then be denied anti-retrovirals again and then be readmitted.
- The College would like to see greater encouragement for HIV testing to allow for earlier diagnosis and provide better prognosis—the proposed changes will only discourage patients to test for their HIV status.

PROGRESS TO DATE IN IMPLEMENTING THE RECOMMENDATIONS OF THE COMMITTEE'S INQUIRY INTO SEXUAL HEALTH (THE COMMITTEE'S THIRD REPORT OF SESSION 2002–03)

6. The College greatly welcomes the emphasis on sexual health and HIV in the Government's health agenda. We wish to bring to the Committee's attention the fact that general practice continues to be a major provider of sexual health services. For example, 80% of contraception is provided in primary care (Source: ONS 2003); and general practice has unmatched accessibility and geographical coverage (Source: Audit Commission 2002).

7. Though the Committee Report helpfully identifies the primary causes of the deterioration in sexual health, it is to be regretted that it gives no consideration as to how these primary factors may be modified. This omission has to be addressed if progress is to be made. This has now been widely acknowledged as the following (and many other references 6–9) show:

“It is encouraging that condom use has gone up but probably not enough to offset the increase in sexual partners” (10).

“The past decade has seen substantial increases in high-risk sexual behaviours in the British population. Although condom use has also increased, this is likely to have been offset by greater increases in unsafe-sex” (11).

8. While the Report also states that the Committee sees “no benefit in preventative approaches based primarily around promoting abstinence”, evidence of the effectiveness of an abstinence component continues to grow in places as diverse as Uganda (12) and the USA (13). As teen birth rates are now at their lowest level in the USA since 1946 (14) and the under 19s abortion rate in the USA is now lower than in the UK, perhaps it is time to reconsider the dismissal of abstinence in the light of these facts.

9. We set out below specific comments relating to the issues and recommendations of the Committee's Third Report of Session 2002–03. In essence, though, the areas that need to be addressed are to obtain some quality and performance markers regarding sexual health into the General Medical Services contract and to place a greater emphasis on educating and training about sexual health and HIV matters.

10. The Committee's Report recommendations in relation to primary care have not been enabled by the new GMS contract.

11. The contract has not addressed the holistic nature of the National Strategy for Sexual Health & HIV, it continues to separate the basic elements of sexual health (eg contraception, cervical cytology and STIs).

12. There are no quality or performance markers for sexual health in essential services to act as a driver for increased quality or awareness of sexual health in general practice.

13. The Committee's Report recommendations in relation to general practice have not been addressed in GPs' contractual arrangements or provision of training.

14. GPs are also aware that there are too many referrals to secondary care which leads to long waiting lists for those with transmissible diseases. Communication between primary and secondary care could be better so it may be helpful, in moving treatment for patients forward, if general practices were empowered to deal with the most basic elements of STD management. If such empowerment were granted, an educational programme (similar to that which enabled GPs to manage drug users) should be provided as a matter of urgency.

15. Recommendation 15 (re chlamydia screening in general practice) is not facilitated by the contract nor to date by the National Chlamydia Screening Programme which has been delayed by a recommendation to await the results of a reinfection study—but there now exists enough published (15, 16) and unpublished (17) evidence to know more about reinfection rates. The interval for repeat screening in those who remain at risk should be no longer than a year and a shorter interval may be more appropriate. It is time to roll out Chlamydia screening to the vast majority of under 25s, as this will be the only way to have an impact given its prevalence and ease of transmission. GP practices would be successful in delivering this service if it is incentivised.

16. Recommendation 22 (re diagnosis and care of HIV) is not supported by the contract at the essential level and very few GPs or PCTs provide or commission enhanced services. Other issues here also need to be addressed such as recognising that HIV/AIDS is a specialist area of health care which requires a multidisciplinary team; and that many HIV/AIDS patients (at least those picked up in obstetric services) are first generation immigrants or asylum seekers with language needs.

17. Recommendation 28 (re potential of primary care as a sexual health service provider and need for training) needs addressing—there are no incentives in essential services.

18. Recommendation 30 (re quality of service from GP & training) also suffers from a lack of incentives and should be recognised as specialised enhanced services.

19. Recommendation 32 (“Improving access to contraception services leading to reduction in abortion rates”) ignores the positive choice by some women of using abortion as contraception, or a planned pregnancy with change of circumstances. This Recommendation needs to go hand in hand with measures to improve life choices and in dealing with peer pressure regarding sexual health. There are many grass roots “say no” campaigns which need support and integration with health providers. There is provision for free

condoms in GP surgeries but there is the question of dispensing repeats. Whatever is appropriate to the needs of particular communities should be supported, with innovative ideas to tackle the health issues in different locations being encouraged.

20. Recommendation 34: there has been an increase in consultations for male libido and erectile dysfunction (ED) problems in the last three years; most treatments for ED do not qualify for NHS prescriptions. The cost shift as outlined in savings on treatment for depression, fertility and marital breakdown should be reflected in a shift in the prescribing budgets to allow treatment for male libido and erectile dysfunction problems within NHS budgets; the suggested results of male sexual dysfunction may not be seen or may be difficult to cost, and are therefore easier to ignore.

21. The sexual health secondary care services are under funded; GPs are under resourced, staffed and trained to be able to suddenly take on this work from secondary care, particularly when dealing currently with the demands of nGMS.

22. A GPwSI with skill and interest in these areas, with separate commissioning of the work with appropriate support staff, would be one way to deal with this; however, PCTs are reluctant to commission enhanced work even that which is already outlined in the contract let alone work outside of it.

23. Recommendation 50: The plan is for access to a Genito-Urinary Medicine unit or specialist family planning within 48 hours by June 2005; currently this is typically two weeks for the GUM and one week for the specialist sexual health clinics in the area. But target setting does not take account of the fact that people cannot be forced to attend to follow or complete treatment. Any policing of targets with penalties will further reduce available services; as an alternative, perhaps strategies and good practice could be identified and encouraged to be rolled out and resourced effectively these areas.

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APPENDIX 25

Memorandum by Médecins du Monde UK (HA 32)

SUMMARY:

Médecins du Monde UK is very concerned that the recent and proposed changes to NHS entitlement (charges for overseas visitors) prevent, and will further prevent, vulnerable members of society from accessing healthcare. We are concerned about the consequences of this for individuals and for public health.

With particular reference to HIV/AIDS, there are some specific public health consequences of denying access to HIV treatment (or to primary care in general) for sections of the population:

- A lack of access to treatment will reduce the take up of voluntary HIV testing, thereby increasing the proportion of HIV cases going undiagnosed;
- Primary care plays an important role in early detection of HIV and is, therefore, essential to help people get treatment and to prevent the spread of the epidemic;
- Provision of treatment to prevent a person's condition worsening also has direct implications for how infectious that person is and, thus, for the spread of the epidemic;
- Individuals who are subject to charges for HIV treatment (or other healthcare) are less likely to complete other courses of treatment to which everyone is entitled free of charge (eg TB or sexually transmitted infections);
- Exclusion and stigmatisation of groups at high risk of HIV infection will not help to reduce the spread of the disease.

The new and proposed regulations undermine effective access to healthcare services, including HIV/AIDS services:

- Only providing "immediately necessary treatment" is not cost effective and will ironically create a system that refuses preventive and curative treatment, but offers treatment when the patient is dying;
- The regulations are not understood clearly by health professionals and NHS service users who are both confused about the conditions to entitlement. This increased confusion creates further barriers to healthcare for socially excluded groups and migrants;
- The new and proposed regulations undermine social cohesion and encourage discrimination;
- The new and proposed regulations are in clear contradiction with government policies on HIV/AIDS, public health and improvement of NHS services;
- The UK Government needs to look into other European countries which safeguard access to healthcare for all.

Other issues:

- The new and proposed regulations conflict with health professionals' duty to care and require the NHS to act as an immigration body;
- The new and proposed regulations do not acknowledge the need to ensure effective access to healthcare for children and pregnant women.

