

Living with the virus

A Scrutiny of HIV Services in London

March 2004



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Greater London Authority
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Chair's Foreword



The spread of sexually transmitted diseases and in particular HIV is a subject of global importance. Indeed the scale and the spread of these diseases is reaching alarming proportions, and in terms of Britain, no more so, than here in London.

The spread of HIV is of the greatest concern and it has become clear that there is now a deep rooted apathy and indeed ignorance amongst the population over the gravity of this disease and its impact.

During the 1980's there were many good intentioned initiatives and programmes, which raised the profile of this issue and went some way to addressing the lack of knowledge which existed over HIV, in particular amongst the most vulnerable groups in society. The dangers of running the risk of infection through drug abuse and the high profile 'Safe Sex' campaigns targeted at young people in 1980's, brought about a noticeable change in attitude amongst people.

However, complacency has set in and the HIV pandemic is continuing unabated and will have greater impact on the capital if the current apathy continues. HIV cases continue to rise, most evidently in London.

Drugs have been developed which prolong the lives of those infected by this deadly virus, but the fact remains that there is no cure and no vaccination against the virus.

From the evidence gathered it was felt by some witnesses that government and the Health Service had not responded effectively. There is therefore an acute need for the government to take the lead on the issue of HIV both in terms of education and prevention. Resources and effort must be backed by a desire to see this issue at the forefront of health debate.

This report seeks to refocus the priorities of the Department of Health and all related health agencies in ensuring that HIV is seen for the reality of the dangers it poses to society. We therefore call upon the Department of Health to publish its HIV strategy for London and embark on a wide reaching educational programme, coupled with a structured public awareness campaign, to ensure that HIV is given priority status on the health agenda once again. Inaction, or a lacklustre response is not an option.

I would like to express my deep gratitude to all the people who gave so generously of their time and expertise to inform the Committee during the evidence sessions. I would also like to extend my thanks to members of the Health Committee and the Scrutiny Team who have all made valuable contributions to this report.

A handwritten signature in dark ink, which appears to read 'Elizabeth Howlett'.

Elizabeth Howlett AM

Chair, London Assembly Health Committee

The Health Committee

The London Assembly's Health Committee was established in May 2002. It has a unique role, in that unlike local authorities and other organisations, it can identify and investigate health issues that are of concern to London as a whole. The Committee is flexible in its remit, and is not bound to issues emanating from individual localities or health authorities.

The Committee can also work across agency boundaries and encourage participation from the voluntary sector, the private sector and local people, ensuring that these diverse views are reflected in its work.

In May 2003, the Assembly agreed the following membership of the Health Committee for the year 2003/04:

Elizabeth Howlett (Chair)	Conservative
Meg Hillier (Deputy Chair)	Labour
Richard Barnes	Conservative
Lynne Featherstone	Liberal Democrat
Noel Lynch	Green
Diana Johnson	Labour

The terms of reference of the Health Committee are as follows:

- To examine and report from time to time on:
 - the strategies, policies and actions of the Mayor and the Functional Bodies; and,
 - matters of importance to Greater London as they relate to the promotion of health in London.
- To liaise, as appropriate, with the London Health Commission when considering the Health Committee's scrutiny programme;
- To consider health matters on request from other standing committees and report its opinion to that standing committee;
- To take into account in its deliberations the cross cutting themes of:
 - the achievement of sustainable development in the United Kingdom; and,
 - the promotion of opportunity;
- To respond on behalf of the Assembly to consultations and similar processes when within its terms of reference.

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Executive Summary

London has the highest level of sexually transmitted infections and the highest proportion of people living with HIV, than any other city in the UK. A third of people living with HIV do not know that they are infected. Although there are drugs that prevent the progression of HIV, there is no cure and no vaccine to prevent its spread. HIV has declined as an issue of concern for both the general public and politicians in the UK and the level of HIV continues to rise. It is expected that the total number of new diagnoses for 2003 will be the highest ever at over 7000 cases.

There are also increasing cases of drug resistant HIV, which means that people have few treatment options if any. There is an urgent need for co-ordinated health promotion, which includes HIV awareness campaigns across London, for both the general population and high-risk groups such as sexually active young people.

The experience of living with HIV in London is a challenging one. Not only in terms of living with a long-term, life threatening condition, but also in overcoming barriers and learning to negotiate access to appropriate services and support. Many of the support services available today were developed, through community action in the 1980's, in response to the emergence of HIV/AIDS. These organisations have built up a body of valuable expertise in understanding how HIV affects communities and they are delivering highly valued services, but there is still much that can be done to improve the way HIV services are delivered in the capital.

Whilst excellent medical care is available from hospitals across London, HIV and Genitourinary Medicine (GUM) clinics face financial pressures and increased volumes of work. There is also a post code lottery for other support services such as family counselling, peer support and support for young people who are infected or affected by the virus. Support and counselling is a vital part of ensuring that the virus is not transmitted to others.

HIV affects people in different ways, with some people successfully taking the medication and living independently, and others needing support or assistance. In this country the HIV pandemic is now having a greater impact on the heterosexual population, including women and children. This calls for appropriate strategies for HIV testing and prevention, and the adequate provision of services to meet the needs of women, children and other emerging population groups infected or affected by HIV. The challenge now for health and social care services in London, is to meet the current support needs and in the light of increasing levels of HIV, meet future needs. This will require concerted action and continued investment in both HIV medical treatment and the social care needs of people living with the virus.

1. Introduction

1.1 HIV (Human Immunodeficiency Virus) is the virus that leads to AIDS. It is transmitted through body fluids, particularly blood, semen or vaginal secretions. Modes of transmission may be through¹:

- unprotected sexual intercourse with an infected partner (the most common);
- sharing needles when injecting, or use of contaminated injection or skin piercing equipment (such as piercing or tattoos with unsterilised equipment)
- transmission from infected mother to child in the womb, or at birth, or through breastfeeding. (vertical transmission)
- from a needle stick injury

1.2 HIV damages the body's immune system, making it difficult to fight other illnesses. After being infected with HIV, a person may live for ten years or more without symptoms or sickness, although they can still transmit the infection to others. When HIV damages a person's immune system, he or she is open to other illnesses, especially infections (e.g. tuberculosis and pneumonia) and cancers, many of which would not normally be a threat. Before effective treatments, if someone with HIV got one of these illnesses the person was said to have AIDS (Acquired Immune Deficiency Syndrome) however, it is no longer a widely-used term. Doctors may instead call this 'late stage' or 'advanced HIV infection'.² **There is no cure for HIV and there is no vaccine to prevent people from becoming infected with the virus.**

Global Impact of HIV

1.3 HIV/AIDS is one of the main health challenges facing the world today. The first case of AIDS was formally diagnosed in June 1981, in San Francisco. Since then HIV/AIDS has left a trail of devastation. Globally millions have died from the disease. Now twenty - two years later, no continent is untouched by the virus and governments across the globe are grappling to control the disease. HIV/AIDs has had a terrible impact on families and individuals, cutting people down in the prime of their life and leaving orphans and broken families in its wake.

1.4 It is eighteen years since a test to detect the presence of HIV became widely available, but HIV continues to spread. To control the disease successfully, will require Governments across the globe to put more emphasis on developing both long and short-term strategies to deal with the crisis. It will require governments to be open and honest about the impact the disease has had in their countries, and commit sufficient resources to implement these strategies. *'The sheer dimension of the death and suffering so revealed is truly fearsome. AIDS is the worst microbially borne global pandemic in more than six hundred years. In just two decades, it has probably killed more people than the 25 million who died in the great European plague of the mid-1300s. In the short decades ahead, at least a comparable number, and perhaps a multiple of it, face a similar hideous death, similarly protracted and painful.'*³

¹ A Rough Guide to HIV, 2nd Edition, 2003; National Aids Trust – Basic Facts about Aids www.nat.org.uk

² Terrence Higgins Trust http://www.tht.org.uk/hiv_info/facts.htm

³ Edwin Cameron, Diana, Princess of Wales Lecture on AIDS December 2003, City Hall, London

Table 1⁴

Regional HIV/AIDS statistics and features, end of 2003					
	Adults & children living with HIV/AIDS	Adults & children newly infected with HIV	Adult prevalence rate [%] *	Adult & child deaths due to AIDS	
Sub-Saharan Africa	25.0 – 28.2 million	3.0 – 3.4 million	7.5 – 8.5	2.2 – 2.4 million	
North Africa & Middle East	470 000 – 730 000	43 000 – 67 000	0.2 – 0.4	35 000 – 50 000	
South and South-East Asia	4.6 – 8.2 million	610 000 – 1.1 million	0.4 – 0.8	330 000 – 590 000	
East Asia & Pacific	700 000 – 1.3 million	150 000 – 270 000	0.1 – 0.1	32 000 – 58 000	
Latin America	1.3 – 1.9 million	120 000 – 180 000	0.5 – 0.7	49 000 – 70 000	
Caribbean	350 000 – 590 000	45 000 – 80 000	1.9 – 3.1	30 000 – 50 000	
Eastern Europe & Central Asia	1.2 – 1.8 million	180 000 – 280 000	0.5 – 0.9	23 000 – 37 000	
Western Europe	520 000 – 680 000	30 000 – 40 000	0.3 – 0.3	2 600 – 3 400	
North America	790 000 – 1.2 million	36 000 – 54 000	0.5 – 0.7	12 000 – 18 000	
Australia & New Zealand	12 000 – 18 000	700 – 1 000	0.1 - 0.1	<100	
TOTAL	40 million [34 – 46 million]	5 million [4.2 – 5.8 million]	1.1 % [0.9-1.3]	3 million [2.5 – 3.5 million]	



00002-E-1 – 1 December 2003



1.5 In 2003 the global HIV/AIDS pandemic killed more than 3 million people and an estimated 5 million people were infected with the virus, bringing to 40 million the number of people living with the virus around the world.⁵ **Globally, half of the new infections occur in young people, with a majority of transmissions (more than 70 percent) occurring through heterosexual sex.** AIDS, which has already claimed more than 28 million lives, is set to reverse half a century of efforts in the developing world, where the pandemic is currently hitting hardest.⁶

1.6 There are some populations that are more vulnerable to HIV/Aids than others. These populations may have limited access to health services, or means of prevention, or may have limited ability to negotiate safe sex. Circumstances such as poverty, inequality, gender discrimination, low social status, and social marginalisation result in less access to the knowledge, means and services necessary to avoid infection.⁷

1.7 UNAIDS estimates that unless a drastically expanded global prevention effort is mounted, an additional 45 million people in 125 low and middle-income countries will have become infected between 2002-2010. **HIV is clearly a global situation requiring a co-ordinated global response.**

⁴ The proportion of adults [15 to 49 years of age] living with HIV/AIDS in 2003, using 2003 population numbers. Regional HIV/AIDS Statistics and Features, end 2003. EPI Slides UNAIDS & WHO

⁵ UNAIDS www.unaids.org

⁶ National Aids Trust – Basic Facts about Aids www.nat.org.uk

⁷ UNAIDS Questions and Answers, November 2003

HIV in Europe

- 1.8 The Department of Health's Strategy for Sexual Health and HIV, points out that the number of new diagnoses in 2000 was the highest on record.⁸ Information published by the European Centre for the Epidemiological Monitoring of AIDS, allows comparison of the United Kingdom with other European Countries. Table 2 below contains data extracted from the Centre's most recent report⁹.

