Open Research Online

The Open University's repository of research publications
and other research outputs

The growing challenge: a strategic review of HIV social care, support and information services across the UK.

Other

oro.open.ac.uk

The growing challenge

A strategic review of HIV social care, support and information services across the UK

Peter Weatherburn
Peter Keogh
Catherine Dodds
Ford Hickson
Laurie Henderson

Original Research Report

Acknowledgements

Forward

The AIDS Funders Forum is an informal group of charitable funders with an interest in HIV. Its membership includes people who have been involved in the HIV epidemic from the very early days, with hands-on experience of working in the HIV voluntary sector and personal experience of living with the virus.

This report appears 10 years after the widespread introduction of anti-retroviral therapies. Availability of effective HIV treatment has transformed the UK epidemic, producing a dramatic reduction in mortality and, for many people living with HIV, an increase in health and well-being. Yet, in spite of medical advances, many services seem to continue to follow a historical pattern. Against this background we commissioned Sigma Research to review service commissioning in the HIV sector in order to inform members' future grant making strategies.

Results in the report indicate that commissioners and providers of services believe that people from ethnic minority backgrounds, migrants, children, carers and people from different age groups have unmet needs. Other findings in this research indicate that many more services have been commissioned recently for Africans, on the basis that Africans make up a significant part of the current UK epidemic. We believe this is a valid focus but are discouraged by the approach to these varied communities as one homogenous population. It seems timely to ask whether configuring services to follow broad epidemiological categories without any further refinement is sufficient. The report further suggests that commissioners and providers believe the needs of gay men are well met. This is a surprise and does not accord with the views and experiences of many gay men living with the virus.

A significant minority of HIV positive people are neither gay men nor Africans. Even within these two groups the experience of living with HIV varies by age, geographical location and length of infection. HIV positive individuals may look at their needs from another starting point – for example, as a woman or an injecting drug user. The picture appears to be, increasingly, one of fragmentation and isolation. This poses the question: do we have the service models to meet the needs of HIV positive people in the third decade of the epidemic?

The report further shows that many of the problems with access to services – including housing and welfare rights – are structural problems, present across health and social care, and are not unique to HIV. HIV support services are funded from budgets which must also contain the increasing costs of anti-retroviral drugs and other medical interventions, and which are therefore subject to continuous attrition and dissaggregation.

Also highlighted is the lack of needs-based planning, the diminishing levels of knowledge and expertise among commissioners and the lack of a national strategic vision. In view of the fact that the Government has established a cross-departmental task force to address the epidemic in developing countries this lack of a national strategic vision is lamentable and has the effect of keeping the issue off the political agenda and almost invisible within local funding priorities. This is a concern both to us as funders and to agencies working within the HIV voluntary sector.

We would like to thank Sigma Research for the careful production of this report and record our indebtedness to everyone who participated in the research and commend it for serious consideration.

Crusaid
The Elton John AIDS Foundation
The Monument Trust

The Derek Butler Trust
The MAC AIDS Fund
The Peter Moores Foundation

January 2007

Contents

Executive summary

1. HIV IN THE UK

- The number of people living with diagnosed HIV in the UK has grown by 6,500 to 7,000 in each of the last 3 years (2003-2005). By the end of 2005, the total number of people living with diagnosed HIV in the UK was over 47,000. There may have been a recent decline in the rate of growth of numbers of people with diagnosed HIV but prevalence continues to increase by more than 10% every year.

- With the introduction of anti-retroviral treatment, the number of people with HIV dying every year radically declined ten years ago and has remained stable ever since (at about 500 deaths per year).

- Prevalence of diagnosed HIV infection is highest in England, then Scotland, Wales and Northern Ireland. Half of people with diagnosed HIV in the UK today live in London.

- In the UK, HIV disproportionately affects men rather than women and adults rather than children.

- There has been a recent decline in the number of people moving to the UK with HIV. In the UK overall, 51% of people living with diagnosed HIV are White, 43% are Black and 6% are of other ethnicities. Among the Black people with diagnosed HIV resident in the UK, 89% are African, 7% are Caribbean and 4% are from other Black groups.

- There has been no decline among the number of domestic HIV infections in the UK, suggesting the number of people living in the UK who acquire HIV (sexually) continues to grow. About 80% of all domestically acquired HIV infections occur as a consequence of sex between men.

2. OBSTACLES TO THE PROVISION OF SERVICES

2.1 HIV is not a political priority, either nationally or locally

- There are no government targets against which NHS or Local Authority performance with respect to HIV prevention or social care, support and information for people with HIV is measured. As a result, local targets concerning HIV are rare.

- Charitable HIV organisations are concerned about the lack of priority given to HIV in national and local policy. They report widespread indifference towards HIV from Local Authority, NHS and some charitable funders. The search for funding is a constant pressure on organisations and in many cases has a serious impact on their service delivery and long-term viability.

2.2 The NHS is (always) in crisis

- NHS HIV commissioners occupy a range of job roles, have a range of backgrounds and skills and are rarely HIV specialists. Many have multiple other priorities and roles, few have received any formal training and many receive no ongoing support. Expertise in service development is not a common skill among commissioners.

- The end of ring-fenced HIV funding is having an effect as the NHS undergoes another restructuring. PCT deficits figure prominently in commissioning decisions – often more prominently than need. Many NHS commissioners feel their role is to save money and monitor and remove existing contracts rather than commission new services.

- HIV social care, support and information services are often seen as secondary to treatment and care budgets. They are constantly under threat and their survival often depends on the negotiating power of commissioners. However, large-scale decreases in the funding of HIV social care, support and information services were not proven.

- Many charities feel it is increasingly difficult to establish and maintain contracts with Local Authorities and Primary Care Trusts. The mainstreaming of HIV figures prominently in these difficulties as does the limited priority attached to social care, support and information for people with HIV.

2.3 Local Authorities are mainstreaming services

- Mainstreaming of Local Authority services threatens to disrupt continuity of HIV social care. In particular, Social Services are increasingly unable to serve the complex and acute needs of the growing population of asylum seekers with HIV. This is putting undue pressure on charities to fill ever-widening gaps in service provision.

3. CHANGES IN SERVICE PROVISION

- Charitable providers have a great deal of expertise in the planning and provision of services – many innovate in response to changing need and changing patterns of HIV infection. However, the lack of a national HIV social care, support and information strategy makes prioritising need problematic. The over-riding impression is of a high volume of aims and needs (and target groups) with no way of prioritising among them. Often one group (or service) cannot gain without another losing.

- Approximately half of charities described cuts in HIV social care, support and information services in the last 3 years but three quarters described introducing new services in the same period. The description of services cut and services started suggests that changing patterns of HIV infection and associated need are less important than the changing political and funding environment (including NHS funding shortfalls, Local Authority mainstreaming and political pressures).

- Looking across all organisations in the UK, very similar services are being cut and launched, and these changes are not usually a consequence of changing need. There are many disparate factors driving innovation but funding, political and NHS and Local Authority priorities are key. The wish lists of service providers suggest there is no consensus about the ideal mix of HIV social care, support and information services for people with HIV, nor the key target groups and needs.

- Needs-led commissioning against strategic aims and objectives is very rare as is tendering of service contracts. The most common reason for funding a service is historical precedent and funding tends to roll forward year-on-year.

4. IMPROVING HIV SERVICES

- The majority of respondents did not think all people with HIV were equally well served by the current configuration of HIV social care, support and information services. Migrants, asylum seekers and ethnic minorities emerged as the groups around which most respondents expressed concern (over one third felt they were under-served and felt that should be targeted for funding by members of the AIDS Funders Forum).

- The majority of respondents thought members of the AIDS Funders Forum should prioritise specific needs of people with HIV when considering future funding especially needs around social care and support, financial security, education, training and employment, housing need, health care needs, legal and welfare benefits.