Médecins du Monde recommends that:

- the Government does not go ahead with the proposed changes to entitlement to primary care;
- an impact assessment to investigate the impact of the recent and proposed changes on individuals, public health and the NHS is carried out;
- the Government re-examine the rules concerning charges for secondary care which were introduced in April 2004 and take action to ensure that vulnerable members of society have access to hospital treatment;
- people living with HIV in the UK have access to treatment and care;
- clear information about access to NHS care is required for both patients and health professionals;
- special attention is paid to the health needs of particularly vulnerable groups such as children and pregnant women to ensure that they have access to healthcare;
- the vitally important role that access to primary care plays in protecting public health is recognised.

INTRODUCTION:

1. *Médecins du Monde* is a medical humanitarian non-governmental organisation which provides healthcare for the most vulnerable populations suffering from crisis and exclusion in both developed and developing countries. As well as providing healthcare, we "bear witness" to human rights abuses, particularly obstacles to healthcare, and advocate for access to healthcare.

2. *Médecins du Monde* has over 20 years of experience in providing medical assistance and in advocating for better access to healthcare. *Médecins du Monde UK* recently assessed needs in East London and is presently launching a health project working with vulnerable groups which will, among other things, document barriers to healthcare.

3. Through our extended experience in providing and documenting access to healthcare in other countries, at a European and a world-wide level, we are extremely concerned about recent and proposed changes to NHS entitlement. As we are already witnessing the impact of similar restrictions to access healthcare in other European countries, we have strong reasons to believe that these changes already impair (and will impair more dramatically in the future) access to healthcare for vulnerable populations as well as access to HIV/AIDS services.

4. As a medical humanitarian organisation, we are concerned that the present and proposed policies initially designed to regulate charging for “overseas visitors” have inadvertent consequences on individual and public health and will prevent vulnerable members of UK society from having effective access to healthcare.

5. For this reason we have urged the Government not to introduce NHS charges at the primary care level and to repeal the changes introduced in April 2004. We have also joined with other medical and refugee organisations to call on the Government not to implement these changes without carrying out a prior in-depth impact assessment. This process should assess the potential impact on the individual, on health services and front-line staff, the voluntary sector and on public health.

Consequences of the new and proposed changes in charges for overseas patients with regards to access to HIV/AIDS

6. Protecting access to healthcare for vulnerable groups—The new and proposed changes to NHS entitlement endanger the core principle of the NHS which is to ensure that “*healthcare should be free, available to all and of uniform quality no matter where people live and whatever their background.*” To make access to healthcare subject to the ability to pay for treatment is against the basic principle of the NHS, which is to provide access to healthcare to everyone regardless of their resources.

7. Although this principle is now 50 years old, it was emphasised in the Queen’s Speech only last month: “*My Government will continue its reform of the National Health Service, offering more information, power and choice to patients, with equal access for all and free at the point of delivery.*”

8. Violation of international law—The new and proposed regulations will be in clear violation of the right to the highest attainable standard of health (article 12 ICESR) as interpreted by the UN Committee on Economic Social and Cultural Rights which monitors States’ observations of the International Covenant on Economic Social and Cultural Rights ratified by the UK in 1976. The General Comment 14 clearly sets out how the right to health should be respected in practice in paragraph 34. “*In particular, States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum seekers and illegal immigrants, to preventive, curative and palliative health services; abstaining from enforcing discriminatory practices as a State policy; and abstaining from imposing discriminatory practices relating to women’s health status and needs.*”

9. ECHR article 3—The new and proposed regulations will potentially create situations in violation of article 3 of the European Charter of Human Rights. Denying access to healthcare for some people can worsen their medical conditions to a stage where it becomes inhuman and threatening for their life.

10. Limited evidence—It is difficult to provide evidence in the form of detailed case studies and statistics at this stage. Firstly, the changes introduced in April 2004 are still poorly understood within the health services and their impact is still trickling through the NHS. Secondly, the changes to primary care are still proposals. Nonetheless, it is clear that both the recent and proposed changes are contradictory to many other areas of government policy and that there are serious grounds for concern about their potential impact on the health of vulnerable people, on public health and on social cohesion.

11. The importance of early detection—People infected with HIV are often diagnosed long after being infected. Restricting access to healthcare services, especially primary care services, will reduce the number of diagnosed people and will increase their medical vulnerability. Early detection of HIV/AIDS is important for several reasons—so that an infected individual can have treatment to prevent their condition worsening, so that they can take action to prevent transmission to others and also so that they can alter their lifestyle to minimise the risks of deterioration in their health.

12. The Chief Medical Officer emphasised the importance of early detection of HIV as a key element in controlling the spread of HIV infection in his Annual Report on Public Health in England in 2003⁴² where he noted that “*a relatively large proportion of people are being diagnosed late in the course of their HIV disease, leading to avoidable illness and death and creating opportunities for the disease to spread more widely within the population.*”

⁴² Chief Medical Officer for England (2003) Annual Report on Public Health in England.

13. Discouraging HIV testing—Linked to this issue of early detection is the impact that a lack of access to treatment will have on uptake of HIV testing. We know from experience in developing countries that availability and affordability of HIV treatment increases uptake of testing and consequently awareness and preventive action against the spreading of HIV. An estimated 33% of people with HIV infection in England remain undiagnosed.⁴³

14. Provision of voluntary HIV testing and counselling is to remain freely available to everyone. This policy is vital to encourage people to take an HIV test and seek advice to prevent transmission of the disease. This policy will be seriously undermined, however, if people know they will not be able to get free treatment after that. According to HIV/AIDS organisations, people within communities of high prevalence for HIV have begun to ask why they should bother to test for HIV if they cannot obtain treatment for it. Restricting access to NHS entitlement will only undermine education campaigns and other measures to raise awareness among these communities.

15. Access to treatment—Over and above its consequences for an individual's health, access to treatment for HIV infected people is also a public health issue. HIV treatment prevents a person's conditions worsening and as the condition worsens they become more infectious. Excluding a part of the population living in the UK to access such treatment, therefore, reduces the chance of tackling efficiently the spread of HIV within the UK. The number of new cases of HIV infection has more than doubled since 1998⁴⁴ and HIV infection is now the fastest growing serious health condition in England.⁴⁵ This approach is in stark contrast to the Department for International Development's policy to tackle HIV/AIDS in the developing world whereby "*the UK supports efforts to provide increased, and eventually universal, access to treatment and care for people with HIV and AIDS*".

16. Undermining control of communicable diseases—The new and proposed regulations undermine measures tackling communicable diseases such as (non-HIV) sexually transmitted infections (STIs) and TB, which are deliberately exempt from charges. However, how can people infected by these conditions effectively access free treatment if they cannot be diagnosed in the first place? Within the framework set out by the new and proposed changes, these medical conditions can only be assessed at a later stage in A&E department. Furthermore, it seems difficult to believe that people in need of treatments which are exempt from charges will know that they are entitled to these treatments, free of charge, when the regulations themselves are very poorly understood among NHS staff.

17. This lack of effective detection will increase risks of communicable disease transmission which are already worrying. As figures from the British Thoracic Society (BTS)⁴⁶ and TB Action Plan⁴⁷ from the Chief Medical Officer show there is a rise among the number of TB cases in the UK and, as the last Health Select Committee report on sexual health⁴⁸ highlighted, there are poor results for tackling STIs within the NHS, where diagnoses of new infections have increased.

18. Incompletion of TB treatment—People receiving treatment for tuberculosis (TB) are likely to be discouraged from completing their treatment if they are faced with a bill for other medical treatments which are not free of charge. Under the regulations for secondary care already in force, people co-infected with TB and HIV have been reported to stop their treatment halfway through when asked to pay for their HIV treatment. This has serious consequences for their health since incomplete treatment fails to cure the disease. It also has serious consequences for public health because lapsed treatment also contributes to the promotion of drug resistant TB which is more difficult and expensive to treat.

19. Access to primary care—It will be unhelpful and contradictory for some services to be free within specialist and often hard-to-access NHS units and not within primary care. Research shows that some groups, including African or Caribbean communities, prefer to use general practitioner services than specialist genito-urinary provision. If some people are denied initial examination and health checks at primary care level, or discouraged by their cost, it is highly likely that prevalence of sexually transmitted infections and other diseases will continue to rise.

20. In his 2003 report on public health, the CMO noted some weaknesses in the provision of HIV/AIDS testing in genito-urinary medicine settings and recommended that "*urgent consideration should be given to ways of expanding non-genito-urinary medicine clinic-based HIV testing services in primary care and community settings.*" The proposals to restrict access to primary care for some groups of the population are in direct contradiction to this policy.