Table 2. HIV infections newly diagnosed. Rates per million population by country for countries in the European Union.¹⁰

Country	HIV infections newly diagnosed. Rate per million population 2002	AIDS cases and incidence rates. Rate per million population 2002
Portugal	256.3	76.7
Spain	Not available	71.3
France	Not available	32.6
Italy	Not available	31.1
Belgium	Not available	18.2
United Kingdom	101.0	13.3
Germany	22.7	9.8
Austria	Not available	9.2
Greece	37.9	8.8
Denmark	48.9	7.1
Sweden	32.5	5.9
Finland	25.1	4.0
Ireland	93.9	2.9
Luxembourg	73.7	2.3
European Union	65.0	26.1

HIV in the UK

- 1.9 According to the Health Protection Agency, there has been a dramatic increase in the number of new infections reported in the UK, against relatively steady levels over the prior decade. At the end of 2002, an estimated 49,500 adults aged over 15 were living with HIV in the UK.¹¹ The Health Protection Agency is currently compiling the data for 2003. Early indication shows that newly diagnosed cases of HIV have increased by 20% between 2002 and 2003.¹² **A third of the people living with HIV in the UK, remain undiagnosed.**¹³ Despite this, HIV has declined as an issue of concern for both the general public and politicians in the UK. This public and political complacency is a barrier to effective prevention, treatment and care efforts.

⁸ The National Strategy for Sexual Health and HIV, Department of Health. 2001

⁹ European Centre for the Epidemiological Monitoring of AIDS. HIV/AIDS Surveillance in Europe. End-year report 2002. Saint-Maurice: Institute de Veille Sanitaire, 2003. No 68

¹⁰ Note: Data for Holland not available

¹¹ Renewing the Focus, HIV and other Sexually Transmitted Infections in the United Kingdom in 2003. Health Protection Agency, November 2003

¹² Health Protection Agency - Press Statement 12th February 2004

¹³ Health Protection Agency - Written Submission

HIV Prevalence and Trends in London

- 1.10 London is one of the world's global trade centres. It is a city of 7.4 million people, the national capital and the centre of a major metropolitan region. London has a highly mobile and ethnically diverse population. It is a city where wealth and privilege exist alongside poverty and deprivation. There are various social factors that contribute to the health problems of the capital. London experiences higher levels of these social problems than are found elsewhere in the country.¹⁴ The health divide between the most affluent and deprived communities in London has widened over the past 10 to 15 years. All these factors contribute to the level of social marginalisation in the capital.¹⁵
- 1.11 Evidence demonstrates a significant correlation between poverty, social exclusion and significant risk factors for the acquisition of HIV. Socially marginalised populations are at greater risk of HIV, and therefore the promotion of HIV awareness and prevention is crucial for the capital.¹⁶ In 2002, there were 16,953 people living with HIV in London.¹⁷ **The Terrence Higgins Trust predict that if the levels of people being seen for treatment continues to rise at the current rate of annual national increase (20%), in less than five years time there will be over 50,000 people diagnosed with HIV and needing care and treatment in London.**¹⁸
- 1.12 The contribution of London HIV cases to the national total of those receiving treatment for HIV remains high at 60%. **In London, there has been a rise in new diagnoses of HIV each year from 1684 cases in the year 1995, to 2684 cases in the year 2002.**¹⁹ **This increase has occurred in the heterosexual population, and not the groups that have historically been associated with HIV infection, such as gay men and injecting drug users.**²⁰
- 1.13 Although the number of people having HIV tests has risen dramatically, it is estimated that a third of the people living with HIV in the UK remain undiagnosed.²¹ The number of people with HIV infection requiring care has increased greatly. Table 3 shows the increases in the numbers of diagnoses. Table 4 shows the rate of diagnosed HIV infected individuals, receiving care per 10,000 of the population by Local Authority. There are large disparities in London with ten-fold differences across the city.²² People are often treated in London, but may be resident elsewhere (for example in the home counties). These people are not reflected in London HIV prevalence figures.

¹⁴ Dr Sue Atkinson: Report to the Health Committee on London's Health 24th October 2002

¹⁵ Access to Primary Care. Greater London Authority, April 2003

¹⁶ South West London HIV & GUM Commissioning Consortium – Written Submission

¹⁷ Health Protection Agency – Written Submission

¹⁸ Terrence Higgins Trust – Written Submission

¹⁹ Health Protection Agency – Written Submission

²⁰ Minutes of Evidence 14th October 2003

²¹ Health Protection Agency – Written Submission

²² Health Protection Agency – Written Submission

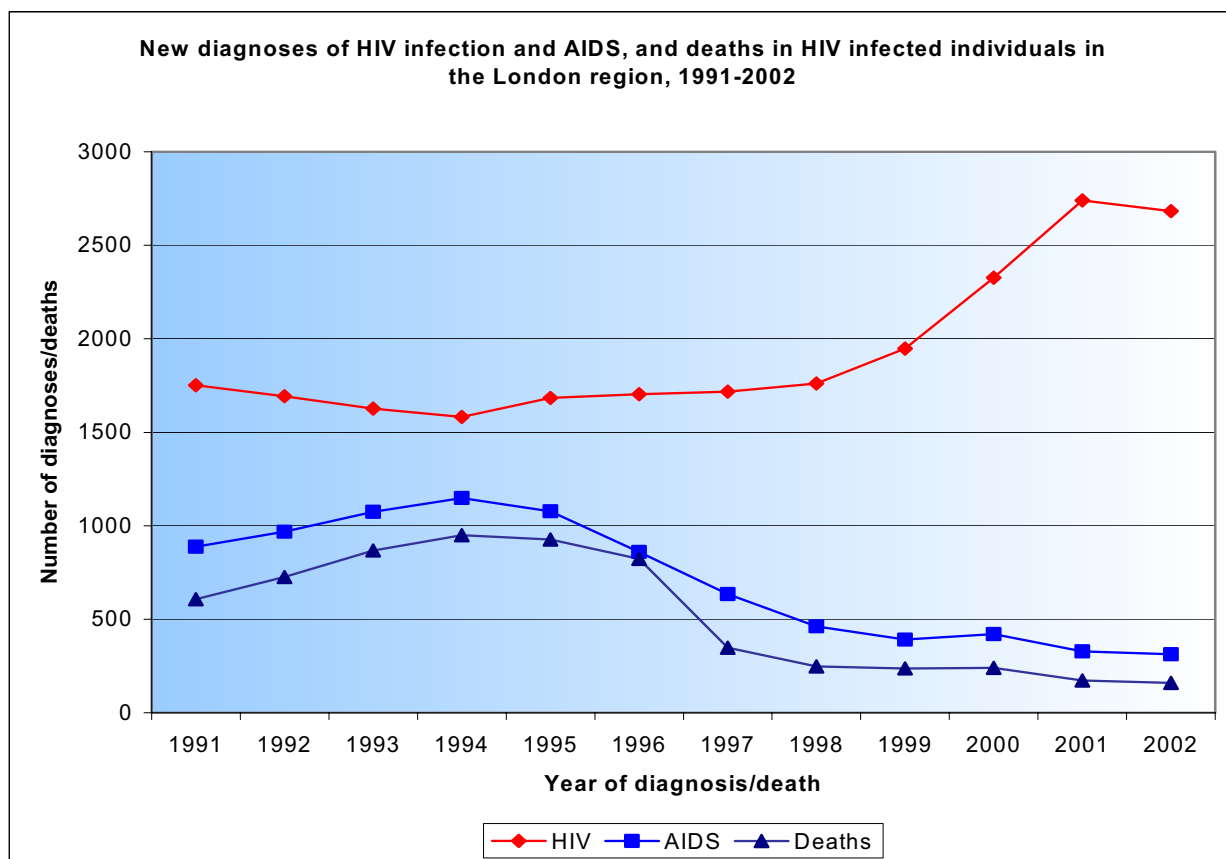


Table 3²³

- 1.14 HIV transmits more readily between individuals in the presence of sexually transmitted infections (STIs). Co-infection with other STIs is a serious concern as these other STIs in the infected individual can and do enhance transmission of HIV to other sex partners. Evidence shows that a person with an untreated STI, is on average six to ten times more likely to pass on or acquire HIV during sex.²⁴ **London has the highest rate of STIs than any other city in the UK.** HIV and STIs are currently the biggest infectious disease problem in London. Gonorrhoea and genital chlamydia, both co-factors for HIV transmission, have increased dramatically in London in the last 5 years. High levels of these bacterial STIs, in groups who are as yet relatively unaffected by HIV, are a matter of serious concern, as they can and do drive the epidemic of HIV infection.²⁵
- 1.15 There has been an outbreak of syphilis in London and up to half these syphilis cases were found to be HIV positive. This syphilis outbreak has been the largest reported in the UK.²⁶ Other STIs are also on the increase. Alarming levels of gonorrhoea and chlamydia in some areas of London, indicate high levels of unprotected sex.²⁷ These rises in STIs are now being seen in the younger end of the sexually active population. We now have young people who are sexually active much earlier, putting them at risk of STIs and HIV. This increase in other STIs is an indication of unprotected sexual activity and has implications for the risk of contracting HIV infection. It indicates the potential for further

²³ Health Protection Agency – Written Submission

²⁴ UNAIDS Questions and Answers, November 2003

²⁵ Health Protection Agency – Written Submission

²⁶ Health Protection Agency – Written Submission

²⁷ London Specialised Commissioning Group – Written Submission

increases in HIV.²⁸ **The risk of HIV infection to young heterosexuals in London is now considerably increased relative to ten years ago and the practice of safe sex is vital.**²⁹ Health and social care services must ensure that HIV prevention and awareness is promoted across the capital, particularly amongst young people.