1 An overview of the HIV epidemic in the UK

This chapter presents an overview of the HIV epidemic across the United Kingdom, using the most recent published data to 1st December 2006. It describes a model of the epidemic and then draws on available data to fill in the sizes and proportions of the different components. Two points need stressing. First, the data about HIV made available through UK public health intelligence systems is some of the best in the world. However, it does not tell us everything we would wish to know in order to better plan services and does not give us a full and even picture across the UK. Second, there are not a finite number of HIV infections to go round. Expressing the epidemic in terms of the proportions attributable to different sections of the population is misleading and we have endeavoured to avoid it. The UK HIV epidemic is composed of a number of smaller over-lapping epidemics among very varied communities. Making these communities compete with each other is unhelpful and divisive. Instead we have used ratios to understand the relative sizes of different groups affected by HIV.

1.1 UK HIV PREVALENCE

The Office for National Statistics estimated there were 60,209,500 people living in the UK in mid-2005. The Health Protection Agency (HPA) estimate that in 2005 in the UK there were 47,025 people living with diagnosed HIV and in contact with treatment services. This was 0.08% of the total population, or about 1-in-1,280 people. This is the prevalence of diagnosed HIV infection. As a consequence the majority of people living in the UK do not personally know anyone living with HIV.

The following sections describe the characteristics of the diagnosed HIV positive population in the UK.

1.1.1 Monitoring systems

In the United Kingdom SOPHID (the Survey of Prevalent HIV Infection Diagnosed, co-ordinated by the Health Protection Agency) counts the number of people living with diagnosed HIV who use clinical services. SOPHID gives a profile of the geographic distribution, gender, age and ethnicity of people with HIV, as well as the most advanced stage of HIV disease they have experienced and their current use of HIV anti-retroviral therapy. It does not tell us about the sexuality or sexual behaviour of people with HIV, or their drug use.

The Centre for Public Health at Liverpool John Moores University publishes detailed data on people living with HIV in the North West of England, including gender, age and ethnicity but not sexuality. This data-set also includes the residency status of people living with HIV.

In Scotland CD4 monitoring data is reported for adults (aged 15 and over) but not children and is collated by Health Protection Scotland, indicating the number of adults living with HIV and in touch with treatment services. This data includes gender but not sexuality or ethnicity.

How people got HIV is, to a large extent, irrelevant to their current situation and needs (although their current sexual behaviour and drug use may not be). Although most of the systems above record how people probably acquired their infection (and it is often a prominent variable in reporting), we do not use it as a surrogate marker for sexuality, a common malpractice in epidemiological reports. This assumption creates an invisibility for both Lesbians and Bisexual men and women with HIV and it renders people who got HIV through injecting drug use or blood products as having no sexuality. We record our opinion that heterosexism continues to prevent the proper monitoring of sexuality in HIV epidemiology despite being a crucial factor in the UK HIV epidemic.

1.1.2 Residence and the positive population

After 20 years of the HIV epidemic there are people living with diagnosed HIV in all areas of the UK. HIV prevalence in the four countries of the UK is shown below.

	mid-2005 total population estimate	People living with diagnosed HIV and seen for care in 2005 [SOPHID 2005 Regional data, Table 1]	% of total population with diagnosed HIV
England	50,431,700	43,335	0.086%
Wales	2,958,600	778	0.026%
Northern Ireland	1,724,400	281	0.016%
Scotland	5,094,800	† 1,912	0.038%
all UK	60,209,500	47,025	0.078%

[† excludes children 14 years and younger of whom there are probably no more than 35]

Prevalence of diagnosed infection is highest in England, then Scotland, Wales and Northern Ireland. However, within each of these countries people with HIV are very unevenly distributed. About half of the people living with diagnosed HIV in the UK, live in London. This means the prevalence of HIV in London is much higher than the rest of the country.
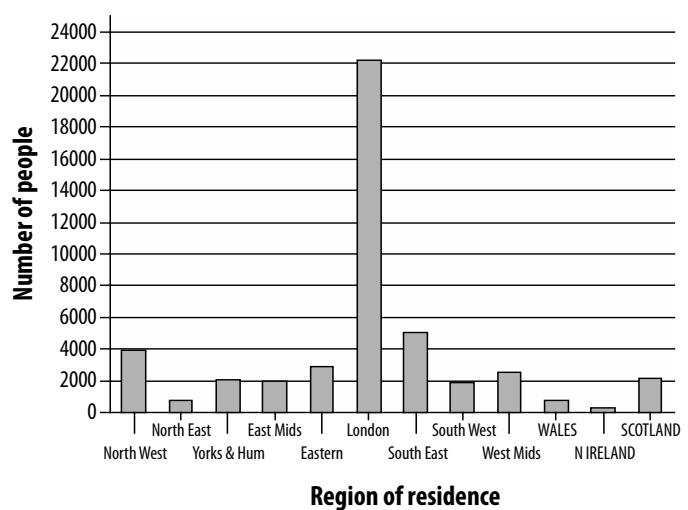
Figure 1 shows the number of people living with diagnosed infection in each region of the UK.

Figure 1: Number of people with diagnosed HIV, seen for care in the UK in 2005. Source: SOPHID 2005, Table 1.

1.1.3 Gender among the positive population

Overall in 2005 there were almost twice as many males living with diagnosed HIV in the UK (30,986) as females (16,039). Since there are roughly equal numbers of males and females in the country this means HIV prevalence in males is approaching twice that in females (actually 1.9-to-1 overall).
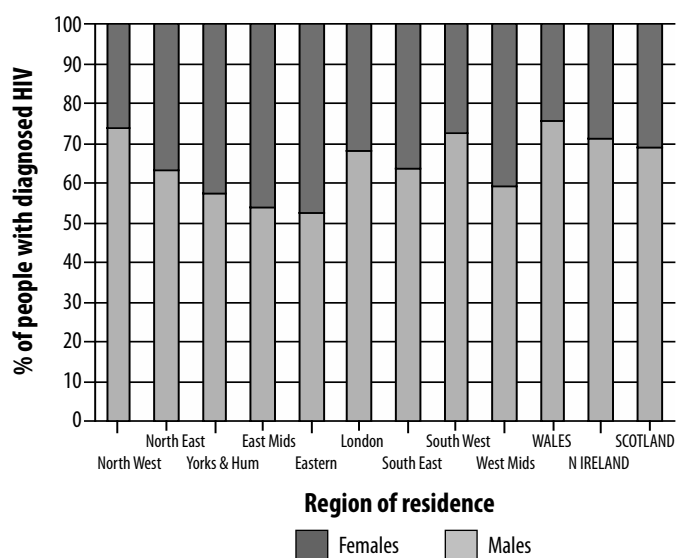
Figure 2 shows the ratio of males to females living with diagnosed HIV in each part of the UK. There are men and women (and boys and girls) living with HIV in all parts of the UK but males with HIV outnumber females with HIV in every part.

Figure 2: Gender ratio of people living with HIV in the UK in 2005. Source: SOPHID 2005, Table 4.

The male-to-female ratio of people living with diagnosed HIV ranges from 1.1-to-1 in the Eastern region of England to 3.1-to-1 in Wales (and 2.8-to-1 in the North West of England).

1.1.4 Age and the positive population

Figure 3 shows the age profile of people living with diagnosed HIV in each part of the UK in 2005.

There are people living with HIV at every age in every area of the UK and the differences in age profile across the UK are not as great as their similarities.

The proportion of people with diagnosed HIV who are under 25 years old is relatively low in all areas.