21. Groups at high risk of infection—The new and proposed regulations do not acknowledge the fact that according to many public health reports some groups of migrants are at particularly high risk of HIV infection. It is particularly inappropriate, therefore, to enact restrictions to access healthcare which will

⁴³ *idem*

⁴⁴ Health Protection Agency (HPA), HIV and other Sexually Transmitted Infections in the United Kingdom in 2003 Annual Report, November 2004.

⁴⁵ Chief Medical Officer for England (2003) Annual Report on Public Health in England.

⁴⁶ Fears over TB infection "hotspot", BBC News, 2004/08/03, <http://news.bbc.co.uk/go/pr/fr/-/1/hi/england/london/3529032.stm>

⁴⁷ Stopping Tuberculosis in England. An Action Plan from the Chief Medical Officer, October 2004.

⁴⁸ House of Commons, Health Committee, Sexual Health, Third report of session 2002–03, volume 1, 11 June 2003.

mainly affect the migrant population. We already know that HIV infected Africans, for example, are unequally accessing HIV/AIDS services and that TB is the most common co-infection among African adults infected with HIV.⁴⁹

22. Stigmatisation—The new and proposed regulations will undermine positive measures to integrate HIV infected people within UK society and will further exclude the migrant population from prevention campaigns and HIV testing. It is very important to effectively detect HIV infected people through testing by targeting groups most at risk of infection through prevention campaigns without stigmatising those groups. The restrictions to healthcare entitlement do not encourage positive integration of the migrant population within mainstream healthcare services, do not encourage those groups to undertake a HIV test and do not help them to be aware of their entitlement to free testing and counselling.

23. Restricting access to healthcare services in general will undermine effective ways of testing HIV, such as routine testing during antenatal care. This policy has been relatively successful in the UK, and HIV diagnosis rates in pregnant women have improved since the late 1990s. However, 25% of cases among pregnant women still go undiagnosed in London meaning that babies are still being born infected with HIV.⁵⁰ Any measures which reduce access to antenatal care or primary care will only further undermine this policy.

24. Defining “immediately necessary treatment”—According to the changes, “immediately necessary treatment” will still be available free on the NHS. This concept, however, is not clearly defined and does not give clear guidelines as to how it can be implemented effectively. If someone is denied access to a primary care consultation and assessment, how will health professionals be able to determine whether treatment is immediately necessary? Any medical condition is potentially urgent if not treated and detected quickly enough.

25. The regulations also contain contradictions about how, in practice, will the concept of free “immediately necessary treatment” be implemented. Health professionals will not be the first person to see the patient. General practice and hospital staff at the reception will be left with the responsibility for assessing patient’s eligibility for medical care. Such implementation of the rules leave the door open to mistakes where patients in need of “immediately necessary treatment” will be turned down on eligibility grounds. It has been reported to us that a pregnant women was refused healthcare by a hospital manager without seeing a health professional although she was bleeding and 7 months pregnant.

26. Cost effectiveness—There is no evidence that the recent and proposed changes will bring any cost savings to the NHS. In relation to HIV, for example, one week’s stay in intensive care is reported to cost almost as much as an annual combination therapy which is now under £10,000. Refusing HIV treatment and accepting to treat the patient in A&E services until her/his medical condition has deteriorated is thus unlikely to result in any cost saving.

27. Increased confusion—*Médecins du Monde UK* does not believe that strengthening rules on access to healthcare bring more clarity to the situation. More checks on entitlement actually create more confusion among NHS staff and among the general public. This, in turn, creates further barriers for vulnerable groups in the UK which will prevent their access to healthcare and will not improve their health.

28. *Médecins du Monde UK* believes that there is an urgent need to inform people of their right to healthcare. Even before amendments to secondary care come into force, (1 April 2004) there was evidence of confusion among NHS staff and among beneficiaries about entitlement to healthcare. The new and proposed changes to entitlement are only likely to increase this confusion and to see health services turn away more people who remain legally entitled to free NHS treatment or to make people wrongly believe that they are not entitled.

29. For example, we have already seen apparent contradictions between the text of the regulations amended in April 2004 and the guidelines on implementation of these regulations. According to recent NHS guidelines on asylum seekers’ entitlement, it is said that “if the claim is finally rejected (including appeals) before the patient has been in the UK for 12 months, they become chargeable for all treatment (including an existing course of treatment) from the date of rejection of the claim, as has always been the case, and they do not become exempt from charges after 12 months’ residence here.”⁵¹ But such implementation does not comply with the amended text of law, which clearly states that no course of treatment should be stopped on entitlement grounds: “where it is established that a person does not meet the residence qualification in paragraph (1)(b) and that person has already received services as part of a course of treatment on the basis that no charge would be made, no charges may be for the remainder of that course of treatment.” The regulations imply that a person would not be charged for an ongoing course of treatment if their status changed, while the implementation guidance affirms that they will be charged.

30. Another example of confusion which already exists concerns the rules on access to healthcare for students. We witnessed the case of a Turkish student who was wrongly denied access by her GP on the basis that she had not completed six months residency yet. She ended up in the walk-in centre where the nurse

⁴⁹ African HIV Policy Network, Annual Report 2003–04.

⁵⁰ Chief Medical Officer for England (2003) Annual Report on Public Health in England.

⁵¹ Implementing the Overseas Visitors Hospital Charging Regulations. Guidance for NHS Trust Hospitals in England. Department of Health, April 2004, paragraph 6.23.

confirmed that she could not register with a GP but agreed to give her some care at the walk-in centre. However, amendment to regulation 4(1)(c)(iii) clearly specifies that an overseas visitor is exempted from charges when “pursuing a full time course of study which is substantially funded by the United Kingdom or is at least six months duration”.⁵² She is still not registered with a GP although she is entitled to NHS care. This case clearly shows that there is worrying confusion about the rules around NHS entitlement which will result in people being wrongly refused access to healthcare services or people who will wrongly believe that they are not entitled.

31. It has been reported to us the case of a dentist informing an asylum seeker that she was not entitled to NHS hospital treatment as she was an asylum seeker. Interpretation of the new regulations to hospital treatment are clearly misunderstood in that case as an asylum seeker is believed not to be entitled.

32. HIV organisations have already noticed difference of interpretations from one hospital to another which makes their work particularly difficult in terms of referral as poor knowledge of exact conditions of entitlement wrongly delay necessary treatments.

33. Need for accurate terminology—Although the new and proposed regulations are designed to target “overseas visitors”, *Médecins du Monde UK* is concerned that people living in the UK will be inadvertently affected. The terminology used in the April 2004 Regulations and the summer 2004 consultation on primary care do not make it clear that these regulations will directly affect vulnerable families, children and individuals residing in the UK.

34. Social exclusion—In practice, people living on the edge are already marginalised within the healthcare system. For these stigmatised groups, asking for more documentary evidence is likely to make it even harder for them to register with NHS services even though they are, and will remain, entitled to such services. *Médecins du Monde UK* opposes tougher regulations on eligibility that could create further barriers to healthcare for stigmatised social groups (migrants, Roma community, homeless people, drug users, sex workers, people with mental health problems, elderly people).

35. Social cohesion—The general public regularly receives misleading and manipulative messages about migrant populations and ethnic minorities. Any emphasis on proof of legal status is likely to encourage discrimination against those groups (refugees, asylum seekers, Black and Ethnic minorities, people from new EU member states, legal migrant workers) and will, therefore, impair their access to healthcare. It will also encourage discrimination based on appearance. People may be prevented from accessing healthcare because of their skin colour or their ability to speak English.

36. Evidence of entitlement may be requested disproportionately from non-white people. Public authorities are required under the Race Relations (Amendment) Act 2000 to eliminate unlawful racial discrimination, promote equality of opportunity and promote good relations between people of different racial groups and assess new policies for their likely impact on race equality. There is an urgent need for the Government to carry out a racial equality impact assessment.