- 1.16 The HIV awareness campaigns of the eighties did much to educate people about high risk behaviour. The current levels of teenage pregnancies and sexually transmitted infections amongst young people indicate that there is an urgent need for education programmes for young people on the risks of unsafe sex.

Recommendation 1:

The Department of Health must establish education programmes for young people that will raise awareness of HIV and the full spectrum of sexually transmitted infections.

²⁸ London Specialised Commissioning Group – Written Submission

²⁹ Health Protection Agency – Written Submission

Table 4: Rates of diagnosed HIV individuals treated in England, Wales and Northern Ireland per 10,000 population of Local Authority residence for 2002³⁰

LA name	2002 total	Population	Rate per 10,000
Lambeth	1603	266791	60.1
Camden	994	198432	50.1
Kensington and Chelsea	793	159147	49.8
Southwark	1202	245416	49.0
Hammersmith and Fulham	796	165476	48.1
Westminster	863	181691	47.5
Islington	801	176103	45.5
Newham	883	244291	36.1
Hackney	729	203352	35.8
Haringey	756	216809	34.9
City of London	25	7216	34.6
Lewisham	705	249451	28.3
Tower Hamlets	550	196630	28.0
Wandsworth	683	260847	26.2
Waltham Forest	469	218649	21.4
Brent	558	263805	21.2
Greenwich	423	215238	19.7
Croydon	631	331530	19.0
Hounslow	333	212668	15.7
Ealing	438	301553	14.5
Merton	258	188348	13.7
Barnet	401	315267	12.7
Enfield	337	274343	12.3
Barking and Dagenham	195	164346	11.9
Redbridge	252	239329	10.5
Richmond upon Thames	157	172808	9.1
Kingston upon Thames	119	147625	8.1
Harrow	165	207988	7.9
Hillingdon	185	243052	7.6
Sutton	117	180174	6.5
Bromley	162	296155	5.5
Bexley	108	218756	4.9
Havering	60	224720	2.7
Not Known	212		
Total	16963	7188006	

³⁰ Data Source: SOPHID 2002 and Office National Statistics (ONS) 2001 – Health Protection Agency

2. Health Promotion and the London HIV Strategy

- 2.1 The lack of pan-London health promotion and prevention initiatives was a common theme through out the written and oral evidence. It was felt that the Department of Health and the NHS have failed to act in this regard. The emphasis on local prevention has not emerged and is too fragmented. The campaign messages of the early eighties reached people at the time, but now there is a need to mount a new awareness campaign, particularly now the pandemic is affecting different communities.
- 2.2 There is also the need for strategic planning to address emerging needs. In the UK the demographics of those living with the virus is changing from gay men to African communities, but even this change is not static. The other trend that needs to be recognised, is the high level of teenage pregnancies, the growth of sexually transmitted infections (particularly amongst young people) and the likely resulting increase in incidence of HIV amongst this population group.³¹ The evidence highlights an emerging epidemic within the Afro-Caribbean community in south London.
- 2.3 There are different types of work and health promotion raising awareness of HIV among high risk communities, but there is concern that these messages are not getting through to the wider community. Mobility in London means that prevention work has to be widespread. London is a tourist and commuter centre and so public health messages have to be delivered in far greater quantity than on a per capita basis to London's resident population. There is a need for a mix of London-wide targeted messages alongside appropriate targeted campaigns.
- 2.4 Prior to the reorganisation of the NHS in April 2002, spending by the former health authorities on core HIV prevention activities varied dramatically. The Department of Health required that 50% of HIV prevention budgets were spent targeting high-risk groups, namely gay men and African communities. At that time in London, the Health Authority spending the greatest percentage on core work was Lambeth, Southwark and Lewisham at 28% (well short of 50%) with Redbridge and Waltham Forest spending only 0.28% on core prevention work.³² It remains to be seen whether the transfer to primary care trusts and the abolition of the ring fence on HIV prevention will have altered this position.
- 2.5 A number of Primary Care Trusts (PCTs) have commented that the overwhelming demand for treatment and care services has meant that funding for HIV Prevention work has not kept pace with the increases in the numbers of people living with the virus, and the need for greater investment given the major challenges in tackling transmission in London. There are competing demands for limited resources³³ Health promotion needs to be coordinated across PCTs, NHS sectors and across London.
- 2.6 The British Medical Association highlight the need to take note of the rising STI (including HIV) prevalence and its costs, against the benefits of prevention, early diagnosis and treatment. 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 one million, in terms of individual health benefits and treatment costs.³⁴

³¹ Minutes of Evidence 18th November 2003

³² Data presented at the 5th annual CHAPS conference, February 2002

³³ London Specialised Commissioning Group – Written Submission

³⁴ British Medical Association – Written Submission

- 2.7 The British Medical Association recommends that sexual health clinics should be encouraged to take a more active role in prevention by increasing publicity and awareness about the services they provide and the benefits of HIV testing and screening. 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. Likewise, primary care has a major role to play in prevention.³⁵ There needs to be more awareness in primary care and other medical specialities regarding HIV symptoms and when to offer testing.³⁶
- 2.8 School education strategies that increase students knowledge of the full spectrum of STIs are essential. In particular developing skills such as negotiating in relationships and using sexual health services should be encouraged, particularly in light of Britain's high rate of teenage pregnancies. *...in the absence of a vaccine or cure, education is the best weapon we have against the rapid spread of HIV...*³⁷
- 2.9 It is essential to confront the population of London with the reality of the HIV pandemic. Community and religious groups could also be educated and involved in raising awareness, particularly since these organisations have great impact at local community levels. Awareness campaigns must address the complacency that exists about HIV and sexual health. An important part of any health education project or awareness campaign should be the involvement of people living with the virus. People living with HIV are more able to bring home the reality of living with the virus.

*'The Government needs to do more to educate people about HIV. There are more and more people getting infected and yet the Government seems to be totally ignoring it. It would be different if one of them had it.'*³⁸

Recommendation 2:

There is an urgent need for co-ordinated pan London HIV awareness which includes a mix of London-wide messages and appropriate local campaigns. We recommend that the London Strategic Health Authorities develop methods for ensuring this approach to health promotion and HIV awareness is implemented across the capital.

³⁵ British Medical Association – Written Submission

³⁶ Newham NHS Trust – Written Submission

³⁷ British Medical Association – Written Submission

³⁸ Focus Group

The Importance of the London HIV Strategy

- 2.10 We were told that before the NHS reorganisation in 2002, a London HIV strategy was drafted. It has not yet been produced due to the staff changes that occurred because of this reorganisation. Although the London HIV strategy has fallen by the wayside, a pan London strategy is still urgently needed to address HIV public health promotion, and outline arrangements for a pan-London needs assessment of HIV services. A pan London assessment will assist in ensuring that HIV services and commissioning reflect real need more accurately, and allow for a more balanced geographical spread of services, instead of services being concentrated in the centre as they are at present. This strategy should facilitate the development of service networks.³⁹ We consider these issues in detail below.
- 2.11 It will also address the balance between meeting needs through the provision of local services and meeting needs through pan London initiatives. With many previous pan London programmes based on networks, relationships and roles that are rapidly changing, (particularly the role of PCTs focusing on local needs) there is a need to review and evaluate, and possibly develop new pan London structures. A strategy will provide a foundation for this.
- 2.12 The experience of living with HIV in London is a difficult one. Not only in terms of living with a long term, life threatening condition, but also in overcoming barriers and learning to negotiate access to new services. There is so much that can be done to improve the way HIV services are delivered in the capital. Strategic co-ordination across the capital will prevent wastage and ensure that the high quality of medical care continues to be provided. It may also assist in ensuring a more accessible and equitable provision of social support.

Recommendation 3:

The NHS London Specialised Commissioning Group must as a matter of urgency, review the draft London HIV Strategy and publish it.

- 2.13 The HIV pandemic is continuing unabated and will have greater impact on London if the current complacency continues. For London to address the impact of HIV now and in the future will require new innovative and integrated solutions across both professional and geographic boundaries.

³⁹ Recommended standards for NHS HIV services, MEDFASH 2003

3. Access to Medical Care

- 3.1 HIV testing and counselling is provided by hospitals through Genitourinary Medicine (GUM) clinics. HIV medical treatment is provided by hospitals through GUM clinics or through separate HIV clinics. Patients can go to any hospital, not just those that are close to where they live. For many people this provides a high degree of confidentiality, however it must be noted that not everyone has the means to travel to hospitals outside their area of residence. The principle behind this is to encourage people with sexually transmitted infections to come forward for treatment.⁴⁰ In London, some marginalised groups still have difficulties accessing health care. Some of this is due to a lack of knowledge about the health care system. This is resulting in people approaching the health service with advanced symptoms of HIV, and consequently, treatment is more difficult.⁴¹

Pressures on Genitourinary Medicine Clinics (GUM)

- 3.2 GUM clinics all over the country are under pressure.⁴² This pressure is adversely affecting the quality of care.⁴³ New diagnoses (of sexual health conditions) made within London GUM clinics have increased by one third from 154,260 in 1995, to 210,711 in 2002. The total number of individuals having HIV tests in GUM clinics in London has nearly tripled over the past seven years (from 42,667 in 1995 to 121,998 in 2002). Considerable pressures are being placed on GUM services in London. The number of people with HIV infection requiring medical care has increased greatly and in addition to HIV, some patients often have other complex medical needs.⁴⁴
- 3.3 Some of the clinics that have experienced recent rapid increases in HIV numbers have had little or no increase in resources. Increases in workload have not been matched by increases in staff.⁴⁵ These pressures on GUM services are resulting in waiting lists for access to services. Waiting times of two weeks for HIV testing at GUM clinics is common in London. The government has agreed to provide an additional £5 million pounds for GUM services nationally, 2003/04.⁴⁶ We welcome this additional financial resource, but we believe that this should be a recurrent amount. We are concerned that these services, which have been responsive to the need of patients and a model of access to health care, are now being eroded.