In every area of the UK between 60-70% of people with diagnosed HIV are in the age group 25-44.
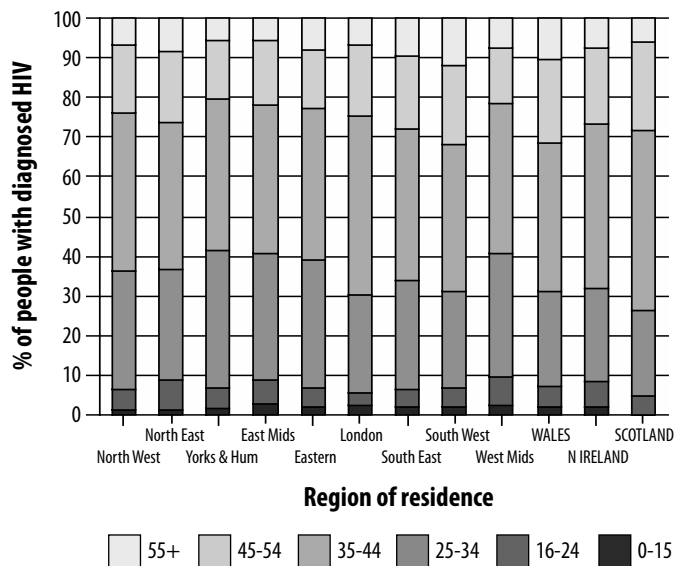
Figure 3: Age of people living with HIV in the UK in 2005.
Source: SOPHID 2005, Table 1.

Gender & age

The age profile of males and females with HIV differs. Fewer older women have HIV than do older men.

Figure 4 shows the number of males and females living with diagnosed HIV in six age groups. The gender ratio of people with diagnosed HIV varies by age. Among children there is exact gender parity with a male-to-female ratio of 1-to-1 (actually 474 males and 474 females under 16 across the UK in 2005).

Among young adults (ages 16 to 24) women outnumber men 1.4-to-1. In older adults, men outnumber women: among 25-34 year olds the male-to-female ratio is 2.2-to-1 and among the 35-44 years olds it is 3.8-to-1.
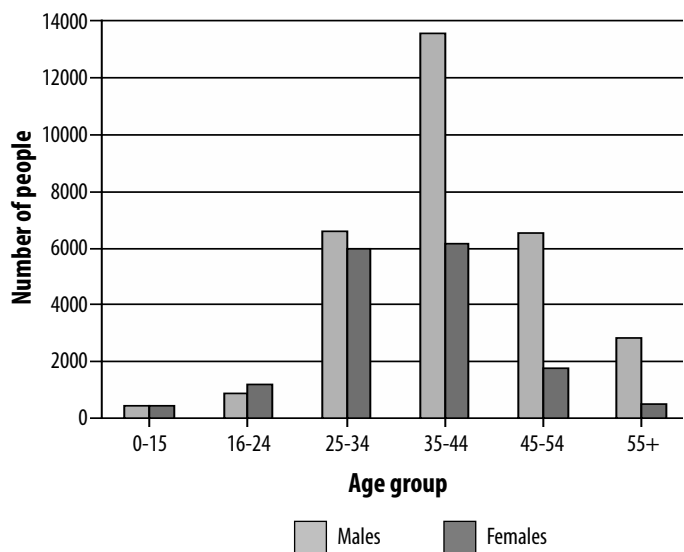
Figure 4: Age and gender of people living with HIV in the UK in 2005. Source: SOPHID 2005, Table 4.

Women with HIV are, as a group, younger than men with HIV, not because more young women have HIV than young men have HIV, but because fewer older women have HIV compared with older men.

Gender & age in North West England

A more detailed picture is provided by enhanced monitoring in North West England (Cook *et al*. 2006) though this shows a similar pattern to the national picture. In the North West there are males and females living with HIV at all ages but there are substantially fewer older women living with HIV.
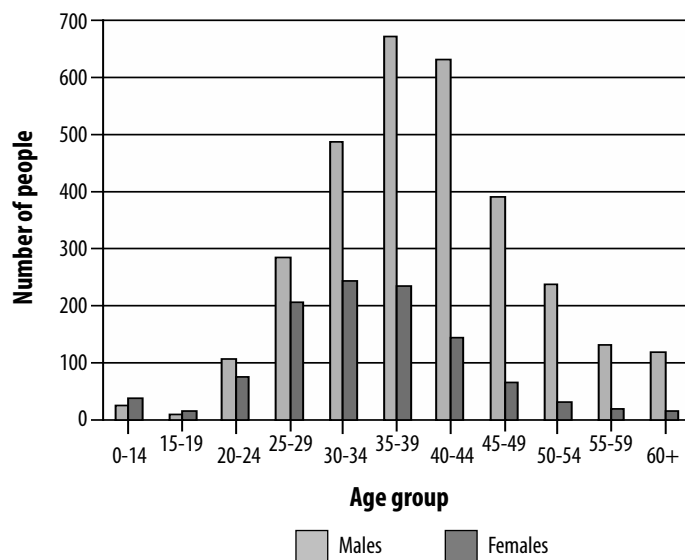
Figure 5: Age and gender of people living with HIV in the North West of England. Source: Cook *et al.* (2006). Table 3.1.

1.1.5 Ethnicity among the positive population

The ethnicity of people with diagnosed HIV and in treatment is not recorded in Scotland. In England, Wales and Northern Ireland all White ethnic groups tend to be grouped together in monitoring data. This masks the ethnic and national diversity among White people with HIV. It should not be assumed that all the White people described here were either British or native English speakers.

There are men and women of every ethnicity living with HIV in the UK but Africans are substantially over-represented. In the UK overall, at the end of 2005, 51% of people living with diagnosed HIV were White, 43% were Black and 6% were of other ethnicities. Among the Black people with diagnosed HIV and resident in the UK, 89% were African, 7% were Caribbean and 4% were from other Black groups.
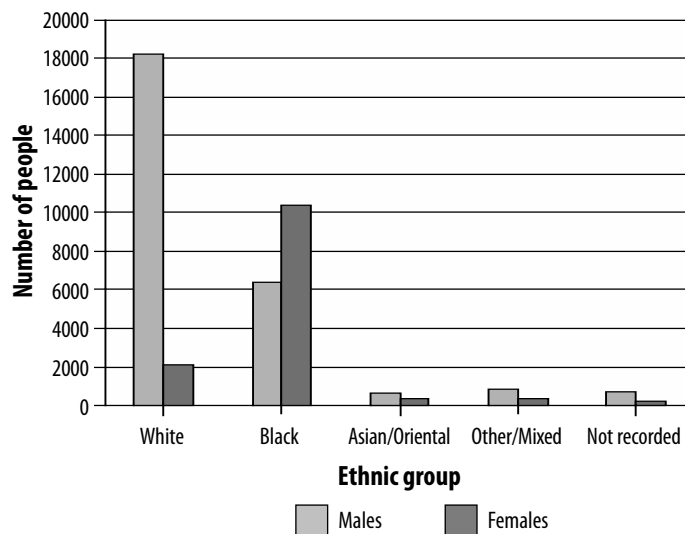
Figure 6: Gender and ethnicity of people seen for HIV care in England, Wales and Northern Ireland in 2004. Source: Mapping the Issues, Supplementary data tables, Part 1, Table H.

The ethnic profile of people with diagnosed HIV differs in men and women. Although only 2% of the total population of the UK are Black, 24% of males living with HIV are Black and 79% of females living with HIV are Black.

The ratio of Africans to other ethnic groups varies across the UK. In the Eastern region of England the ratio is 1.2-to-1 Africans to all other ethnic groups (ie. more Africans than all other groups put together). In Northern Ireland there is a 1-to-4 ratio of Africans to all other groups (ie. only 1 in 5 people with HIV are Black African).

1.2 CHANGE IN THE POPULATION OF PEOPLE LIVING WITH HIV

Figure 7: Ethnicity of people living with HIV in England, Wales and Northern Ireland. Source: SOPHID 2005, Table 3.

The number of people living with undiagnosed and with diagnosed HIV changes through a variety of routes. As HIV infection remains incurable, the number of people with HIV in the population only decreases as people with HIV die or leave the UK. People join the HIV positive UK population either by being a person living in the UK who becomes newly infected or by being a person with HIV who starts living in the UK. All people who move to the UK with HIV who are diagnosed here are reported as a new diagnosis, whether they had been previously diagnosed in their country of origin or not.