37. Contradictory policies within the Government—The new and proposed changes are directly contradictory to other areas of government policy, undermining the aim of joined up government. The effects of these changes to NHS entitlement will work against, or in contradiction to, the following areas of government policy and strategy:

- As outlined previously, denying treatment to people living with HIV in the UK is in stark contrast to the Department for International Development (DFID)’s HIV and AIDS strategy for the developing world which states that “Many vulnerable people cannot access the services they need because of cost. This is why the UK Government is committed to ensuring that affordability is never a barrier to accessing health and education, or to services such as HIV testing and contraception.”;⁵³
- The fact that vulnerable groups will be unable to access healthcare as a result of these changes may seriously undermine the Government’s programme of action to tackle health inequalities launched in 2003;⁵⁴
- Similarly, refusing to treat people before they become emergency cases will consequently put more strain on A&E services which are already stretched to the limits. Such a workload within the A&E services may impact on the quality of care and the waiting time that is already very lengthy. It will consequently go against the Government’s recent efforts to reduce pressure on A&E services.
- Furthermore, as described previously, denying access to HIV treatment and to primary care services is likely to seriously diminish the effectiveness of the recently announced Tuberculosis Action Plan;⁵⁵

⁵² The National Health Service (Charges to Overseas Visitors) (Amendment) Regulations 2004, regulation 4(1)(c)(iii).

⁵³ DFID, Taking action. The UK’s strategy for tackling HIV and AIDS in the developing world, July 2004.

⁵⁴ DOH, Tackling health inequalities: a programme for action, July 2003.

⁵⁵ Stopping Tuberculosis in England. An Action Plan from the Chief Medical Officer, October 2004.

- The measures are also likely to have a divisive effect on social cohesion and could lead to further exclusion of already marginalised groups thus undermining efforts to tackle social exclusion. Specifically in relation to HIV, this could undo a great deal of progress made in this area: “In the UK, early intervention that specifically focused on the needs of marginalised groups prevented the higher rates of HIV infection experienced by many other countries”.⁵⁶

38. Learning lessons from other European countries—*Médecins du Monde*, through its European network, is already witnessing the impact of similar restrictions on access to healthcare in other European countries. Similarly, we are aware of positive examples from other countries where access to healthcare is not restricted or where safety nets have been established to try and ensure that vulnerable people are able to access healthcare when they need it. *Médecins du Monde* welcomes moves to ensure that a person’s health and the health professional’s duty to care are rightly acknowledged. In Italy, for example, the law asks health professionals not to denounce undocumented migrants and not to reveal their identity to the authorities in order for them to fully enjoy healthcare services without fear of being arrested or deported. In Spain, everybody living in the country is entitled to healthcare regardless of their legal status.

OTHER ISSUES

39. Separation of health services from the immigration system—Restricting the duty to care will undermine the role of health professionals. It will create a particular conflict for health professionals, who will be torn between compliance with the law and compliance with their duty to care and patient confidentiality.

40. People in need of healthcare are already, and will be increasingly, deterred from going to healthcare services in fear of being denounced to the immigration services. Recently, we heard of a man hit by a car who refused to go to A&E services for fear of being arrested. We also heard of immigration officers coming to maternity units in hospitals to interview women who had recently given birth. *Médecins du Monde UK* considers that healthcare needs to be kept separate from immigration rules.

41. Children—Neither the recent or proposed changes mention children. It remains unclear what children are entitled to, in the case where their parents are not eligible to NHS care. *Médecins du Monde UK* is extremely concerned about the impact of these changes on children. Any measures which discourage HIV testing among pregnant women or which deny mothers-to-be access to HIV treatment, will result in more babies born infected with HIV. We find it unacceptable that this, preventable, situation should occur in Britain today.

42. Infant immunisation—If children have no access to healthcare services because of their parents’ status, how will they have access to immunisation and be able to complete it successfully? Immunisation is essential to give children the best chance of developing immunity against infectious diseases in a safe and effective way and minimises their risk of catching the diseases. Ignoring the importance of infant immunisation and not providing access to healthcare for children whose parents are not entitled is very likely to increase the number of children at risk of catching to a disease and to trigger outbreaks of the disease. It is also important to stick to the immunisation schedule, as a delay can leave a baby unprotected and can increase the chances of adverse reactions to some vaccines, such as pertussis (whooping cough).

43. Pregnant women—Neither the new or proposed regulations mention the situation of pregnant women. Denying access to antenatal and postnatal care to pregnant women on eligibility grounds will endanger the mother and baby’s lives. It will increase risks of maternal and foetal complications and death, especially for vulnerable women who are already 20 times more at risk of maternal death.⁵⁷

44. *Médecins du Monde UK* believes that the situation of pregnant women is seriously neglected within the framework of the new and proposed regulations as has been witnessed by refugee and medical organisations. We know of two cases of pregnant women who had been refused antenatal care by the Hospital Manager without seeing a midwife or a doctor. One was a failed asylum seeker and was refused antenatal care. Another one (case quoted earlier on) was also a failed asylum seeker but was in need of “immediately necessary treatment” as she had pre-term bleeding and seven months pregnant. She was not seen by a clinician and was denied antenatal care unless she would sign an undertaking to pay for it. What is more, the Hospital Manager reported the client’s whereabouts to the Home Office. In each case, the midwives were oblivious of the fact that pregnant women were turned away and were very surprised to find out when the women turned up for birth had previously been refused antenatal care.

45. From our experience in other European countries, *Médecins du Monde UK* believes that pregnant women should not be excluded from access to healthcare services. In Germany, for example, pregnant women have only got two options to give birth safely. First, they can choose to give birth anonymously in some cities but will have to give up their baby to adoption services. Alternatively, they can get pre and postnatal care, the necessary vaccinations and medical tests provided that they inform the German Home Office of their presence in the country. This option implies that women will be threatened of being deported after giving birth. Both options put pregnant women particularly at risk and endanger both the woman and

⁵⁶ DFID, Taking action. The UK’s strategy for tackling HIV and AIDS in the developing world, July 2004.

⁵⁷ “Why mothers die 99/97?”, www.cemadh.org.uk/publications/CEMDreports

baby's lives, as the woman will look for alternative ways to give birth in order not to give up her baby or to avoid to be deported with her child. Furthermore, babies born in Germany to undocumented parents are also denied any necessary medical care because they do not have an official birth certificate.

RECOMMENDATIONS

46. *Médecins du Monde UK* urges the Government not to go ahead with its proposed restrictions in access to primary healthcare, and instead to ensure that vulnerable members of society have effective access to healthcare. People in need of primary healthcare should not be excluded from it on the grounds of immigration status.

47. We call on the Government to investigate carefully what implications restricted access to free NHS primary care would bring for individuals, wider society and the NHS, before introducing any changes. This impact assessment should seek to measure the effects in terms of the impact on the individual, on health services and front-line staff, the voluntary sector, on particularly vulnerable groups, on public health and social exclusion. There should also be a race equality impact assessment as required under Race Relations Amendment Act 2000.

48. The Government should re-examine the rules concerning charges for secondary care that were introduced in April and should instead ensure that vulnerable members of society have access to secondary care.

49. In line with the above recommendations, we call on the Government to recognise the ethical, public health and economic arguments against denying access to HIV treatment. People living with HIV in the UK should have access to treatment and care.

50. *Médecins du Monde UK* calls on the Department of Health to clarify an already confusing situation relating to NHS entitlement. We consider that there is a serious need for clear information about NHS entitlement to be disseminated to the general public and to health professionals. This information should particularly address the needs of vulnerable groups.

51. We call on the Government to pay particular attention to the health needs of especially vulnerable groups, such as children and pregnant women, when considering any measure which will have an impact on their access to healthcare.

52. *Médecins du Monde UK* considers the link between primary care and public health is vital and urges the Government to recognise the vitally important role that universal access to primary care plays in protecting public health.

APPENDIX 26

Memorandum by the BMA (HA 33)

The British Medical Association has called on the Government to tackle the current sexual health crisis, reduce the soaring rates of sexually transmitted infections and address the humanitarian and public health consequences of the proposed changes in the charges for overseas patients. The BMA therefore welcomes the Health Select Committee's inquiry into new developments in HIV/AIDS and sexual health policy.

The BMA shares the Committee's concerns, contained in its report on Sexual Health in June 2003, which concluded that the service was in "a state of crisis". The BMA was encouraged to see that the report recommended more resources, including doctors, for sexually transmitted infection (STI) prevention and treatment.