⁴⁰ Minutes of Evidence 4th November 2003

⁴¹ Minutes of Evidence 14th October 2003

⁴² House of Commons Health Committee, Sexual Health, Third Report of Session 2002-03 Volume 1.

⁴³ British Association for Sexual Health and HIV-Written Submission

⁴⁴ Health Protection Agency – Written Submission

⁴⁵ Newham General Hospital – Written Submission

⁴⁶ Report of the Independent Advisory Group on Sexual Health and HIV. Response to the Health Select Committee Report on Sexual Health. January 2004

Recommendation 4:

Whilst we welcome the additional financial resources for Genitourinary Medicine (GUM) services and sexual health, we believe the Government must provide continuing funding to ensure the continued availability of appropriate treatment and care for sexually transmitted infections.

Role of Primary Care

- 3.4 The National Sexual Health and HIV Strategy envisages that primary care will play a greater role in the treatment and management of sexual health including HIV.⁴⁷ At one hearing, it was reported that primary care has been involved in the treatment and care of sexually transmitted infections in different ways, but that the new GP contract might constitute a barrier to future involvement. Under this contract, general practice will be able to opt out of providing certain medical services, and this may fragment the provision of sexual health services at primary care level.
- 3.5 Under this new system primary care trusts (PCTs) will be able to choose whether or not to purchase certain medical services through primary care. Purchasing decisions will be influenced by funding priorities. We were informed that there is anxiety at the moment that PCTs will not be obliged to buy these services at local levels, so that even where practices are willing to provide aspects of sexual health care they may not be funded to do it.⁴⁸
- 3.6 Primary care has an important role to play in health promotion and HIV awareness. The GP and primary healthcare team are often best placed to facilitate access for people with HIV to local health and social care services. A significant obstacle to the effective provision of these aspects of care is the current shortage of GPs and other primary care staff. This shortage is acute in London and means that people with HIV in London will not be able to fully benefit from the potential role of primary care, until ways are found to address the shortage.

*'When it came to getting a GP, regardless of my status, I had no choice of a GP. In my area there was only one GP taking patients onto his list.'*⁴⁹

- 3.7 Concerns were expressed about whether primary care is actually an appropriate setting to provide HIV medical care. It was generally felt that the place for the management of HIV is in the specialist setting, but it was also recognised that people living with the virus may need to see a GP for non-HIV related ailments. It was also felt that the need for general practice, as partnership in HIV care is critical.⁵⁰

⁴⁷ The National Strategy for Sexual Health and HIV. Department of Health 2001

⁴⁸ Minutes of Evidence 14th October 2003

⁴⁹ Focus group

⁵⁰ Minutes of Evidence 14th October 2003, Minutes of Evidence 4th November 2003

- 3.8 The evidence highlights that most people living with HIV will use their HIV/GUM clinic as a primary care centre. Reasons for this include the general problems of access to primary care, a lack of capacity (especially in single-handed practices) and confidentiality (HIV/GUM clinics are legally obliged to adhere to very strict guidelines on this, but practices are not bound by such strict guidelines). A consultation exercise showed that 70% of the people consulted were concerned about issues of confidentiality in general practice.⁵¹
- 3.9 With regards to GPs delivering aspects of sexual health care, 60% of people who took part in the consultation did not think it was a good idea to involve GPs in HIV testing and counselling. This figure was the same regardless of a person's HIV status. 14% of people said that they already used their GP for sexual health services and a further 16% said that they would be likely to do so in the future, but 60% said they would not use such services.⁵² The survey also showed that almost 80% of those consulted had experienced some form of prejudice or discrimination since their diagnosis. Health service staff were common sources of this discrimination. In almost 45% of cases, people with HIV stated that the health services had discriminated against them, and where professionals were named, GPs and Dentists were the most common.
- 3.10 This highlights that there is a need for training around HIV issues for all primary care staff. It is very important that healthcare professionals are provided with appropriate training before any moves are made to extend the role of primary care in the management and treatment of HIV. This is vital to instil confidence in people living with the virus, of the ability of primary care to deliver both sexual health and non-HIV related health care.

Recommendation 5:

Primary Care Trusts should ensure that training on HIV issues is provided for all primary care staff. The standards of confidentiality in primary care must be developed to the same level of confidentiality adhered to in Genitourinary Medicine (GUM) clinics.

- 3.11 The Medical Foundation for Aids and Sexual Health recently published a new document containing recommended standards for NHS HIV services. These discuss the role of primary care in diagnosing infections and also provide a resource for assisting GPs to help people access care in the community such as mental health, voluntary sector services and social services. We welcome these standards and hope that they will go some way to ensuring that people receive a high standard of care irrespective of the point of access to the health care system.

*'My GP has been aware of my HIV status since 1992, and my clinic keep him informed. I have found his help invaluable over the years.'*⁵³

⁵¹ National Consultation of People with HIV on the National Sexual Health and HIV Strategy, December 2001. http://www.ukcolition.org/HIV_Strategy/Consultation_Report/consultation_report.html

⁵² National Consultation of People with HIV on the National Sexual Health and HIV Strategy, December 2001.

⁵³ Focus Group

4. HIV Testing and Treatment

- 4.1 Given that almost a third of people remain undiagnosed, there is an urgent need to increase opportunities for testing.⁵⁴ Unfortunately, the willingness of people to come forward for testing is seriously hampered by stigma and fear of discrimination. It is common knowledge that people living with the virus have extreme difficulty accessing financial services, other forms of discrimination are well documented.
- 4.2 Stigma and fear prevent people from seeking HIV care and going for testing. This is dangerous as it leads to late diagnoses, limiting the potential for the immune system to recover, and favouring the onward transmission of HIV. Recent research shows that the most common reason given for testing was the onset of symptomatic HIV, with 58% of people being tested when they had become actively unwell, 17% being tested antenatally and 15% testing only after the death or diagnoses of a partner. Less than 2% of those questioned were diagnosed as a result of an unprompted visit to a GUM clinic.⁵⁵
- 4.3 Routine HIV testing goes some way to addressing the issue of stigma, and increases the level of testing. The GUM clinic at Chelsea & Westminster and Charing Cross Hospital routinely offers HIV testing to all patients attending the clinic. This provides an opportunity to test both a wider section of the community and high-risk groups such as young sexually active people, with informed consent.⁵⁶
- 4.4 Confidentiality must continue to underpin all testing policies and testing must be supported by appropriate support services, such as pre-and post-test counselling. There is also the need to improve testing through the better use of fast HIV testing technologies and increased availability of HIV testing at more flexible times.

Recommendation 6:

All Genitourinary Medicine (GUM) clinics should ensure that attendees for sexually transmitted infections other than HIV should be offered the opportunity to test for HIV.

- 4.5 We asked whether HIV testing should be rolled out in programmes similar to breast cancer screening. In their revised approach to preventing the spread of HIV, published in April 2003, the US Centre for Disease Control stress the need to make HIV testing a routine part of medical care, and to implement new models for diagnosing HIV outside medical settings.⁵⁷ Health economists at Yale have recently demonstrated three-yearly routine, voluntary HIV screening, when performed in all but the lowest incidence populations, can be justified on both clinical and cost-effectiveness grounds, and that a one-off screening of the entire US population might also prove cost-effective.⁵⁸ We were informed that the impact of stigma,

⁵⁴ Terrence Higgins Trust - Written Submission

⁵⁵ Terrence Higgins Trust - Recent Migrants Using HIV Services in England, October 2003

⁵⁶ African HIV Policy Network and National Aids Trust – Written Submission

⁵⁷ NAM Aids Treatment Update September 2003

⁵⁸ Paltiel AD. 2nd International AIDS Society Conference on HIV Pathogenesis & Treatment, 2003, abstract

might hinder such widespread testing in the UK, but that by encouraging people to test for other STIs such as chlamydia, the practice of testing would become more common and through that familiarity, people will become more ready to go for HIV testing.⁵⁹

- 4.6 We acknowledge that there is the need to consider the social impact of HIV testing, so that solutions can be developed to deal effectively with problems, such as barriers to financial services and other types of HIV related stigma and discrimination. We consider HIV testing and counselling to be a critical element of HIV awareness and prevention. Awareness of one's HIV status will enable a person to monitor their condition effectively and take any necessary treatment. It also enables a person to take steps to prevent onward transmission.

Recommendation: 7

A third of people who are HIV positive remain undiagnosed. The Department of Health should evaluate the benefits and feasibility of a routine HIV screening programme.

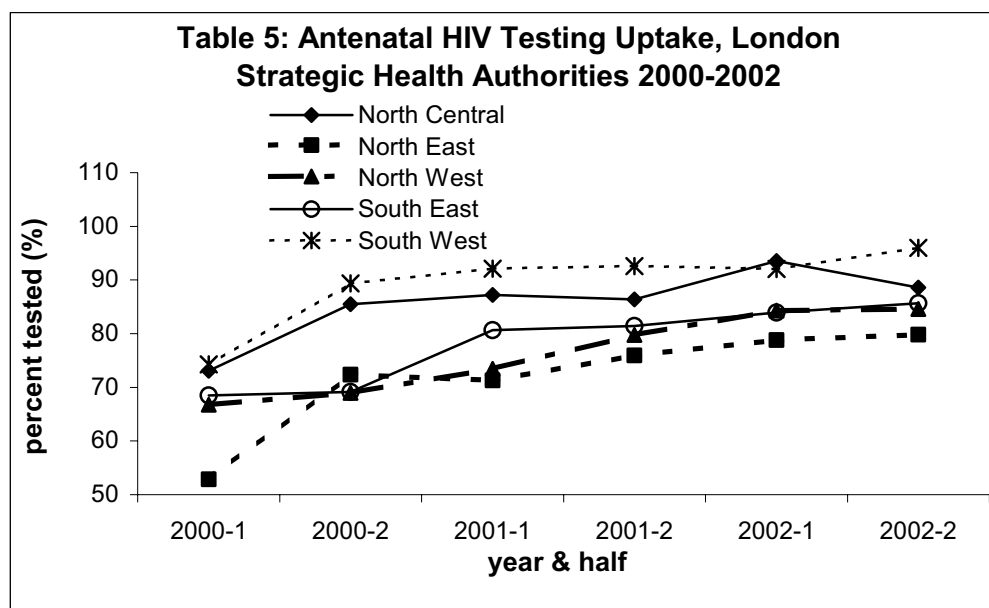
Preventing Mother to Child Transmission

- 4.7 Mother-to-child transmission of HIV (vertical transmission) cannot be prevented unless the mother is diagnosed before the child is born. Proposals for universal HIV antenatal testing were initially made by the Department of Health in 1994, and were implemented in 1998.⁶⁰ **Due to the success of this initiative in London, over 80% of HIV-positive women, who are pregnant, are diagnosed before giving birth.** The number of pregnant women in London taking up HIV testing as part of their routine antenatal care has risen steadily from 66% in 2000 to 86% at the end of 2002. (See table 5 below) **This is one of London's success stories and is an example of how wider testing has prevented the onward transmission of HIV.**

1187.