1.2.1 Leaving the population of people with HIV

Although it must be true that some people with HIV emigrate from the UK, there is no evidence concerning the numbers who do so.

The Health Protection Agency collates reports of deaths of people with diagnosed HIV. Figure 8 shows the number of people with HIV who have died in the UK each year since 1991, irrespective of the cause of death.

The annual number of deaths among people with HIV increased through the early 1990s to a peak of 1,726 people in 1995. It has fallen dramatically following the introduction of HIV anti-retroviral therapy and from 1998 onwards the number of deaths among people with HIV has been stable at around 500 each year. In the past few years, over half of the people with HIV who died had not received an AIDS diagnosis.

Figure 8: Deaths among people with HIV in the UK since 1991. Source: HPA New Diagnoses Quarterly Surveillance Tables, No 72:06/3, Table 1, data to end Sept 2006.

1.2.2 Joining the (diagnosed) positive population

The two main ways of joining the positive population of the UK are not routinely distinguished in HIV reports and epidemiology.

Reports of HIV diagnoses include both people who moved to the UK with HIV and those who acquired HIV while living in the UK. In the absence of other research, new diagnoses of HIV are often also taken as evidence of new infections. But we need to be very careful when making this elision. Acquiring HIV (a negative event we are trying to reduce) and having HIV diagnosed (a positive event we are trying to promote) are two very distinct events. The distinction becomes particularly important when we try to use HIV diagnoses data to inform HIV prevention planning.
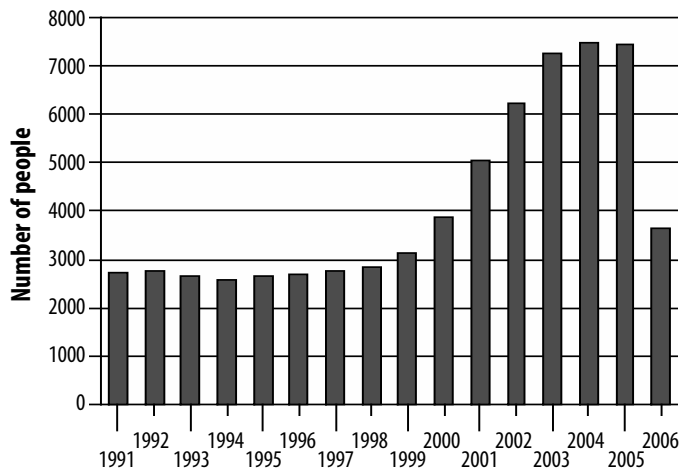
Figure 9: New diagnoses of HIV infection in the UK since 1991. Source: HPA New Diagnoses Quarterly Surveillance Tables, No 72:06/3, Table 1, data to end Sept 2006.

The following figures do not show the patterns of people living in the UK who are acquiring HIV (and who could be influenced by prevention here) but the number of people being diagnosed with HIV. Figure 9 shows the number of people each year who were first diagnosed with HIV in the UK. This is the number of people joining the diagnosed HIV positive population each year. The number includes both new infections in people living in the UK and new people arriving in the UK with prior HIV infection.

Up to and including 1998 there were under 3000 new HIV diagnoses being made in the UK each year. Since 1998 there has been a steady rise in new diagnoses of infection to over 7000 in 2003, 2004 and 2005. Although the number of people in the graph will increase as more reports come in (the 2005 and 2006 columns especially will get taller), there has been a decline in the rate of increase in the last few years.

Gender & ethnicity of people being diagnosed with HIV in the UK

Figures 10 and 11 use the same scale to show variation by ethnicity in the number of men and the number of women who have been diagnosed with HIV in the UK since 1995 (when surveillance started to record ethnicity).

Although ethnicity is missing for a relatively large proportion (especially of men), patterns are clear. HIV diagnoses has increased in both genders and in every year more men were diagnosed than women. African people are very prominent in both genders but especially among women.
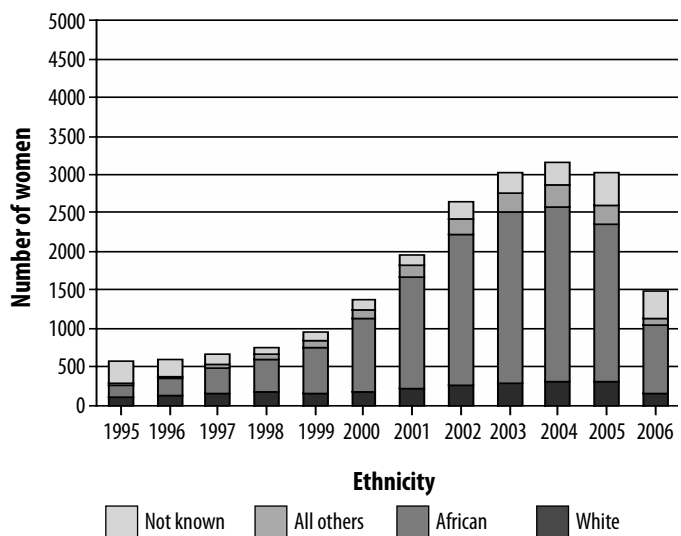
Figure 10: New diagnoses of HIV infection among WOMEN in the UK by ethnicity. Source: HPA New Diagnoses Quarterly Surveillance Tables, No 72:06/3, Table 10, data to end Sept 2006.

Among men, diagnoses have increased every year among White men, African men and less so among men from other ethnic groups. Among women, diagnoses have increased very notably among African women and less so among White women and women from all other ethnic groups.

Considering only Black African people being diagnosed with HIV in the UK (Figure 12) we see annual increases among both men and women every year from 1995 to 2003. However, there has been a recent decline in new diagnoses among both genders. This should not be confused with a decline in the number of African people living with HIV in the UK – this number is still increasing every year, just not as quickly as previously.

In every year since 1995 more Black African women than men were diagnosed with HIV in the UK. There has been a gradual increase in the ratio of women-to-men from an average of 1.3-to-1 in 1995-7 to 1.9-to-1 in 2003-5. In other words, among Black Africans the predominance of women living with HIV has increased.

Considering only diagnoses in White people (both British and non-British) there have been increases in the number of new diagnoses every year since 1995, among both men and women (Figure 13). There has been no indication to date of a decline in the number of new diagnoses each year.

In every year more men than women were diagnosed but there has been a gradual decline in the ratio of men-to-women from an average of 7.2-to-1 in the three years 1995-7 to 5.5-to-1 in the three years 2003-5.