The BMA is particularly concerned that the increasing incidence of STIs is leaving genito-urinary medicine (GUM) clinics unable to cope. The workload of GUM clinics increased by around 50% between 2002 and 2003. Many patients are not being seen within the 48-hour target but have access to the service only after weeks of delay.

THE CONSEQUENCES OF THE NEW AND PROPOSED CHANGES IN THE CHARGES FOR OVERSEAS PATIENTS WITH REGARD TO HIV/AIDS SERVICES

In its response to the consultations on the proposed changes to eligibility for both primary and secondary care, the BMA expressed concern about both the humanitarian and public health consequences of the changes, particularly in relation to failed asylum seekers. The difficulties faced by this particularly vulnerable group were also outlined in the BMA's 2002 report, *Asylum seekers: meeting their healthcare needs*.

The BMA's main area of difficulty concerns refusal of free ongoing HIV care to people who are in the country without proper authority. In theory, if public health and humanitarian concerns are put aside, there is an obvious argument for excluding from treatment people who have not obtained proper permission to be in the UK. In practice, however, this is likely to mean that some people who are already impoverished

and on the margins of society are abandoned when effective treatments are available to help them. Doctors' ethical training is based on the notion of an ethical duty to respond to "need". It is also in society's interests to ensure that treatable diseases, especially those that are transmissible, are not ignored since ultimately this could be a problem for the wider society.

Therefore in correspondence with ministers, the BMA has previously expressed concern about exclusion of this group of patients:

- on humanitarian grounds in that health professionals should not be obliged to refuse care to patients in need because they cannot pay;
- the fact that the entitlement regulations are complex means that it is difficult for health professionals to assess precisely who is entitled to free care and it should not be part of their job to do so; and
- on public health grounds if patients with transmissible infections are refused appropriate treatment.

Doctors in some parts of the country are already expressing concern to the BMA about the withdrawal of all health and social care support from failed asylum seekers. They are not necessarily immediately deported and they currently have no right of appeal, even though a judge ruled that abandonment of such people can amount to inhumane and degrading treatment. (*S, D and T v Secretary of State for the Home Department*, [2003] EWHC 1941.) It is important to stress that late HIV infection especially in people from overseas is likely to be associated with other serious conditions such as TB. High viral loads in patients with untreated HIV allow more ready sexual transmission—possibly into the resident population.

From a public health perspective, the majority of serious HIV-related morbidity and mortality in the UK is associated with missed or late diagnosis, which suggests that accusations of "health tourism" in this context are misplaced. If, for example, people arriving into the UK from Africa with HIV were treatment tourists, they would access treatment earlier rather than turning up as emergencies in A&E with undiagnosed infection as is currently the case.

Primary care is currently being encouraged by Government to take on a bigger role in the diagnosis of HIV and, for public and individual health reasons, this should not be discouraged. The BMA would welcome the introduction of flexibility on this issue. We would very much welcome the opportunity to work with the Government in drawing up guidelines on managing this population group in ways that reflect doctors' ethical obligations towards vulnerable patients.

A very important part of HIV prevention, especially for those who were infected with HIV overseas, among whom women outnumber men, is the prevention of transmission from mother to child. Appropriate interventions before, during and after birth can reduce the risk of HIV transmission from mother to child from 25–35% to under 2%, but in order to achieve this, ongoing medical care and social support is crucial. Aside from the moral and public health arguments, there is also an economic argument for preventing mother-to-child transmission. Fewer HIV-infected children requiring complex monitoring and treatment for their HIV infection will potentially mean lower costs to the NHS. The BMA would be deeply concerned if women in the UK are denied this treatment or its associated support as a result of their immigration status.

As an additional point, it is internationally acknowledged that a programme of social support and medical care for those infected helps to reduce the fear and stigma associated with the disease, resulting in more effective prevention of new infections.

PROGRESS TO DATE IN IMPLEMENTING THE RECOMMENDATIONS OF THE COMMITTEE'S INQUIRY INTO SEXUAL HEALTH

The BMA welcomed the recommendations contained in the Health Select Committee's 2003 report on sexual health. However, recent reports have subsequently drawn attention to the increasing numbers of new diagnoses of sexually transmitted infections (STIs) in the UK. Since 2002, almost all STIs have been on the increase, with gonorrhoea, syphilis and chlamydia among the most common.

According to the latest figures from the Health Protection Agency (HPA):

- HIV diagnoses at 6,780 in 2003 was more than double the 3,093 diagnoses in 1999.⁵⁸
- In 2003 there were an estimated 53,000 people living with HIV in the UK, of whom 14,300 (27%) were undiagnosed.⁵⁹
- the total number of HIV-infected patients seen for care in the UK rose by 16% from 31,861 in 2002 to 37,079 in 2003.⁶⁰

⁵⁸ www.hpa.org.uk/cdr/pages/hiv_STIs.htm#quarterly_SEP04.

⁵⁹ HPA annual report 2003.

⁶⁰ HPA HIV/STI annual reports 2002 and 2003.

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- In 2003, genital chlamydia was the most common diagnosis made in genito-urinary medicine (GUM) clinics in the United Kingdom (UK).⁶¹
 - In 2003, diagnoses of uncomplicated gonorrhoea decreased by 4% in England, Wales and Northern Ireland.⁶¹
 - Between 2002 and 2003 diagnoses of primary and secondary syphilis increased by 28% (1399) in men and 32% (181) in women in England, Wales and Northern Ireland.⁶¹
 - Genital warts remain the most prevalent viral STI diagnosed in England, Wales and Northern Ireland.⁶¹

The recent Department of Health announcement (26 January 2004) of a new £300 million programme over three years to modernise sexual health services and to run an advertising campaign is welcome and the BMA is pleased that the Secretary of State for Health has recognised the need to act now. The £130 million to modernise GUM clinics and other STI diagnosis and treatment providers will be needed to cope with the increased level of demand that will result from the raised awareness of the advertising campaign. It is important to ensure investment to increase capacity comes early enough to respond to increased demand fostered by the campaign. Furthermore, the BMA welcomes the £80 million to speed up roll-out of national chlamydia screening programme.

The BMA is particularly concerned that the increasing incidence of STIs is leaving genito-urinary medicine (GUM) clinics unable to cope. There were 2,046,848 attendances during 2003 compared to 968,842 attendances in 1997 (House of Commons' *Hansard*, 13 December 2004, col 969W). Opening times are sometimes limited to 21 hours a week with many operating from portakabins. Access to clinics is not fast enough, with waits of up to 12 days for urgent cases and eight weeks for general check ups. There must be a reduction of the current lengthy waiting times to GUM clinics. The HPA (20 November 2004) published the first national audit of GUM waiting times which showed that less than one third of people are currently seen within 48 hours—the new target for an appointment to be seen from the time of first contacting a service. The BMA welcomes this target but is concerned about ability to meet it.

The public health white paper *Choosing Health: making healthier choices easier* (2004) uses the phrase “from referral” in promising 48 hour access to GUM services. The BMA is pleased to have received an assurance from the Secretary of State for Health that “referral” in this context should be taken to include “self-referral” and that the Government has no intention to limit the open access nature of GUM.

BMA RECOMMENDATIONS

Policy makers

- Policy-makers need to take note of rising STI prevalence and its costs, against the benefits of prevention, early diagnosis and treatment in the context of the health of the nation.
Costs of STIs include preventable infertility, ectopic pregnancy, hospital admissions for pelvic inflammatory disease, and psychological distress. The risk factors for STIs overlap with those for HIV, and some STIs facilitate the transmission of HIV. The average lifetime treatment costs for an HIV positive individual is calculated to be between £135,000 and £181,000, and the monetary value of preventing a single onward transmission is estimated to be somewhere between £500,000 and £1 million in terms of individual health benefits and treatment costs.
- Funding should be targeted at GUM clinics which suffer chronic underinvestment.
From a survey conducted with GUM clinics, the British Association for Sexual Health and HIV estimates that a third of the money allocated in 2003–04 to primary care trusts (PCTs) for GUM services did not get through to clinics and the money was spent on alternative priorities. Such money should be ring-fenced and monitored to ensure that it is spent on sexual health services.
- As part of the broader strategy to improve sexual health, Ministers should note the importance of including sexual health in Healthcare Commission's inspection criteria.
The proposals are currently out for consultation and the BMA will be responding.