⁵⁹ Minutes of Evidence 4th November 2003

⁶⁰ Health Protection Agency – Written Submission



HIV Drugs

- 4.8 HIV medical treatment is a complex issue sometimes involving the care of whole families. Known as HAART. (Highly Active Anti-Retroviral Therapy), it is not simply taking a few pills, but involves close medical monitoring.⁶¹ The treatment works by reducing the level of HIV in the body (viral load) and keeping it low, ideally reducing it to an undetectable level. This is achieved by taking a combination of drugs that attack the HIV and prevent it from reproducing in the body. This enables the immune system to function more effectively.
- 4.9 There are side effects as a result of reaction to the drugs and as a result of the direct effects of the drug or combination of drugs. More common side effects in the latter category include nausea or drowsiness, reduced sex drive, blood abnormalities such as neutropenia or anaemia, reduced bone density and lipodystrophy (alterations in the distribution of body fat). Other more serious side effects such as some forms of cancer can also develop.⁶² The impact of HAART has changed HIV infection from a degenerative illness to a chronic manageable disease, extending both the life expectancy and the quality of life.⁶³

Drug Resistance and the Challenge of Adherence

- 4.10 Unfortunately anti-HIV drugs do not lead to a cure; they simply suppress the virus. We were informed that in due course the virus would become resistant. Drug resistance is a complex issue that clinicians grapple with. HIV can become resistant if the drug regime is not strictly adhered to. **Drug resistant HIV can also be transmitted to another person, thus severely limiting treatment options for that person.**⁶⁴ The Health Protection Agency has a system of monitoring drug resistance. This is a highly complex area, but monitoring such cases is vital. **They report that cases of drug resistant HIV are increasing.**

⁶¹ Minutes of Evidence 14th October 2003

⁶² North Central Strategic Health Authority - Written Submission

⁶³ South West London HIV and GUM Commissioning Consortium - Written Submission

⁶⁴ Minutes of Evidence 14th October 2003

- 4.11 Resistance to the main categories of drugs means that treatment options are severely limited. At present, this is a very small number of people and the drugs are actually very effective in the majority of people.⁶⁵ **This reinforces the need to continue to undertake prevention initiatives with people who are already infected, as well as with those who are not infected.**
- 4.12 The pressures on people taking these drugs are immense. It means taking the drugs in the prescribed way – at certain times, with food or on an empty stomach etc. These conditions must be strictly adhered to for the drugs to work. Adhering to the drugs regime can be complicated. *‘The life of the HIV positive person on treatment means that you have to take your medication on a balanced meal, but a lot of us cannot afford a decent meal.’*⁶⁶ There are also particular difficulties in adherence for teenagers. Body and Soul, report that young people especially, struggle to adhere to their drugs.
- 4.13 This reinforces the argument for ensuring that a range of services and support are available for people with HIV, not just to take the drugs, but to help them to adhere to the drug regime and address the conditions in their lives that might make adherence difficult. Body and Soul provide a forum known as Teen Spirit, which provides a unique range of services, incorporating peer support, educational activities and one to one support for young people.⁶⁷ In their evidence NAM state that the continued funding of effective treatments education for people living with HIV across London, will help to ensure an improved doctor-patient dialogue, greater adherence and improved health and well being.⁶⁸
- 4.14 These types of services are particularly valuable and the role of the voluntary sector in providing these types of services cannot be overemphasised, however as we discuss later in the report, the provision of support services across the capital is varied and not everyone is able to access the type of support they need.

The Issue of Co-infection

Co-infection can significantly complicate the management of HIV.

- 4.15 Syphilis and HIV Co-infection
There has been an outbreak of syphilis in London that is the largest reported in the UK. Since 2001, 980 diagnoses have been reported, 684 in men who have sex with men, and 296 in heterosexuals. Controlling this epidemic is vital because sexually transmitted infections such as syphilis further fuel the HIV epidemic.
- 4.16 Tuberculosis and HIV Co-infection
HIV does not make TB more infectious, but an HIV positive person may become more vulnerable to TB than an otherwise healthy person. There are indications that co-infection with TB and HIV is an increasing problem in London. Studies in London suggest that approximately 12% of patients with TB are HIV positive. In

⁶⁵ Minutes of Evidence 14th October 2003

⁶⁶ Minutes of Evidence 18th November 2003

⁶⁷ Body and Soul – Written Submission

⁶⁸ National Aids Manual (NAM) – Written Submission

some cases, co-infection with TB may make treatment with anti-HIV drugs difficult due to the interaction between these and the anti-TB medication.⁶⁹ In an earlier report, we highlighted the need for routine HIV testing for TB patients. Globally, TB is a leading cause of death amongst people who are HIV positive. It is important that people with TB are offered HIV counselling and testing so that appropriate treatment regimes can be initiated.⁷⁰

4.17 Hepatitis B and HIV Co-infection

Hepatitis B becomes a chronic liver disease for 5% of those people who have it. This becomes higher for a person who is living with the HIV. (10-20%). Hepatitis B can slowly damage the liver and the rate of damage is quicker if a person has HIV as well. This damage results in cirrhosis and cellular carcinoma.⁷¹ Mainliners report that many of those people at risk of Hepatitis B, are still not accessing the Hepatitis B vaccination, and consideration must be given to improving or expanding widespread access to the Hepatitis B vaccination throughout London.⁷²

4.18 Hepatitis C and HIV Co-infection

Rates of infection suggest that intravenous drug users are still at risk of HIV through unsafe injecting. A third of intravenous drug users have evidence of current or past Hepatitis C infection, and a fifth have current or past Hepatitis B.⁷³ Hepatitis C is now one of the most significant causes of liver associated morbidity in HIV positive individuals. For those with hepatitis co-infection, treatment options may be limited, as some HIV treatment may adversely affect the liver and cause previously controlled Hepatitis C to become active.⁷⁴ Mainliners report that more needs to be done in this area. There is no vaccination for Hepatitis C and prevention messages and practices are necessary to contain it and prevent further spread.

4.19 The long-term prognosis of HIV infected patients on HIV treatment remains unknown. However, many of those individuals who started on the treatment when it first became available in 1996 (and who have been able to adhere to the medication) are still alive. Experts believe that where people living with HIV adhere successfully to treatment they will have normal life spans and die of old age or of other natural causes. Crucially this depends on the ability of the person to adhere to long-term medication and on the development of improved new drugs to replace the older ones.⁷⁵

⁶⁹ Health Protection Agency – Written Submission

⁷⁰ Tuberculosis in London – London Assembly Health Committee November 2003

⁷¹ London Light House – Written Submission

⁷² Mainliner – Written Submission

⁷³ Mainliners – Written Submission

⁷⁴ Newham NHS Trust – Written Submission

⁷⁵ London Specialised Commissioning Group – Written Submission

5. Providing HIV Treatment and Care in London

- 5.1 In London, hospital HIV services have continued to develop in line with the changing epidemic and to reflect the needs of patients. **We applaud clinicians and hospital staff for their work in creating services that are patient centred, even before the emergence of the NHS Plan.** Although we have outlined issues that we believe must be considered in order to improve the provision of care for those living with the virus, we acknowledge that the HIV services in the NHS and voluntary sector offer some of the best quality of care available, far better than many other disease areas.
- 5.2 The commissioning of HIV treatment and prevention services has been shaken up by a number of recent national developments. The impact of the mainstreaming of HIV budgets following the removal of the ring-fence on HIV funding (first for treatment and care and then for HIV prevention) has been compounded by the change in commissioning arrangements arising from *Shifting the Balance of Power in the NHS*.⁷⁶ HIV medical care is identified as a specialised service, and comes within specialised commissioning arrangements. HIV prevention services and other sexual health services are not identified as specialised, and are therefore commissioned through local arrangements by individual Primary Care Trusts (PCTs).⁷⁷
- 5.3 In London, HIV medical care is commissioned through a pan-London consortium. All London PCTs are part of this consortium, but there is one lead PCT for each of the five NHS sectors.⁷⁸ The lead PCT coordinates the work on behalf of other PCTs within that sector. In addition to addressing strategic planning issues, the pan-London HIV consortium coordinates the process of determining the amount of funding needed for HIV services each year. Once a proposed amount is agreed, each of the sector HIV commissioning teams (based on the 5 NHS sectors) negotiates appropriate service agreements with their local providers (including the voluntary sector). The voluntary sector is responsible for providing a range of support services including advice, practical support, counselling, advocacy and liaison, employment support, training and skills development, complementary therapies, respite care and peer support.

The Issue of Commissioning

- 5.4 We were informed that this system of commissioning allows contracts to be developed with a focussed number of providers who have demonstrable expertise. It enables services to be delivered across a larger geographical area, offering economies of scale, and reducing administration and management costs.⁷⁹ The evidence shows that in some ways these consortium arrangements have probably helped stabilise the commissioning of HIV services in London in comparison to other PCTs across the country, however, in spite of this progress the current commissioning system in some ways is unwieldy.⁸⁰ The Terrence Higgins Trust reports that services are commissioned in an uncoordinated and uneven way within London. HIV is the only specialised condition that is commissioned at London level, sector level and at PCT level and this

⁷⁶ Medical Foundation for AIDS and Sexual Health – Written Submission

⁷⁷ Minutes of Evidence 4th November 2003

⁷⁸ Appendix D

⁷⁹ South West Strategic Health Authority – Written Submission

⁸⁰ United Kingdom Coalition of People Living with HIV; Hammersmith and Fulham Primary Care Trust – Written Submission

causes complexities for the voluntary sector providers who wish to bid to provide HIV services.