Among Whites the predominance of men living with HIV has decreased but there are still 5.5 White men diagnosed with HIV for every White woman diagnosed.
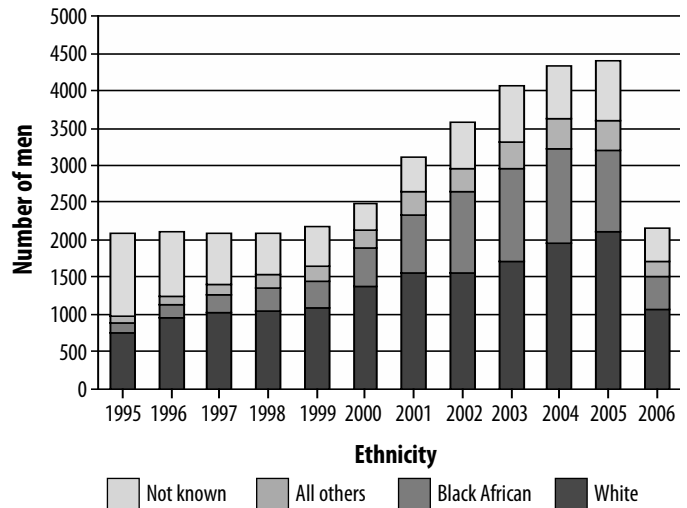
Figure 11: New diagnoses of HIV infection among MEN in the UK by ethnicity. Source: HPA New Diagnoses Quarterly Surveillance Tables, No 72:06/3, Table 10, data to end Sept 2006.
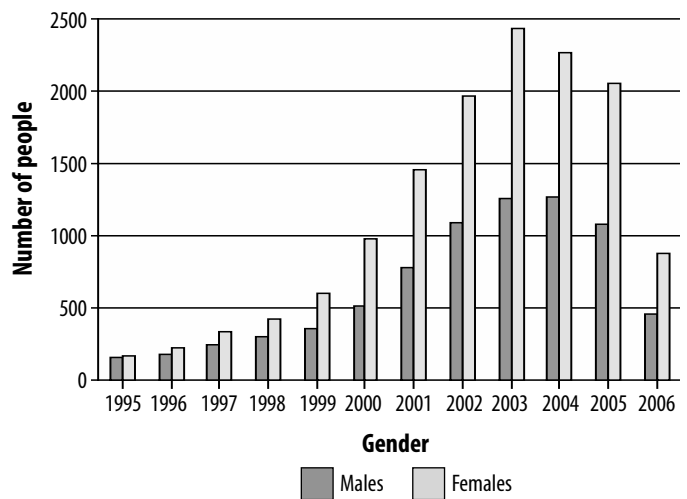
Figure 12: New diagnoses of HIV infection among BLACK AFRICANS in the UK. Source: HPA New Diagnoses Quarterly Surveillance Tables, No 72:06/3, Table 10, data to end Sept 2006.
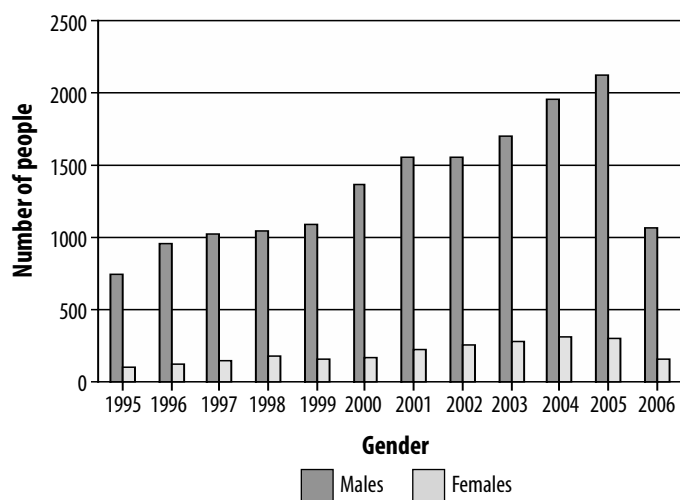
Figure 13: New diagnoses of HIV infection among (British and other) WHITES in the UK. Source: HPA New Diagnoses Quarterly Surveillance Tables, No 72:06/3, Table 10, data to end Sept 2006.

Moving to the UK with (undiagnosed) HIV

People with HIV move to the UK from across the world. When these people enter the NHS they are reported as a new HIV diagnosis even when they have previously had their infection diagnosed (and treated) in another country.

Global region of infection is reported for all people seen for HIV care in the North West of England. In the North West, 44% of people first seen for HIV care in 2005 had acquired their infection abroad (Cook *et al*. 2006, p.31; Table 2.9). In other words, among all the people first seen for HIV care in the North West of England in 2005, almost as many had moved to the UK with HIV infection as acquired it here.

Across the UK, country of infection is now reported for infections acquired abroad sexually or through injecting drug use (but not for the much smaller number of vertical or iatrogenic infections). However, for homosexually acquired infections and for infections associated with injecting drug use some data is still often missing. In Figure 14, infections whose location was unknown have been distributed between the UK and abroad in the same proportions as those infections where location was known.

Figure 14 shows the number of diagnoses made each year of infections thought to have been acquired abroad. There has been a large increase in these diagnoses since 1998, including a four-fold increase in the five years from 1998-2003. IDU account for a small proportion of these diagnoses. While the numbers reported will rise for recent years (especially 2005 and 2006) it appears that the annual number of new diagnoses of HIV in the UK, that have been acquired abroad is now declining.

The number of MSM diagnosed with HIV acquired abroad gradually fell throughout the 1990s but has risen since 2000. Although the *proportion* of infections sexually acquired abroad that are in MSM has gradually fallen (mainly due to a large increase in the number of infections heterosexually acquired abroad), MSM are still heavily over-represented in diagnoses acquired abroad. The smallest proportion MSM represented in all infections sexually acquired abroad was in 1993 when MSM represented 8% of new diagnoses. While it is unclear what proportion of all men and women entering the UK are MSM, it is likely to be far smaller than 8%.

The largest change has been in diagnoses of infections heterosexually acquired abroad. These have risen every year since

IDU = injecting drug use
MSW+WSM = men having sex with women AND women having sex with men
MSM = men having sex with men

Figure 14: New diagnoses of HIV infection acquired abroad via sex or injecting drug use. Source: HPA New Diagnoses Quarterly Surveillance Tables, No 72:06/3, Table 5, data to end Sept 2006.

1997 but now appear to be in decline. It is not the case that the large increase in diagnoses of infections heterosexually acquired abroad has been in people living in the UK who acquired their infection on a foreign trip. The decline is due to changes in patterns of migration into the UK.

Where abroad infections were acquired is known for heterosexually acquired infections. Figure 15 shows the predominance of Africa in all infections heterosexually acquired outside the UK. This includes both people who moved to the UK with HIV and people who live in the UK but acquired HIV while on a foreign visit. By far the largest number of diagnoses and the bulk of the increase in all diagnoses are among people who acquired their infection in Africa.

If we exclude people acquiring their infection in Africa (Figure 16) we see that there has also been an increase in infections acquired in Latin America and the Carribean, Asia and to a lesser extent Europe. However, the volume of diagnoses from all these regions combined is eight to ten times smaller than the number from Africa alone.

Becoming infected while living in the UK

The other way in which people living in the UK join the positive population is when they become infected with HIV (either in this country or abroad). It is the number of these events that HIV prevention in the UK is trying to reduce. In North West England, of the 401 people seen for HIV care for the first time in 2005 who were known to have acquired their infection in the UK, 79% were men who acquired HIV during sex with another man, 16% were men and women who

Figure 15: New diagnoses of HIV heterosexually acquired abroad. Source: HPA New Diagnoses Quarterly Surveillance Tables, No 72:06/3, Table 5, data to end Sept 2006.
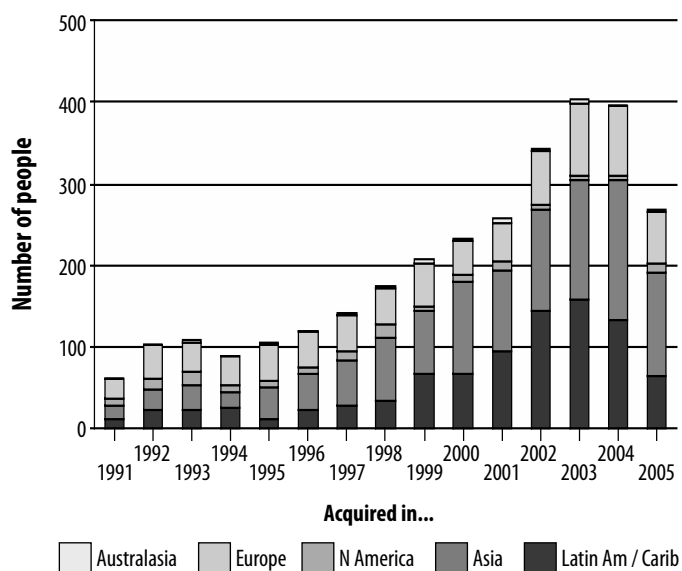
Figure 16: New diagnoses of HIV heterosexually acquired abroad other than in Africa. Source: HPA New Diagnoses Quarterly Surveillance Tables, No 70: 06/1, Table 7a, data to end March 2006.

acquired it during heterosexual sex, 4% acquired it during injecting drug use and 1% acquired it from their mothers during birth or breast feeding (Cook *et al.* 2006, p.31, Table 2.9). So four-out-of-five people acquiring HIV in the North West of England in 2005 were men who got HIV during sex with another man.