GUM services

- More GUM facilities that are geographically accessible are urgently required, with longer opening hours, more trained staff and increased funding.
Clinics are currently faced with rising rates of STIs, a lack of resources (such as experienced personnel, adequate space, and new funds for expanded screening) and an increase in demand for services such as improved diagnostic testing.

⁶¹ The UK Collaborative Group for HIV and STI Surveillance. Focus on Prevention. HIV and other Sexually Transmitted Infections in the United Kingdom in 2003. London: Health Protection Agency Centre for Infections. November 2004.

- Clinics should also be encouraged to take a more proactive role to increase their publicity and should also be available away from city centres. Therefore the BMA welcomes government proposals for more community-based STI services.

Young people

- There should be proper investment in sexual health service provision that young people feel comfortable using. This would reduce the burgeoning levels of STIs.
- School education strategies that increase students' knowledge of the full spectrum of STIs are essential and should be a core part of the National Curriculum.

Education strategies also develop young people's skills such as negotiating in relationships and accessing/using sexual health services. Well designed sex education programmes have been shown to be effective and education tailored for adolescents, which supports and promotes healthy behaviour and attitudes regarding sexual healthcare, remains an essential part of schooling.

- Sexual health services should be available to all young people and should be accessible (in terms of opening hours and location) to those still in full time education.

The BMA publication, Consent, rights and choices in health care for children and young people offers comprehensive practical guidance on the ethical and legal issues which arise in the healthcare of patients under 16 years of age. More young people's clinics are needed and it is also important that school-based professionals (including school nurses) are able and willing to refer young people to GUM clinics as well as providing some aspects of sexual healthcare themselves.

- As well as their key role in preventing unintended pregnancies, community family planning clinics have a key role to play in the prevention of STIs and should target their services directly at adolescents via accessible, drop-in services.

Health professionals

- General practitioners and other health professionals working in the field of sexual health should receive more training about the diagnosis and management of STIs.

There is a lack of commissioning of sexual health services by PCTs despite practices being willing and able to carry out this work. The new general medical services contract highlights sexual health as enhanced service.

- All healthcare professionals dealing with sexual health must be non-judgemental, able to reassure individuals and to maintain confidentiality.

Healthcare providers should maintain their knowledge of the most recent information relating to STIs, their prevention and control, and provide appropriate medical management for an illness.

- There should be improved training for primary care staff in discussing sexual histories and counselling.

When appropriate, general practitioners should refer patients to GUM clinics, where staff have the expertise to assist in partner notification, education and counselling. GUM services can also play an important role providing training and working in partnership with primary care on these aspects of care. Adopting proactive healthcare behaviour in both the prevention and early detection of STIs is essential. Early diagnosis will prevent long-term health implications posed by STIs.

- The provision of risk-reduction counselling (such as guidelines on safer sex, routes of transmission) should be a standard part of STI clinical care.

It is essential that anyone involved in sexual health has the training to be able to both thoroughly understand modes of transmission and guidelines for safer sex, and feel comfortable discussing sex and sexuality. This is more difficult when sexually transmitted infections are not the clinician's main responsibility. Training may therefore be required to overcome potentially counter-productive embarrassment or unease among healthcare workers.

- With the current move towards a greater plurality of service providers for STI diagnosis and treatment, strengthening and prioritising partner notification is an important measure in preventing the spread of STIs.

It should involve careful history taking to identify all potentially infected partners, and requires better support services for those who have to inform a partner(s) as this can be daunting. This should include advice on who to notify, and follow-up to ensure adherence to treatment. Partner notification is a particular area where close collaboration between sexual health specialists and primary care is urgently needed.

 FURTHER RECOMMENDATIONS

Based on the evolving HIV and STI epidemics, policy-makers and others should also give urgent consideration to:

- Reviewing and strengthening primary prevention efforts directed at homo/bisexual men.
- Offering and recommending annual HIV testing to homo/bisexual men attending GUM clinics.
- Promoting further voluntary confidential HIV testing of migrants from sub-Saharan Africa in settings other than GUM clinics where migrants may present for healthcare, for example in general practice.
- Developing further studies of the sexual behaviour within the UK of migrants from sub-Saharan Africa and HIV positive individuals in order to better inform primary and secondary prevention efforts.
- As the numbers of HIV infections due to heterosexual transmission within the UK rises, surveillance resources devoted to risk factor follow-up of newly diagnosed HIV-infected heterosexuals should increase to ensure there is no loss of timeliness in monitoring this evolving situation.
- Extending routine screening for infectious syphilis to sexually active HIV positive homo/bisexual men attending all centres providing treatment and care. Research is also needed to determine the impact of syphilis outbreaks on HIV transmission amongst homo/bisexual men.
- In view of increases in gonococcal antimicrobial resistance, reviewing and disseminating updated national guidelines for the treatment of gonococcal infections which should encourage regular local audit of therapeutic efficacy.

 APPENDIX 27

Memorandum by Linda Grant (HA 35)

LOCAL HIV HEALTH AND SOCIAL CARE CRISIS: JANUARY 2003

I am writing with an important briefing for you as someone strategically involved in Health and Social Care Planning and Provision in Leicester, Leicestershire and Rutland.

We have seen a sudden, dramatic and unpredicted increase in the number of new HIV+ people in this area since March 2002. Statistics and a graph showing the sudden upsurge are below.

These statistics are **not known** amongst Planners and Policy Makers. Since the ring-fencing for HIV funding was removed several years ago, no-one locally has been collating statistics on new HIV+ diagnoses. The “sophid” statistics being used for planning are those up to the end of 2000, which as you can see from the graphs overleaf are woefully out-of-date.

Up until March 2002, we were seeing new Service Users at a rate of less than six per month. Between March 2002 and September 2002 this jumped to 10 per month, since then it has accelerated to 13 per month. Our caseload has trebled in less than three years.

INCREASING RATES OF NEW SERVICE USERS: LEICESTERSHIRE AIDS SUPPORT SERVICES, APRIL 1999–JANUARY 2003

<i>Period</i>	<i>HIV+</i>	<i>Affected</i>	<i>Total SUs</i>	<i>Asylum</i>	<i>Asylum</i>	<i>Asylum</i>
				<i>Seekers/ Visas HIV+</i>	<i>Seekers/ Visas Affected</i>	<i>Seekers/ Visas Total</i>
1 April 1999–31 March 2000	115	49	164	5	1	6
1 April 2000–31 March 2001	165	67	32	15	6	21
1 April 2001–31 March 2002	219	83	302	24	6	30
1 April 2002–30 September 2002	255	106	361	58	21	79
–End Jan 2003	305	108	413	93	22	115

Of particular concern is the number of Asylum Seekers, Refugees and people on Visas within this. Although 28% of the total, they represent 77% of all new Service Users. This has frightening implications for existing service provision (unable to cope) and for prevention work (the next “wave” of infections are likely to be those acquired locally, by heterosexual women, which potentially will not “show up” for 3–10 years and *which may also be drug-resistant*: see below).

These people are presenting to us with acute and complex needs, which far outweigh those of the people we have traditionally seen previously. They are in acute poverty, have no recourse to “the public purse” or Social Services (since April 2002 when responsibility for housing, food and the £10 voucher per week were

given to NASS). They have no Social Support, friends or family to assist them. The threat of violence from people from the Countries they are fleeing makes “Peer Support’ anathema. They have serious housing needs (eg people living in rooms scarcely big enough for a mattress in Dickensian conditions) heating and clothing needs, and this coupled with stress regarding their immigration status contributes to rapid deterioration in health with obvious implications for costs to the Health Service. We are aware of people being kept on the Ward because the accommodation they have been assigned is “uninhabitable’. Language barriers and medical understandings are very difficult issues. Some people are being given Combination Therapies (expensive drugs designed to slow the progression of HIV) when they do not have the order, routine or resources (including food) to adhere to the necessary strict regimens. This has serious consequences for the individual, for Public Health, and for the optimal use of limited health care resources. Adherence below 95% typically leads to “Treatment Failure’’: faster disease progression for the individual, higher treatment costs, and drug-resistant HIV. This will result in an increase of transmission of resistant virus to the next wave of newly infected individuals.