- 5.5 For voluntary sector providers the commissioning process causes confusion and wastes resources on excessive bureaucracy and repetition. This is compounded by a failure of NHS commissioners to meaningfully engage with people living with the virus. As a result, these processes are not properly providing for the needs of the diverse communities affected by HIV in London.⁸¹ *Some (predominantly support / social care) services are purchased across the board, whereas other services are purchased on a borough by borough basis, suggesting there is insufficient cooperation between health and social care commissioning bodies to come up with a unified approach. This fragmented approach makes it difficult to identify what or where the processes are, and effectively excludes people from having any input.*⁸²
- 5.6 The United Kingdom Coalition (UKC) report that there are no standards of quality involved in the specialist commissioning process. There is also little or no linkage between specialist commissioning and social and primary care. The UKC highlights the confusion and lack of transparency over who commissions services in the capital and where such services are commissioned. They report that the commissioning process is secret and until most recently, all but impervious to outside influence. Although there is some commitment to involving stakeholders, including patients, there is little patient and public involvement at a strategic and ongoing level.
- 5.7 The Medical Foundation for Aids and Sexual Health report that they are concerned about the ability of PCTs, faced with a plethora of competing priorities, to commission HIV services effectively. They report that in some PCTs, those responsible for HIV commissioning have been newly appointed to the role and have not had the opportunity to develop an understanding of the complex issues involved, for example the importance of ensuring prevention work with young people, marginalised and stigmatised population groups, or addressing the multiple care needs of families that are infected and affected.⁸³
- 5.8 The need to simplify the commissioning arrangements is particularly acute for voluntary sector providers. These organisations could otherwise spend a great deal of time negotiating a plethora of small contracts. **They might also end up having to turn away individual service users whose PCTs have decided not to contract their services.** Such a fragmented scenario inevitably promotes inequalities in service quality and access. **The omission of any mention of HIV from the current NHS Planning and Priorities Framework is also undoubtedly having the effect of de-prioritising HIV within many PCTs and Strategic Health Authorities, despite the recent rapid increases in HIV prevalence, and this is a cause for serious concern.**⁸⁴

*'You try to use services and you find that there are long waiting lists, or you are not allowed to use them because you live in the wrong borough.'*⁸⁵

⁸¹ United Kingdom Coalition of People Living with HIV-Written Submission

⁸² United Kingdom Coalition of People Living with HIV-Written Submission

⁸³ Medical Foundation for Aids and Sexual Health -Written Submission

⁸⁴ Medical Foundation for Aids and Sexual Health -Written Submission

⁸⁵ Focus Group

- 5.9 The London Specialised Commissioning Group (which oversees the commissioning consortium) recognises that there are some difficulties inherent in the commissioning arrangements and initiated a review of HIV commissioning arrangements in June 2003. This review is now well underway and it is hoped an agreed commissioning process for the future will emerge from this review. **We were informed that the new arrangements will be available by early 2004 and we look forward to receiving them.**⁸⁶
- 5.10 In summary, the evidence emphasises some structural problems with the commissioning system. In implementing the policies emanating from *Shifting the Balance*, it must be recognised that for HIV there are difficulties with regards to the notion of 'local services for local people'. People living with the virus may not wish to access services locally and due to their diversity, the local services provided may not address their specific needs. Commissioners must be extremely well informed and must understand the complexities of the issues surrounding HIV in order to commission effectively and efficiently.
- 5.11 It is clear that there are benefits to be gained from pan London commissioning of specialist HIV services – i.e. services delivered in hospitals – and that this should continue, provided that the organisation leading the commissioning process contains sufficient expertise and resources to manage this effectively. This is also a way of ensuring that access arrangements can be maintained, without placing a significant level of financial risk on hospitals.⁸⁷ There is a need to ensure that HIV commissioning is co-ordinated in an appropriate way in order to ensure consistency in service provision across the capital and to facilitate and enable voluntary sector service providers to work together instead of against each other.

Costs and Resources

- 5.12 There are financial pressures facing HIV services. With increasing numbers of newly diagnosed individuals requiring these services, drugs budgets and infrastructure costs are rising at a substantial rate. New drugs such as Fuzeon (T20) and diagnostic tests e.g. viral resistance, also add to financial pressures. The London Specialised Commissioning Group informed us that in order to address this challenge, each year commissioners in London consider HIV growth trends and specific pressures such as high cost drugs within the context of overall NHS pressures. They report that the financial resources committed in London to date have been able to keep pace with increases in drugs budgets but have not fully addressed infrastructure pressures within the hospitals providing HIV care.
- 5.13 Recently published research contradicts this and shows that only one in eight clinicians believe that they have enough resources to manage their current workload. In 2003, 79% of clinicians reported that their drugs budget would be overspent by the end of the year. More than two thirds of clinicians feel that their ability to provide services is getting worse.⁸⁸
- 5.14 There is generally a lack of prioritisation of HIV and Sexual Health in NHS planning priorities throughout England.⁸⁹ Although London PCTs have reflected a commitment to sexual health in their local delivery plans, the plans contain few detailed proposals and

⁸⁶ London Specialised Commissioning group – Written Submission

⁸⁷ North Central Strategic Health Authority -Written Submissions

⁸⁸ More Disturbing Symptoms – How primary care trusts are managing the rising challenge of sexual health and HIV, and how specialist clinicians view their progress. December 2003 Terrence Higgins Trust, British HIV Association and The National Association of NHS Providers of AIDS Care and Treatment

⁸⁹ Terrence Higgins Trust – Written Submission

few indications of investment increases, despite the increase in the numbers of people accessing HIV services.⁹⁰ Coupled with the increasing cost of drugs, there is considerable concern about the future provision of HIV medical care.

5.15 The prevalence of HIV is rising rapidly, and in addition to the provision of medication, the population groups increasingly affected have wide and complex care needs. Budgets for HIV treatment and care need to keep pace with the increase in demand. There is fear that budget pressures, along with the invisibility of HIV in national NHS planning and priorities guidance, may result in a withdrawal of funding for support services in order to pay for medication. Similarly, we are anxious about the potential for dis-investment in HIV prevention initiatives. Such a move would be dangerously shortsighted, not only for public health reasons but also from an economic point of view. **It has been estimated that each case of HIV prevented saves £0.5-1m.**⁹¹

5.16 Future funding will also need to be sensitive to changes in the demography of the pandemic within the UK. Mainliners, for instance, demonstrate how the change in drugs usage, from heroine to crack cocaine, which needs more frequent injections, must be paralleled by changes in funding for more needle exchange programmes. The increase in the numbers of newly diagnosed women must also be taken into account in the commissioning process, as it calls for women-centred strategies for HIV testing and prevention. Adequate resources will also need to be allocated in future years to allow for growth and to reflect any changes in drug technology, for example the development of new antiretroviral drugs.⁹²

Provision of Care – Local Authorities

5.17 Local Authorities all take different approaches towards what, if any, support services should be provided or funded in their boroughs. In outer London boroughs, where there are fewer people living with the virus, there is far less provision and less likelihood of there being a nearby voluntary sector service organisation. **There are also fears that coupled with the planned removal of the government funded aids support grant (which represents the only ring fenced HIV funding provided to local authorities) HIV will become de-prioritised by local authorities.**⁹³

5.18 There is the need for the development of a framework that will specify the minimum HIV services that should be provided by each social service department across London. This framework could be based on the outcome of the needs assessment discussed in the chapter two. Once again, the London HIV strategy would be the ideal vehicle to initiate this approach.

Recommendation: 8

The Department of Health should disseminate good practice and minimum standards of care and support services.

⁹⁰ Review of Strategic Health Authority Local Delivery Plans 2003, Terrence Higgins Trust

⁹¹ Medical Foundation for AIDS and Sexual Health – Written Evidence

⁹² Evidence – British HIV Association

⁹³ African HIV Policy Network and The National Aids Trust – Written Submission

Provision of Care – Voluntary Sector

- 5.19 The provision of voluntary sector support services across London is patchy. In the absence of both a needs assessment and any quality criteria, services are those that have developed over the years and survived until today. Pressures on providing treatment have put care and support services under threat.⁹⁴ There has been a lack of investment in organisational development that has left smaller organisations particularly at risk leading to the demise of a number of smaller providers that were highly regarded by people living with the virus.⁹⁵ This has made it incredibly difficult to construct partnership approaches within the voluntary sector to London-wide problems.
- 5.20 Some of these difficulties were caused by a lack of capacity, but the evidence highlights that the commissioners of services played a role in this destabilisation, by failing to provide organisational development support over many years, and by introducing tendering processes that few organisations had any experience of participating in.⁹⁶ Voluntary sector organisations contributed to this destabilisation by failing to grasp the potential of partnership working.⁹⁷
- 5.21 Voluntary sector providers of HIV services still face an inadequacy of resources in the face of increasing demand for their services. Harbour Trust report that they share office space with a housing rights organisation and have no provision on site to provide cooked meals, alternative therapies, or training courses. They provide hardship funding, but are only able to sustain this through fundraising by volunteers and the assistance of local pubs and churches. Body and Soul is a voluntary sector organisation providing (among other services) crucial support for children and teenagers infected and affected by HIV. They face imminent closure if they fail to secure new accommodation. They have had to reduce client services because of the inadequacy of their current accommodation.
- 'I was diagnosed in 1999, but back then Body and Soul had a really big building with lots of space. Now they are reduced to just one room and they have to select people for support groups, based on need. A lot of other groups have either closed or are once a month rather than once a week, it is all to do with money.'*⁹⁸
- 5.22 Crusaid highlight the plight of excellent organisations that are losing increasing amounts of statutory funding. Although the National HIV and Sexual Health Strategy highlights the fourfold increase in HIV and emphasises the role of the voluntary sector there appears to be no funding to support the sector.⁹⁹ There is a need for consistency in funding which will allow continuity and assuredness of service provision through the voluntary sector. Chapter two highlights the need for pan-London assessment of the changing needs of people living with the virus. This will enable commissioners to determine the types of services required and the demand for such services. This should then be accompanied by an assessment of how appropriate the distribution of NHS resources for sexual health are

⁹⁴ United Kingdom Coalition – Written Submission

⁹⁵ United Kingdom Coalition – Written Submission (Cited :Closure of Body Positive and Blackliners)

⁹⁶ An example here would be the inclusion of Community Legal Service accreditation within tender arrangements for advice and advocacy services when only one of the potential tender candidates already held that accreditation – United Kingdom Coalition- Written Submission

⁹⁷ United Kingdom Coalition – Written Submission

⁹⁸ Focus Group

⁹⁹ Minutes of Evidence 18th November 2003

now.¹⁰⁰ It is hoped that any resulting changes in the organisation and co-ordination of service provision will then result in significant improvements in the delivery of HIV support services.