Figure 17 shows UK figures for HIV diagnoses where the infection was acquired in the UK sexually or through injecting drug use (IDU). Infections acquired vertically (during birth or breast feeding) or iatrogenically (via blood, blood products or human tissue) are grouped together in *other*.

Unlike diagnoses of HIV acquired heterosexually abroad, the number of domestic diagnoses has continued to rise each year and shows no sign of declining.

The number of diagnoses of infections heterosexually acquired in the UK has slowly increased every year. However, the largest number of diagnoses are of infections acquired by men during sex with men and these are also increasing every year.

1.3 UNDIAGNOSED HIV INFECTION

All HIV infections must be undiagnosed for a time and most infections will eventually be diagnosed. The HPA estimates the proportion of all HIV infections that have been diagnosed is approximately two thirds, meaning that at the end of 2005 an estimated 63,500 adults aged over 15 years were living with HIV in the UK, of which 20,100 (32%) were unaware of their infection (The UK Collaborative Group for HIV and STI Surveillance, 2006).

IDU = injecting drug use
MSW+WSM = men having sex with women AND women having sex with men
MSM = men having sex with men
other = including vertical and iatrogenic transmission

Figure 17: New diagnoses of HIV acquired in the UK.
Source: HPA New Diagnoses Quarterly Surveillance Tables, No 72:06/3, Table 5, data to end Sept 2006.

We know far less about people living with undiagnosed HIV than we do about people with diagnosed infection. However, it is likely that the profile of people with undiagnosed HIV is similar to that of people with diagnosed HIV. A survey of Gay men in London (Dodds & Mercey 2005) which tests saliva samples for HIV, found that 59% of men who had HIV had been diagnosed. This estimate has remained stable for 10 years, suggesting that the diagnosed population and the undiagnosed population are growing at the same rate (albeit for different reasons). The proportion of all infections that are diagnosed is a less useful concept than the length of time people spend with undiagnosed HIV. There is little data available about what this average length of time is but CD4 count at diagnosis is associated with length of time since infection and is used as a surrogate marker.

The HPA runs a CD4 surveillance system which collates first CD4 count after diagnoses. Unfortunately the reporting of this data does not distinguish between people moving to the UK with HIV and those living in the UK who acquire HIV. The data is usually reported by the route of infection conflating domestic and migratory infections. Consequently, a comparison between MSM infections and heterosexual infections is also a comparison between predominantly domestic infections and predominantly imported infections. What the national CD4 surveillance data show is that there has been a gradual rise in first CD4 count among domestic / MSM infections, suggesting a gradual reduction in the length of time between infection and diagnosis. However, there has been no change in the average first CD4 count among imported / heterosexual infections.
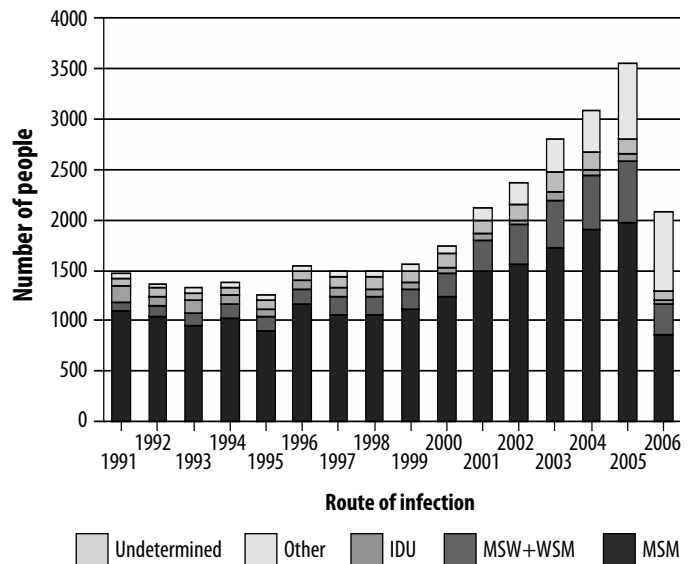
1.4 CHANGE IN SIZE OF THE POSITIVE POPULATION

The number of people living with diagnosed HIV gets bigger as more people are diagnosed and gets smaller as people with diagnosed infection die or move out of the UK. Figure 18 shows the difference between new diagnoses of HIV infection and deaths among people with diagnosed HIV over the past fifteen years.

It has never been the case that the population of people with diagnosed HIV has got smaller. Every year more people have been diagnosed than have died.

However, in the early 1990s the rate at which the population was increasing was in decline. From 1991 to 1996, the number of new diagnoses each year was between 2577 and 2752, and the numbers of deaths varied between 1145 and 1726.

Figure 18: Difference between new diagnoses and deaths in people with HIV. Source: HPA New Diagnoses Quarterly Surveillance Tables, No 72:06/3, Tables 1 & 2, data to end Sept 2006.

Since 1998 the number of people diagnosed with HIV each year has climbed to more than 7,000 in 2003, 2004 and 2005. During this time the number of people with HIV dying each year has remained steady at about 500. Hence, across each of the last 3 years the absolute number of people with HIV resident in the UK has increased by about 6,500 to 7,000 per year.

1.5 SUMMARY: HIV INFECTION IN THE UK

- **The population of people living with HIV in the UK has grown by 6,000 to 7,000 in each of the last 3 years. By the end of 2005, the number of people with diagnosed HIV resident in the UK was over 47,000. There may have been a recent decline in the rate of growth of numbers of people with diagnosed HIV but prevalence continues to increase by more than 10-15% every year.**

- **The number of people with HIV dying every year radically declined ten years ago and has remained stable ever since (at about 500 deaths per year).**

- **Prevalence of diagnosed HIV infection is highest in England, then Scotland, Wales and Northern Ireland. However, half of people with diagnosed HIV in the UK today live in London.**

- **In the UK, HIV disproportionately affects men rather than women and adults rather than children.**

- **There has been a recent decline in the number of new diagnoses among migrants with HIV, suggesting the number of people moving to the UK with HIV has stopped growing. In the UK overall, 51% of people living with diagnosed HIV are White, 43% are Black and 6% are of other ethnicities. Among the Black people with diagnosed HIV and resident in the UK, 89% are African, 7% are Caribbean and 4% are from other Black groups.**

- **There has been no decline among the number of domestic HIV infections, suggesting the number of people living in the UK who acquire HIV (sexually) continues to grow. About 80% of all domestically acquired HIV infections occur as a consequence of sex between men.**

2 Research methods and participants

2.1 METHODS, RECRUITMENT & EXCLUSIONS

The main part of this report is based on a survey of key informants who work or volunteer with agencies that provide social care, support or information to people with HIV or commission such services. The survey was available for completion online at a specific website. The questionnaire was prepared and hosted using an online internet survey instrument <www.demographix.com>. The design of the web-survey allowed data to be captured and viewed as soon as the respondent pressed 'submit' at the end of the survey. The survey was available for completion online for five weeks from 26th April to 31st May 2006.

Recruitment was via email invitation to lists generated from multiple sources. We sent invitations to 1111 unique email addresses. We sent each email address an invitation to participate in the survey and at least one reminder 7-10 days later. Overall, about 10% of email invitations were returned as undeliverable, suggesting about 1,000 people were invited to participate. We also asked all those invited to participate to pass on the invitations to other key stakeholders in their locality.

A list of 330 current charitable and AIDS service organisations (ASOs) across the UK was purchased from NAM. This was augmented by a list of all members of the African HIV Policy Network, and Sigma Research's own email lists. Ultimately, 456 email addresses for staff and volunteers of charitable organisations were used to invite participation.