At Leicestershire AIDS Support Services we are unable to meet these increasing demands. Our Hardship Fund, Complementary Therapies Fund and most significantly The Foodbank, (which has supported adherence by supplying food for people on incomes below benefit level) have all run out of money. Up until March 2002 we raised on average **£15k** per year through donations and fundraising to maintain these services. At January 2003 due to the increase in destitute Service Users the forecast spending has risen to **£52k** per year and we simply cannot raise this amount locally.

LASS Direct Services are reeling under the weight of new and complex demands. We are aware of other Service Providers also experiencing serious capacity issues.

The new Asylum requirement brought into effect from 8 January 2003 will make this situation much worse. From that date any “in-country” applications will **NOT** be entitled to NASS support: food, shelter and clothing. (*Refugee Council statistics 2001: almost 50,000 people applied “in-country”*)

The likely result of this new policy will be to create tens of thousands of destitute Asylum Seekers who have no support from NASS, no food, shelter or clothing. Many of them will be HIV positive. They may or may not be aware of this.

This has serious Crime and Disorder implications as well as Public Health issues. People who are destitute and unable to work are likely to turn to crime, particularly theft or prostitution, to live. Even without selling sex, recreational sex is likely to be one of the few pleasures available, and a human comfort.

We suggest that it is highly unlikely that people in such situations will use condoms. We predict therefore, that the next “wave” of infections will be those being acquired locally now, through heterosexual sex. These are unlikely to “show up” for some years, until those individuals become ill.

This of course leads to the importance of Prevention work. Given that this pattern of infection is completely predictable, we ought to be able to intervene. We have several major problems however:

1. Political and Public Complacency. Statistics for Sexually Transmitted Infections are soaring throughout the UK. There is no “condom culture”. HIV and Sexual Health have dropped off the political and public agenda. “The public” do not perceive themselves to be at risk. The current epidemic of sexual ill health including soaring Chlamydia infections is evidence of this. Because it is not a “target”, there is no investment or concern from funders.
2. Political unpalatability. It is very difficult to describe the structural and epidemiological problems related to HIV positive Asylum Seekers and Refugees without appearing to describe the individuals as “problems”. No one (except perhaps far-right political groups) wants to do this.
3. Capacity. Current Service Providers such as ourselves are unable to cope as it is. More investment is needed for effective health promotion. The proposed devolution of the Health Promotion Agency and consequent loss of Sexual Health as a specialist function could not be more badly timed. “Generic” Health or Education workers—a vital resource which we must strategically tap into if we are to address this crisis—will not undertake sexual health work as it is unpopular, difficult and embarrassing. They **must** be properly informed, resourced and co-ordinated. Who will take responsibility for this?

I urge you now that you have this information to please be mindful of it in any planning or financial forums in which you are involved. There are serious capacity issues to be addressed, and strategic *long-term* planning must be undertaken. Please use whatever influence you have to ensure that despite its unpopular nature, this crisis is not ignored or “left to someone else”. Thank you for taking the time to read this briefing. Please contact us for any further information.

FUTURE PREDICTIONS:

We are unable to locate any body able to give an overall statistics on the numbers of new Asylum Seekers and Refugees coming into the area. Other Councils are buying up housing stock and placing their own Asylum Seekers and Refugees in these, and so not even Leicester City Council are able to give a clear estimate. What we do know is that many people are coming from countries such as Zimbabwe, which have 25% HIV prevalence rates. It is reasonable to assume that of every 100 people coming into the area daily

from such countries, 25 will be HIV+ or have AIDS. These diagnoses are “turning up” from amongst women who are pregnant and routinely tested as part of antenatal procedures, or on the Infectious Diseases Ward where people are turning up extremely ill, with no other likely cause. Given that the vast majority of people with HIV will not show dramatic symptoms for some years after infection, the people that we are currently seeing can only form “the tip of the iceberg”.

Annex

THE EMERGENCE OF AN UNDERCLASS OF DESTITUTE PEOPLE WITH HIV/AIDS
IN LEICESTER

At the end of September 2004, LASS analysed our half-year Service User trends, outputs and outcomes:

- It has been a deeply disturbing six months. In that time, 28 people with HIV surviving on nil income, many on an ongoing basis have emerged.
- This is a direct result of Government Policy (see previous briefing “*Local HIV Health and Social Care Crisis: January 2003*”).
- The results for our services have been immediate. We have had to cut our Foodbank Voucher service to a time-limited **three-month only** service, as it is simply unsustainable for the increasing number of destitute people coming to us. It is nothing short of shocking that we are having to cut something designed to assist people with HIV to meet their basic nutritional needs. After twelve weeks of giving people £7.50 per week for food we must now say “We are sorry, we cannot give you any more food vouchers.” We are left wondering how such people will eat; and therefore how they have any hope of adhering to their HIV medication presuming that they have any, or maintain basic health.
- The focus of our other direct services is shifting to work with other organisations, to try to help people meet the most basic of survival needs; to producing information about soup kitchens; looking for places for people to sleep and for coats and shoes.
- If the current trends continue; then 40–60% of the new service users with HIV that we see each month will end up destitute within 12–18 months of our first seeing them. We now see **14 new people with HIV every month**. 40–60% of that is 6–8 people each month. **This means that the dozens of destitute people with HIV could become over a hundred in a year.**
- The impact of this will affect us all as service providers, planners and commissioners.
- Our concerns are worsened by further recent Government Policy changes. In April 2004, hospital charges were introduced for overseas visitors requiring people to prove they have a right to free treatment. Charges are now being proposed for Primary Care, excluding emergency treatment. HIV drugs are **not** excluded. This means that someone with HIV who cannot produce evidence in a hospital to prove they have a right to free treatment will not be given anti-retroviral HIV drugs (ARV). They will only be treated in A&E if they become seriously ill and require admission. The likely consequences of this include:
 - People without HIV treatment will become ill much faster, and for longer.
 - “Treatment” would then occur in cases of serious illness via A&E requiring hospitalisation, at £500 bed-costs per day; as opposed to £800 a month for the preventative ARV treatment.
 - Healthcare resources are being diverted to provide a surveillance system for the immigration services.
 - It is unethical to wait for someone to become critically ill before giving any treatment when the situation could be cost-effectively averted by an earlier intervention.
 - Like section 55 of the NIA Act last year; these changes in National Policy are potentially disastrous for our work.

These developments have profound implications on all levels. For the individuals with HIV, their health and survival needs are under serious threat. For local Service-Providers, the acute needs of destitute people may overload capacity. There are also serious crime and disorder implications as well as Public Health issues. People who are destitute and unable to work are likely to turn to crime, including theft or prostitution, to live. Even without selling sex, recreational sex is likely to be one of the few pleasures available, and a human comfort. We suggest that it is highly unlikely that destitute people will be able to prioritise obtaining condoms.

Further implications for forward transmission include:

- To deter people from being tested for HIV—if there is no treatment, what incentive is there to test?
- To increase the number of undiagnosed people.
- To in turn increase the number of infections.
- People not on ARV are more infectious due to higher levels of detectable virus.

This paper is not a comprehensive explanation of all of the issues but is a very brief overview of some of the most disturbing trends we have seen in the last six months. We first mapped out our concerns in the briefing “*Local HIV Health and Social Care Crisis: January 2003*”, copies still available. Prior to that point, we had worked with people on nil income relatively rarely; and almost always in a transitional situation whilst awaiting benefit decisions. The question was about how much assistance the person might receive and when; not about whether they would receive anything at all. Nevertheless, our Foodbank expenditure rose from £4,827 in 2000–01 to £23,176 in 2003–04.

By April 2004, we were providing services to seven people on nil income; of whom four were in a temporary nil-income situation but three had no prospect of any further income. By the end of September 2004 this had risen to 28 people on nil income, of whom nine are in a temporary transitional situation (awaiting benefits and likely to qualify) six are “uncertain” (we do not yet know if they are likely to receive benefits due to uncertain pending decisions) and 13 have no prospect of any further income. We have extrapolated our predictions overleaf directly from this.