Involving People Living with the Virus

- 5.23 The involvement of people living with the virus in the processes of planning, designing and delivery of both HIV and wider health services is vital. The evidence points to a lack of client involvement in shaping services. This is acknowledged by the London Specialised Commissioning Group who informed us that involvement is currently insufficient. They are considering ways in which such involvement might be improved and they have recently developed a patient and public involvement strategy which aims to bring service users into all levels of their planning processes.¹⁰¹
- 5.24 The involvement of people with HIV is also lacking in many of the HIV service provider organisations. Employing HIV positive staff may not always be a priority, and in some cases, HIV positive staff within these organisations are as worried about disclosing their status as they would be had they been employed outside the HIV sector.¹⁰² People living with the virus should be consulted during the commissioning process.
- 5.25 It must be acknowledged that the stigma attached to HIV, and the strong desire of many people living with the virus for confidentiality, act as significant barriers to the involvement of HIV positive service users. This may be even more the case when it comes to the participation of people with HIV in general patient involvement initiatives such as Patient Forums.¹⁰³ However, this must not be used as an excuse. Without the involvement of people with HIV in NHS and voluntary sector service planning, there is nobody to reflect the needs and concerns of people with the virus at strategic levels. These views are even more crucial in the face of financial pressures, particularly when decisions are being taken to rationalise services.
- 5.26 A variety of methods of involvement should be developed. Some of these methods should take the need for confidentiality into account. Providing a range of ways for service users to comment verbally or in writing ensures that all clients can have an impact on service delivery. There is also a need to equip people living with the virus who wish to be involved quite openly and at strategic levels, by providing them with training and support that will enable them to participate effectively.

Recommendation 9

All Primary Care trusts need to develop ways to facilitate the involvement of people living with HIV. This might be through formal structures such as Patient Forums or through other more informal methods.

¹⁰⁰ Barnet Primary Care Trust – Written Submission

¹⁰¹ Minutes of Evidence 4th November 2003

¹⁰² Minutes of Evidence 18th November 2003

¹⁰³ Medical Foundation for Aids and Sexual Health – Written Submission

6. Meeting Future Needs

- 6.1 The Sigma Research report '*What do you need*' explores the challenges faced by people living with HIV, and found that most people reported problems relating to anxiety, depression, sleep, sex and self-confidence.¹⁰⁴ Differences in social status, educational levels, immigration status and stigmatisation also have a strong impact on the needs levels of people living with the virus. '*Project Nasah*', identified that there are a range of needs disproportionately experienced by black African people living with HIV in the UK, most of whom are resident in London.¹⁰⁵
- 6.2 Some of the most significant challenges for people living with the virus include:¹⁰⁶
- coping with the psychological and physical effects of a long-term, life-threatening condition;
 - the stigma associated with HIV and the resulting fear, secrecy and misinformation;
 - adhering to treatment, which often involves strict and demanding regimens of different drugs to be taken at different times;
 - maintaining good sexual health and preventing onward transmission of HIV. This can be particularly challenging for young people, whose confidence and self-esteem in relation to sex may be low and who may be facing the transition from childhood to young adulthood, with the potential for first sexual activity;
 - managing the impact of HIV on partners, friends and family members and the stress that this may cause for them;
 - for migrant communities, especially asylum seekers, there are additional challenges, for example being dispersed without a transfer of medical care to new providers, resulting in an interruption of treatment; living in shared accommodation without adequate facilities for refrigeration and private storage of medication; or lack of access to an appropriate diet.

These challenges bring up a wide range of complex support needs considered in more detail below.

Children and Young People

- 6.3 There are particular issues for children and young people living with the virus, as well as for their families. Paediatric HIV must be considered as a family condition, as there are needs for adequate information and support to be provided to parents and siblings, irrespective of their HIV status.¹⁰⁷

¹⁰⁴ Weatherburn P, et al, *What Do You Need? Findings from a National Survey of People Living with HIV*, Sigma Research, University of Portsmouth, 2002

¹⁰⁵ Weatherburn P, et al, *Project Nasah: an Investigation into the HIV Treatment Information and other Needs of African People with HIV Resident in England*, Sigma Research, University of Portsmouth, 2003

¹⁰⁶ Medical Foundation for Aids and Sexual Health – Written Submission

¹⁰⁷ South West London HIV & GUM Commissioning Consortium – Written Submission

- 6.4 In particular, families require support to:
- ◆ Decide what information is appropriate to share with the child or young person and develop strategies for sharing information.
 - ◆ Meet the emotional needs of infected and affected children, especially those affected by parental ill health, bereavement, fostering or adoption.
 - ◆ Enable children and young people to understand their condition, clinical monitoring and treatments, and the importance of adherence.
 - ◆ A “safe” place for families with children to meet to give and receive peer support
 - ◆ Negotiate issues of disclosure, stigma and discrimination, especially with schools and primary care providers.¹⁰⁸
- 6.5 Methods of required support outlined by parents include providing workshops on child specific issues, particularly on treatments, and specialised children’s counsellors.¹⁰⁹ More work needs to be done with young people in general both to protect them from ignorance and possible infection but also to address discriminatory attitudes of future generations. This kind of work has to be highly creative and delivered by peers in appropriate settings. It ranges from educational work in schools, through to peer support in terms of sex and sexual health.
- 6.6 The issue of HIV positive children who do not know of their status is an issue of growing concern. Many children who are HIV positive do not know that they are HIV positive because their parents have found it very difficult to tell them. As these children become older and reach the age of sexual maturity, these issues will need to be addressed. Services will need to develop to help them manage their transition into adulthood.
- 6.7 The integration of children with HIV is a very complex and difficult issue. Many parents do not wish to disclose their child’s status because of stigma and discrimination. There are incidents of children who are HIV positive, who have been bullied and discriminated against at school because of the ignorance that still abounds.¹¹⁰ Such ignorance prevents children living with HIV, from participating in everyday school activities such as trips, because parents would have to give the drugs to the school. On school trips, all children on any sort of medication are required to sign off their drugs with the school, and parents fear that it might be recognised that these are HIV drugs. Issues such as school disclosure become even more complex when the child or young person is unaware of their own status. Schools and colleges need to develop policies and awareness around HIV both for children and staff, but such policies should not be driven by fear.
- 6.8 Alongside this, the children with negative status who have parents who are HIV positive may number many more, and they will have a different set of support or educational needs. We were informed that there are very few services for these children and they are not seen to be in need by statutory agencies such as social services¹¹¹ All infected and affected children need a safe confidential space where they can ask questions about HIV and build support networks which will assist in making HIV less frightening for them. We have received written evidence from Body and Soul, which provides support services to both infected and affected children and young people. This is an example of how the

¹⁰⁸ South West London HIV & GUM Commissioning Consortium ; United Kingdom Coalition – Written Submission

¹⁰⁹ United Kingdom Coalition – Written Submission

¹¹⁰ Minutes of Evidence 18th November 2003 : Poverty and HIV Lessons from the Hardship Fund, Crusaid and Terrence Higgins Trust 2003

¹¹¹ Minutes 18th November

voluntary sector can meet such a crucial need. The need to support and adequately invest in such organisations is vital.

Adults

6.9 The range of support services required depends on the circumstances of the adults concerned, and as such, services need to be diverse and wide ranging. Apart from culturally specific services operating in some areas, there is a lack of provision for heterosexuals, particularly single heterosexuals (of either sex). Heterosexual men are particularly marginalised and, particularly in African communities, likely to be in denial about HIV issues. More work is needed to encourage and support appropriate peer group leaders who can provide support for other members of minority groups.¹¹² We recognise that it may not be possible to provide for every need. The main issue is to meet medical needs and crucial support needs and to provide these services in such a way that service users are empowered to help both themselves and others.

6.10 The United Kingdom Coalition of People Living with HIV and Aids, report that in order to mitigate the dependence on service providers, they have always concentrated on enabling individuals to resolve their own problems. Programmes such as the Living Well schemes enable individuals to manage their long-term condition. Peer Support is appreciated by many people living with the virus. The notion of being able to dip in and out of peer support according to ones need, appeals to many people, however there is little provision for this.¹¹³ Peer support and counselling is also needed for sero-discordant couples.¹¹⁴ Particularly around the issue of negotiating safer sex. There must be support that minimises the chances of onward transmission. We were informed that this type of support is minimal.¹¹⁵

*'I would like peer support. I would like somewhere to go to talk about HIV, because at the moment I don't have that. Really it is to gain support from others and ask them 'What drugs are you taking? How are you finding them? What do you do if you get certain side effects?'*¹¹⁶

6.11 There is a need for increased support for newly diagnosed people, to help them adjust to living with the virus and to inform them about the availability of services. Much of this work has been best carried out by other people living with the virus in peer settings. Unfortunately, there is little in the way of resourcing for such groups. There is also an urgent need for more widely available support courses for newly diagnosed people. Unfortunately, not all commissioners consider this a priority across London.¹¹⁷

6.12 Counselling services are successfully used by many to attempt to deal with their situations. However, demand for professional counselling far outstrips supply with providers advising four to seven week waits for appointments. For some this results in referral to mental health services instead, because the individual's distress is so severe.

¹¹² United Kingdom Coalition – Written Submission

¹¹³ United Kingdom Coalition – Written Submission

¹¹⁴ Where, one person is negative and the other HIV positive.