A Department of Health list of 427 sexual health leads and other key NHS stakeholders formed the basis of English NHS targets for recruitment. This was augmented by a list of HIV leads in Welsh Health Boards (n=25), and a similar list for Scottish NHS Boards (n=36). With no pre-existing lists accessible we contacted all Northern Ireland NHS Boards and asked them to nominate a HIV or sexual health lead. Ultimately these activities led to 492 commissioners, sexual health leads and other key stakeholders in NHS HIV services being invited to participate. Finally, a list of 163 UK Local Authority HIV leads across the UK was also purchased from NAM.

Recruitment to the survey was also facilitated by an email from Crusaid to all the referring agents and organisations for their Hardship Fund. A single email encouraging participation was sent to about 1200 email addresses.

2.1.1 Exclusions

To qualify for the survey respondents needed to work or volunteer for a UK agency that provided social care, support or information to people with HIV or commission such services. We received 394 online responses. Of those that completed the survey online 5% (n=20) had been invited to do so by someone who had already completed the survey (that is they were not invited by us directly).

Six returns were excluded for technical reasons: 2 were duplicate records which had been submitted twice online; 4 were repeat respondents (who had completed it more than once). Another 11 responses answered fewer than ten questions and were excluded on the basis that insufficient data had been received. Finally, 6 responses were excluded on the basis that they neither worked nor volunteered for a UK agency that provided HIV social care, support and information or commissioned such services. This left a sample of 371 people who worked (n=363) or volunteered (n=8) for a UK agency that provided social care, support or information to people with HIV or commissioned such services.

2.1.2 Qualitative interviews

Although the methodology used in this review is quantitative, the project specification allowed us to carry out a limited number of qualitative interviews, to add detail on a particular group or issue. To facilitate this, we invited all survey participants to leave contact details if they were willing to take part in follow-up telephone interview. Of the 371 qualifying participants, 197 volunteered for follow-up interviews.

One-to-one confidential telephone interviews were conducted with eight commissioners and ten charitable providers in June and July 2006. Respondents were selected in order to maximise variation between urban and non-urban, high and low prevalence areas. The interviews lasted between 20 and 40 minutes each, were digitally recorded and transcribed. Two researchers conducted a thematic content analysis on each transcript. The results of these interviews enrich and inform the results contained in chapters 3 and 4.

2.2 SURVEY PARTICIPANTS

Of the 371 respondents, the vast majority currently **worked** in a job related to services for people with HIV (98%, n=363). The remainder currently **volunteered** for an organisation providing social care, support or information to people with HIV (2%, n=8). Those in a job related to HIV either worked for a charity (46%, n=164); or a Local Authority (22%, n=80); or in the NHS (31%, n=112). The majority of those that worked in the NHS, worked for a Primary Care Trust or equivalent (24%, n=84) rather than an NHS hospital or Community Trust (7%, n=24) or Strategic Health Authority (1%, n=4). Since only four respondents worked in a Strategic Health Authority and 24 worked in NHS Hospital (or Community) Trusts, these were merged with Primary Care Trust staff. This merger of all NHS staff also overcomes problems with classification of respondents working in Scotland and Wales where it was not clear whether Local Health Boards (in Wales) and NHS Boards (formerly Health Boards, in Scotland) were the equivalent of English Primary Care Trusts or Strategic Health Authorities.

All respondents who worked in a job related to HIV were asked three compulsory questions to establish their relationship to the provision of services for people with HIV.

- *Does the organisation you work for provide social care, support or information directly to people with HIV?*

If they said YES, they were also asked:

- *Does your job involve fundraising or managing contracts for the provision of social care, support or information for people with HIV?*

All those that worked in HIV were also asked:

- *Do you commission HIV services?*

These questions were meant to filter the providers of service from the commissioners. Answering YES to the first question above, led to three pages of questions on the provision of service. Answering YES to the second (as well) led to a fourth page of questions on fundraising for the provision of service. Answering YES to the commissioning question led to two pages of questions on the commissioning of HIV services.

All respondents were also asked:

- *Do you currently volunteer for an organisation providing social care, support or information directly to people with HIV?*

Those that said YES were asked:

- *Does your role involve managing contracts or fundraising for the provision of social care, support or information to people with HIV?*

Answering YES to the first question above led to 3 pages of questions on the provision of services from the organisation they volunteered for. Answering YES to the second (as well) led to a fourth page of questions on fundraising for the provision of services.

Forty respondents currently volunteered for an organisation that provided services for people with HIV, of which 8 did not work in a job related to HIV. Of the 32 respondents that worked in a job related to services for people with HIV, 11 stated that they volunteered for the same organisation that they worked for. The other 21 respondents listed 24 organisations which they volunteered for, but were not employed by.

In the following table column two (*Does your job (role) involve fundraising or managing contracts for the provision of social care ... to people with HIV?*) is a subset of column 1 *(Does the organisation you work (volunteer) for provide social care... directly to people with HIV?)*. That is respondents were only asked the second question if they answered YES to the first about working for an organisation involved in the provision of HIV services. Column three *(Do you commission HIV services?)* was asked of all respondents that worked in jobs related to HIV.

Working or volunteering in HIV (n=371)	Does the organisation you work (volunteer) for provide social care... directly to PWHIV?	Does your job (role) involve fundraising or managing contracts for the provision of social care ... to PWHIV?	Do you commission HIV services?
Charity / ASO **STAFF**	**98%** 161/164	**63%** 102/161	**0%** 0/164
Charity / ASO **VOLUNTEERS**	**100%** 40/40	**38%** 15/40	n/a
NHS **STAFF**	**46%** 54/118	**41%** 22/54	**37%** 44/118
Local Authority **STAFF**	**58%** 47/81	**20%** 16/47	**42%** 34/81
ALL **STAFF**	**72%** 262 / 363	**53%** 140 / 262	**21%** 78 / 363

There were PROVIDERS of social care, support or information services to people with HIV working in a variety of NHS contexts, in Local Authorities and in charities. When we discuss the PROVIDERS of service in all that follows, we usually mean all providers of service irrespective of their job role or the type of organisation in which they worked. When we refer to the provision of services from within the charitable sector we state this explicitly.

Among all respondents that worked in a job related to services for people with HIV, 23 (6%) answered *No* to the question on the provision of services and *No* to the question on the commissioning of HIV services. The vast majority (20 out of 23) worked in the NHS in strategic, policy or management roles but did not have a direct commissioning or provision role in HIV. These twenty were considered NHS providers, though they were not included in the questions on the funding or commissioning of services. The three charitable staff members that said they did not work for an organisation that was involved in direct service provision were also involved in strategic or policy dimensions of HIV service provision – they are included as charitable providers in all that follows.

2.2.1 NHS HIV commissioners

Of the forty-four NHS commissioners, five did not reveal which NHS organisation they worked for on the basis of concerns about anonymity. Of the remaining 39 respondents, 1 worked in Wales, 5 in Scotland, and 33 in England.

The 33 English Primary Care Trust staff commissioned HIV services on behalf of 54 English PCTs. Among the English PCT commissioners, two thirds (64%, 20 of 32) were the HIV Commissioning Lead for the PCT that employed them and three quarters (75%, 24 of 32) were the Sexual Health Lead for the PCT that employed them. Finally, 42% (18/31) were also Teenage Pregnancy Leads for the PCT that employed them.

Commissioners from five (of 14) Scottish NHS Boards were also represented among NHS commissioners along with one from a Welsh Local Health Board. We received no response from any NHS commissioning staff in the 4 NHS Boards in Northern Ireland.

Among the 44 PCT, NHS Board, or Local Health Board commissioners four did not disclose their job titles. The remaining 40 described 33 different job titles. Twelve (30%) of NHS HIV commissioners were public health professionals, including 3 *Directors of Public Health*, an *interim Director of Public Health* and an *Associate Director of Public Health*. Two others listed their job titles as *Consultants in Public Health* and three were *Public Health Specialists* – of these one specialised in *HIV Service development* and another in *Sexual Health*. The remaining two Public Health professionals were *Public Health Development Managers*.