We are flagging up what we are seeing as a direct result of Government Policy changes and feel that we have a responsibility to work together with our partner agencies in an attempt to avert the growing crisis. This will require attention to service provision and into planning for people in such dire straits; but also requires lobbying at the highest levels. These developments run counter to almost every aim, objective and target set out in the National Strategy for Sexual Health and HIV.

APPENDIX 28

Memorandum by Mr Nigel O’Farrell, Consultant Physician (HA 36)

ELIGIBILITY FOR HIV TREATMENT

We agree with Pollard and Savulescu⁶² that not only are the new guidelines directed towards recovering costs for HIV from overseas visitors unethical, but they could also lead to an escalation of new cases in the UK by failing to treat highly infectious cases with advanced immunosuppression. In our West London hospital, the majority of new HIV cases present with low CD4 counts and medical complications that usually require urgent treatment. These individuals invariably have minimal financial resources. Pre-test HIV discussion with these high-risk individuals includes treatment issues and the likelihood that highly active antiretroviral treatment (HAART) will be recommended, if not immediately, then in the near future. If the guidelines are to be implemented, this discussion will have to include the information that the government will seek to recover medical costs from patients who may be extremely ill with conditions causing respiratory distress such as *Pneumocystis carinii* pneumonia and tuberculosis or cytomegalovirus retinitis that may result in irreversible blindness. Our estimation is that the psychological distress that this will cause both patients and those involved in pre test discussion alike will be considerable.

Back in the mid eighties before antiretrovirals were available, many individuals were counselled that there was little point in getting tested if bad news was the most likely outcome. Surely we cannot go back to this era. Individuals with advanced immunosuppression are more likely to have high viral loads rendering them highly infectious when compared to others diagnosed early on or those on HAART. By not offering free treatment to this group who cannot afford HAART, the risk of new infections is likely to be increased considerably. In addition to the human rights issues, the public health aspects of the new guidelines appear to have been glossed over and require urgent attention by HIV commissioning groups.

APPENDIX 29

Letter from the Chief Medical Officer, Sir Liam Donaldson, Department of Health to the Chairman of the Committee (5H 1B)

RE: HIV VIRAL LOAD AND THE RISK OF HIV TRANSMISSION

At the Health Select Committee evidence hearing on 10 February on New Developments in HIV/AIDs and Sexual Health Policy, Melanie Johnson suggested that I write to clarify some of the issues around HIV viral load and the risk of HIV transmission.

Highly active antiretroviral therapy (HAART) where effective can significantly reduce HIV viral load (ie amount of HIV virus in a sample). An undetectable HIV viral-load is the goal of anti-HIV treatment. But as Melanie Johnson indicated, a reduced or undetectable viral load does not mean that a person is not

⁶² Pollard AJ, Savulescu J. Eligibility of overseas visitors and people of uncertain residential status for NHS treatment. *Br Med J* 2004; 329: 346–349.

infectious. The patient information booklet HIV and Sex produced by the National AIDS Manual provides a useful summary on this issue. It states that although many people with undetectable viral load in their blood also have an undetectable viral load in their sexual fluids, this is not always the case. Some people with undetectable viral load in their blood have quite high viral load in their sexual fluids which could be high enough to infect someone.

The NAM booklet also indicates that studies conducted in men have found that having an untreated sexually transmitted infection, particularly gonorrhoea, increases the chance that viral load will be detectable in semen. HIV can also be present in cells and these could transmit HIV even when a person has an undetectable viral load.

Through its national health promotion work the Department funds, amongst others, the Terrence Higgins Trust and the African HIV Policy Network to produce information resources which also address the needs of people living with HIV. These include messages on the importance of using a condom, not only to prevent further transmission but also to avoid the transmission of other STIs and drug-resistant HIV.

February 2005

APPENDIX 30

Memorandum by William Ford-Young (HA 37)

BACKGROUND

- GP contract does not marry with National Strategy for Sexual Health & HIV or NSF for Children & Young people (which also contains much policy re sexual health) yet GPs see vast numbers of at risk patients and provide 80% of contraceptive services.
- Holistic nature of sexual health and levels of service provision in National Strategy ignored by GP contract—different elements of service in the Strategy are segregated and placed in various separate “add-on” elements of the contract or are not included at all.
- Enthusiastic GPs will include sexual health provision at the basic level of “essential services” but with out reward or performance/quality management, BMA negotiators will state that sexual health (apart from patients with symptoms) does not fall into “essential services”.
- The comprehensive “National Enhanced Service for More Specialised Sexual Health” is beyond most practices skills & capabilities at present and very few PCTs are commissioning such services.
- The National Chlamydia Screening Programme at present is not supported by the contract, yet is probably the most important element of the National Strategy, now further supported by “Choosing Health”, that could be a main driver to improve the sexual health of the nation.
- No nationally provided or recognised education & training programme to support and skill-up GPs & Practice Nurses.

THE WAY AHEAD

- Evolutionary change of contract to provide incentive and quality/performance management for sexual health at basic levels (eg level 1 of Strategy)
- Support good coverage of chlamydia screening programme in general practice by overcoming barriers— financial, resource & time, training & skills.
- Support national GP led (eg RCGP) validated course for holistic sexual health (perhaps along similar lines to very successful course for managing substance misusers in general practice).

IF I COULD CHANGE ONE THING TO BE AN EFFECTIVE DRIVER FOR SEXUAL HEALTH IMPROVEMENT AT PCT LEVEL

- Concentrate on chlamydia screening programme.
 - Evidence based
 - Tackles the most common STI
 - Can be delivered in large variety of health care (& non health care settings) thus giving patients choice, skilling up generic workers, tackling attitudes and normalising sexual health
 - Acceptable to the patients
 - Acts as in-road into other STIs and risk-taking behaviour
-

APPENDIX 31**Letter from the Parliamentary Clerk, Department of Health, to the Clerk of the Committee (HAIC)**

RE: INQUIRY INTO NEW DEVELOPMENTS IN HIV/AIDS AND SEXUAL HEALTH POLICY.

Thank you for your letter of 14 January 2005, seeking further information for the Health Committee's inquiry.

In respect of the information from the review of GUM services, this is still very much a work in progress. The Department has not yet had the opportunity to consider the data which has been provided so far which is only part of an in-depth two year review of services across the country. Ministers will receive reports in due course. Under the circumstances, therefore, you will understand that it is not appropriate to make information available at this time.

The Committee also asked about analyses of costs or potential savings arising from the changes to the charging regimes for overseas visitors, particularly in relation to HIV/AIDS services. As regards the hospital charging regime, NHS trusts have never been required to submit statistics on the costs of treating overseas visitors (a proportion of whom will, at any rate, be entitled to receive hospital treatment at no charge), so there is no baseline from which an estimate of savings could start. Moreover, it is worth making the point that the underlying rationale behind the changes introduced last year to the hospital charging regime was not only to save the NHS money by charging overseas visitors who are not eligible for free treatment, but also to protect free access to the NHS for all those who are entitled to it. This has positive benefits in much more than just monetary terms.

For primary medical services, on 14 May John Hutton launched a public consultation on proposals to exclude overseas visitors from eligibility to free NHS primary medical services. The consultation ended on 13 August.

We are currently working through some of the complex issues that the proposals have raised. Equally, Ministers are considering the responses to the consultation with a view to deciding the best way forward.

Costs and savings related to the treatment of overseas visitors will vary depending on which of the options Ministers decide to adopt but these are not the main drivers for the proposed changes.

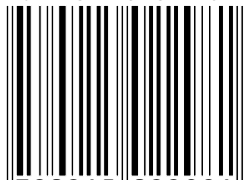
The main thrust of the proposals is to strengthen the current system so that general practice staff and overseas visitors are in no doubt about who is eligible to receive free NHS primary medical services. The intention is for any new rules to be fair, transparent and less bureaucratic to operate and which can be enforced sensibly.

In the interests of public health, the consultation proposed to adopt the same list of exempt diseases that apply in secondary care for which no charges can be made. In addition, the consultation also sought views on any primary medical services that consultees considered should continue to be freely available on public health grounds. Ministers are considering these as part of the overall response to the consultation. The proposals also made clear that anyone who required treatment as a result of an emergency or that in the clinical opinion of the health care professional was immediately necessary that this would continue to be provided free of charge.

As you will appreciate, we are not yet in a position to share any further details with the Committee at this stage.

January 2005

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