¹¹⁵ Minutes of Evidence 18th November 2003

¹¹⁶ Focus Group

¹¹⁷ Terrence Higgins Trust–Written Submission

Mental health services are also essential for some people living with the virus. Psychological support is often needed and can assist a person in adhering to treatment. In many places, mental health services are sadly lacking for those with HIV.¹¹⁸

Unemployment and Poverty

- 6.13 Poverty and ill health are problems that go hand in hand, often creating a vicious circle of deprivation. The evidence shows that unemployment and poverty are common amongst people living with the virus. A positive diagnosis of HIV can cause unexpected consequences. Problems can range from homelessness, loss of job or even domestic violence to the long-term impacts of ill health such as debt and depression. Each of these can cause economic problems. This is further compounded by discrimination, particularly in employment.
- 6.14 HIV is not only a medical issue; it is also a social issue that has a major economic impact on people's lives. The majority of people who live with HIV are at the age where they would normally be at the height of their economic influence and contributing to society, both economically and socially, and they have been unable to do so. Policies and strategies around supporting people with HIV should not be purely medical. There is now a need to look more in-depth at the holistic person and their social situation and design policies that will enable people living with HIV to live more economically independent lives.¹¹⁹

Employment Support

- 6.15 One of the principal challenges facing those living with the virus is finding employment and combating discrimination at work. In extremely rare circumstances having HIV can be a genuine bar to undertaking specific occupational tasks. This would include invasive or exposure prone procedures in medical settings, such as conducting surgery where there is a significant risk of blood to blood contact. Otherwise, HIV related discrimination is unwarranted and unjust.¹²⁰
- 6.16 As well as experiencing discrimination people living with the virus also experience fear of discrimination. A few well-publicised cases of blatant discrimination caused by sheer ignorance serve to perpetuate this very real fear amongst individuals. Employment discrimination can occur from the outset of the recruitment process when a person declares their status on pre-employment health forms leading to non-appointment on that basis only. Other forms of discrimination may be denial of promotion; denial of access to training and other assistance with internal advancement because it is considered wasted time investing in a person with HIV.¹²¹ In many circumstances, it is often the heightened sensitivity of employers which itself becomes discriminatory. Others panic at the thought of having someone with 'AIDS' on staff and fear the disruption this may cause amongst their workforce. Workers who disclose their HIV diagnosis face dismissal, or subtler forms of "redundancy" despite employment law. The reluctance of people sacked in this way to take any action is often for fear of further disclosures of status and discrimination.

¹¹⁸ Newham NHS Trust –Written Submission

¹¹⁹ 18th November

¹²⁰ African Policy Network – Written Submission

¹²¹ United Kingdom Coalition- Written Submission

- 6.17 For those people living with the virus there are also difficulties in combining the management of their condition with employment. A common complaint is the difficulty of accessing clinics (or any other HIV services) outside standard working hours. Opportunities to meet and receive peer support from people with similar experiences are often perceived as a means of overcoming isolation and loneliness, but for those that work full time access to such courses is limited. Both statutory and voluntary sector service providers must ensure that thought is given to providing services in the evening.

*'With combination therapy, a lot more people are able to work. All of these HIV centres open 9-5. If you are working you cannot access the services. I think the attitude is that if you are working you cannot be that ill and you don't deserve the services.'*¹²²

*'When I was looking for a group it was in the day. Just because I was unable to go in the day time, does not mean that I am not interested in maintaining my health'*¹²³

- 6.18 The success of the anti-HIV treatments means that many people living with the virus are well enough to re-enter the work place. A growing area of need is employment support, assisting people to obtain and retain meaningful employment. The type of support needed includes individual support for those who are considering entering or re-entering the work force, and specialised careers advice.

- 6.19 Workplaces need to ensure that they have disability policies that are sensitive to the needs of those with HIV. The workplace is still extremely HIV unfriendly.¹²⁴ Increased work with employers is needed to ensure that they are fully aware of the need to have comprehensive employment policies and practices that include HIV.

*'When you start working, you can't tell people what is really going on in your life and maybe you have to take time off. For some people going back to work becomes an even greater problem.'*¹²⁵

- 6.20 The 'Positive Futures' project, established by several HIV organisations in London, with financial support from the LDA among others, is a ground breaking initiative in assisting people with the virus to seek employment and to develop personal skills and goals. There is also a need for employers to model best practice in their support of people with HIV in the workplace, including up to date employment policies.

*'I don't think of death, I'm planning, I'm planning to study to get my degree. I'm planning to get a job... I want to live, life is sweet you know. I want to live just like everybody else, get better and feel strong within myself...I am not going to let this wear me down, I am not going to let it kill my spirit or stop me from doing what I have to do.'*¹²⁶

¹²² Focus Group

¹²³ Focus Group

¹²⁴ Minutes of Evidence 18th Nov

¹²⁵ Focus Group

¹²⁶ My Heart is Loaded; The Health Foundation, Positively Women, Queen Mary University, Terrence Higgins Trust.2003

Appendix A List of Recommendations

Recommendation: 1

The Department of Health must establish education programmes for young people that will raise awareness of HIV and the full spectrum of sexually transmitted infections.

Recommendation: 2

There is an urgent need for co-ordinated pan London HIV awareness which includes a mix of London-wide messages and appropriate local campaigns. We recommend that the London Strategic Health Authorities develop methods for ensuring this approach to health promotion and HIV awareness is implemented across the capital.

Recommendation: 3

The NHS London Specialised Commissioning Group must as a matter of urgency, review the draft London HIV Strategy and publish it.

Recommendation: 4

Whilst we welcome the additional financial resources for Genitourinary Medicine (GUM) services and sexual health, we believe the Government must provide continuing funding to ensure the continued availability of appropriate treatment and care for sexually transmitted infections.

Recommendation: 5

Primary Care Trusts should ensure that training on HIV issues is provided for all primary care staff. The standards of confidentiality in primary care must be developed to the same level of confidentiality adhered to in Genitourinary Medicine (GUM) clinics.

Recommendation: 6

All Genitourinary Medicine (GUM) clinics should ensure that attendees for sexually transmitted infections other than HIV should be offered the opportunity to test for HIV.

Recommendation: 7

A third of people who are HIV positive remain undiagnosed.

The Department of Health should evaluate the benefits and feasibility of a routine HIV screening programme.

Recommendation: 8

The Department of Health should disseminate good practice and minimum standards of care and support services.

Recommendation: 9

All Primary Care trusts need to develop ways to facilitate the involvement of people living with HIV. This might be through formal structures such as Patient Forums or through other more informal methods.

Appendix B List of Written Submissions

African HIV Policy Network
Barking, Havering and Redbridge NHS Trust Hospitals
Barnet Primary Care Trust
British Medical Association
Body and Soul
British Association for Sexual Health and HIV
British HIV Association
Crusaid
Dr Joseph Healy
Hammersmith and Fulham Primary Care Trust
Harbour Trust
Havering Primary Care Trust
Health Protection Agency
Hounslow Primary Care Trust
Kings College Hospital and Lighthouse Kings Centre
London Borough of Camden
London Borough of Enfield
London Borough of Hammersmith and Fulham
London Borough of Waltham Forest
London Health Observatory
Mainliners
Mayday NHS Trust
Medical Foundation for Aids and Sexual Health
National Aids Manual (NAM)
National AIDS Trust
National Association of Providers of AIDS Care and Treatment (PACT)
Newham General Hospital (Greenway Centre)
NHS Organisations in London (including the London HIV Consortium and London Specialised Commissioning Group)
North Central London NHS Sector Primary Care Trusts
North East Strategic Health Authority
Pan London HIV Consortium
Positively Women
Royal College of General Practitioners
South East London NHS Sector
South West London HIV and GUM Commissioning Consortium
Terrence Higgins Trust
United Kingdom Coalition of People Living with HIV and AIDS

Appendix C List of Hearings

14th October 2003

Dr Penny Bevan - Deputy Regional Director of Public Health, Department of Health
Ruth Lowbury - Executive Director Medical Foundation for Aids and Sexual Health
Dr S Singh - Royal College of General Practitioners
Dr Helen Maguire - Health Protection Agency
Dr Barry Evans - Health Protection Agency
Dr Jane Anderson - Honorary Secretary British HIV Association

4th November 2003

Dr Simon Barton - Chairman, The National Association of NHS Providers of AIDS Care
and Treatment (PACT)
Barbara Gill - Head of Specialised Commissioning, London Specialised Commissioning
Group
Steve Peacock - North West London Strategic Health Authority
Robert Maragh - Association of Directors of Social Services
Dr Joseph Healy

18th November 2003

Bernard Forbes - Chairman United Kingdom Coalition of People Living with HIV and AIDS
Thandi Haruperi, UK Coalition of People Living with HIV and AIDS
Dr Max Sesay, Chief Executive, African HIV Policy Network
Elizabeth Crafer, Director, Positively Women
Christina Kono, Adult Support and Volunteer Co-ordinator, Body and Soul
Robin Brady, Chief Executive, Crusaid
Steven Inman, Head of Grants & Projects, Crusaid

Appendix D London NHS Sectors

North East Sector

Local Authorities

Barking and Dagenham
City of London
Hackney
Havering
Newham
Redbridge
Tower Hamlets
Waltham Forest

South East Sector

Local Authorities

Bexley
Bromley
Greenwich
Lambeth
Lewisham
Southwark

North West Sector

Local Authorities

Brent
Ealing
Hammersmith & Fulham
Harrow
Hillingdon
Hounslow
Kensington & Chelsea
Westminster

South West Sector

Local Authorities

Croydon
Kingston
Merton
Richmond
Sutton
Wandsworth

North Central Sector

Local Authorities

Barnet
Camden
Enfield
Haringey
Islington

Appendix E Health Committee Publications

The Health Committee has also produced the following scrutiny reports, which can be downloaded free at: <http://www.london.gov.uk/assembly/reports/health.jsp>

Tuberculosis in London

November 2003

Should Fluoride be added to London's Water?

November 2003

GP Recruitment and Retention: the Crisis in London

June 2003

Access to Primary Care

A joint London Assembly and Mayor of London Scrutiny Report
April 2003

Infant Immunisation

January 2003

Smoking in Public Spaces Report

April 2002

Appendix F Principles of Scrutiny

The powers of the London Assembly include power to investigate and report on decisions and actions of the Mayor, or on matters relating to the principal purposes of the Greater London Authority, and on any other matters, which the Assembly considers to be of importance to Londoners. In the conduct of scrutiny and investigation, the Assembly abides by a number of principles.

Scrutinies:

- *aim to recommend action to achieve improvements;*
- *are conducted with objectivity and independence;*
- *examine all aspects of the Mayor's strategies;*
- *consult widely, having regard to issues of timeliness and cost;*
- *are conducted in a constructive and positive manner; and*
- *are conducted with an awareness of the need to spend taxpayers money wisely and well.*

More information about the scrutiny work of the London Assembly, including published reports, details of committee meetings and contact information, can be found on the GLA website at <http://www.london.gov.uk/assembly/index.jsp>

Appendix G Orders and Translations

For further information on this report or to order a bound copy, please contact:

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tel. 020 7983 4397

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