Only eight (20%) of NHS commissioners stated that their job title included the words *commissioner* or *contracts*. Five stated that their job title was *Commissioning Manager* of which just one stated they were the *HIV Commissioning Manager*. Another one described their job title as *Commissioner* and another as *Commissioning Lead for HIV/Sexual Health*. Finally one described their job title as *Contract Manager HIV*.

Twelve HIV commissioners described their jobs as managers or co-ordinators, usually of sexual health services. Although 75% of English NHS commissioners were also PCT sexual health leads, just one described their job title *as Sexual Health Lead*. Of the remaining NHS commissioners, 3 had job titles concerning health promotion and another three were nurses.

HIV specialism was rare in the current job roles of NHS HIV commissioners. More than a quarter (27%) said *little* of their current job was concerned with HIV, and 60% said *less than half* their job was concerned with HIV. Only 20% of NHS commissioners said that *more than half, most* or *all* of their current job was concerned with HIV.

Among NHS commissioners 13% had been in their current job less than a year and 38% less than three years. One third (32%) had been in their current job more than 5 years. However, long-term experience of the HIV sector was the norm among NHS commissioners: 60% had worked in the HIV sector more than five years.

2.2.2 Local Authority HIV commissioners

Of the thirty-four Local Authority commissioners, three did not reveal which Local Authority they worked for on the basis of concerns about confidentiality. Of the remaining 31, 1 worked in Wales, 2 in Scotland, and 28 in England.

Among the 34 Local Authority (LA) commissioners two did not disclose their job titles. The remaining 32 described 25 different job titles. Less than a fifth (n=6, 19%) had the words commissioning or contracts in their job title and only half of these were HIV specialists. A much larger proportion (n=15, 47%) described their role as Team Manager or Service Manager or Team Leader. Again, those that were specific about the team they managed were not all HIV specialists.

A quarter of LA commissioners (n=8, 25%) were social workers, the majority of whom were HIV specialists. 7% (2 of 29) of English LA commissioners were also PCT Commissioning Leads for HIV and 3% (1/29) were PCT Sexual Health Leads.

HIV specialism was not the norm in the current jobs of LA commissioners. Almost half (45%) said less than half of their current job was concerned with HIV. Among LA commissioners 9% had been in their current job less than a year and 42% less than three years. One third (30%) had been in their current job more than 5 years. However, long-term experience of the HIV sector was relatively common among LA commissioners: 45% had worked in the HIV sector for more than five years.

2.2.3   NHS HIV service providers

Of the 74 NHS providers of services, one did not reveal which NHS organisation they worked for. Of the remaining 73, 2 worked in Northern Ireland, 2 in Scotland, and 69 in England. Overall 60 different NHS organisations were represented.

Among the 74 NHS providers three did not disclose their job title. The remaining 71 described 59 different job titles. Half (49%, n=36) had jobs or roles in the provision of clinical services. Included were 24 nurses, 6 consultants, 5 psychologists and 1 senior occupational therapist. The majority of nurses were HIV specialists including clinical and community nurse specialists.

The remainder of the NHS providers were split between those that played a managerial, strategic or planning role (30%, n=22) and direct contact workers (21%, n=15) usually concerned with (sexual) health promotion; community development or social care.

None of these NHS providers were also commissioners of HIV social care, support or information services, but 30% (n=22) of those working in England were designated Sexual Health Leads for their PCT and 11% (n=8) were the Teenage Pregnancy Leads for their PCT. Most, but not all of these PCT leads held managerial, strategic or planning roles.

HIV specialism was relatively common among NHS providers. Over a third (39%) said most or all of their current job was concerned with HIV, but a similar proportion (38%) said less than half, little or none of their job was concerned with HIV.

Among these NHS providers, 12% had been in their current job less than a year and 36% less than three years. However, long-term experience of the HIV sector was the norm among NHS providers: 70% had worked in the HIV sector for more than five years.

2.2.4   Local Authority HIV service providers

Among the 47 Local Authority (LA) providers all disclosed where they worked. The 47 responses came from staff of 37 Councils: 5 respondents from 3 Councils in Scotland, 3 respondents from 3 Councils in Wales; and 39 respondents from 31 Councils in England.

All 47 Local Authority providers disclosed their job titles. More than half (57%, n=27) were social workers or support workers (6%, n=3). The bulk (23%, n=11) of the remainder were care managers, service managers or care co-ordinators.

HIV specialism was the norm in the current jobs of LA providers. Two thirds (65%) said most or all of their current job was concerned with HIV, and only a fifth (21%) said less than half, little or none of their job was concerned with HIV. Among LA providers, 11% had been in their current job less than a year and 43% less than three years. More than a third (41%) had been in their current job more than 5 years. Long-term experience of the HIV sector was common: more than half (55%) had worked in the HIV sector for more than five years.

2.2.5 Charitable & voluntary sector providers

164 respondents worked for a charity that provided social care, support or information to people with HIV. Six of these respondents declined to name the organisation they worked for. The remaining 158 respondents worked for 90 different UK charities.

Of those respondents that worked in the HIV sector, 32 also volunteered for a charitable organisation concerned with HIV, including 21 people who volunteered for an organisation other than the one they worked for (11 volunteered for the same organisation where they were employed). In addition 8 people **volunteered** for an organisation providing social care, support or information to people with HIV but did not work in the HIV sector.

Including both workers and volunteers, 111 different charities were represented as providers of HIV social care, support and information. They include the largest and smallest HIV-specific charities in the UK and other charities with a focus on population groups including specific migrant or minority ethnic populations, children and Lesbian, Gay and Bisexual populations. While the majority of organisations were based in England, representation from Wales (5 organisations) and Scotland (6 organisations) was reasonable. Responses from Northern Ireland were more problematic with only one HIV charity responding.

Of the 164 workers in the charitable sector only 1 did not describe their job title. Just under a third (29%, n=47) of respondents who worked for a charity probably held the most senior post in their organisation. Job titles included: *Director* (n=16); *Manager* or *General Manager* (n=16); *Co-ordinator* (n=8); *Chief Executive Officer* (n=6) and *Managing Executive* (n=1).

A similar proportion (33%, n=53) held senior positions usually concerned with managing specific aspects of service delivery or specific functions of the organisation. These jobs primarily concerned service management (n=20) or service co-ordination (n=13) but were also described as *Team Leader* (n=3); *Director of Services; Head of Services etc*. The remaining third (38%, n=63) worked in a range of roles primarily concerned with service delivery directly to people with HIV.

HIV specialism was the norm in the current jobs of charitable providers: almost three quarters (74%) said most or all of their current job was concerned with HIV. Among workers in charities half (49%) had been in their current job less than three years and a third (30%) had been in their current job more than 5 years. However, long-term experience of the HIV sector was common: two thirds (64%) had worked in the HIV sector more than five years.

Forty respondents volunteered for an organisation providing HIV social care, support and information. Among those (11) that worked and volunteered for the same organisation, volunteering roles operated as an extension of their paid work. Thus, individuals applied their particular skills to provide services that extended beyond the working hours or job roles for which they were formally responsible, and this was identified as voluntary work.

Long-term experience of the HIV sector was relatively common among volunteers: more than a third (38%) had volunteered in the HIV sector more than 10 years and two thirds (68%) had done so for more than five years.

2.3 WORK EXPERIENCE AND SPECIALISM

There were no statistically significant differences between how long workers had been in their current job and their role or organisational type – that is providers and commissioners had been in their current jobs for a similar length of time. Moreover, there was no relationship between length of time in the HIV sector overall and current job role or organisational type.

However, HIV specialism was considerably more common among HIV providers compared to HIV commissioners. This relationship held irrespective of the type of organisation worked for. For example, 53% of commissioners said *less than half, little or none* of their current job was concerned with HIV compared to 20% of providers.

How long have you been in that job?	% All workers n=358	% NHS commissioners n=40	% LA commissioners n=33	% NHS providers n=74	% LA providers n=47	% ASO providers n=164
<6 months	5.3	5	3	4	0	8
6-12 Months	8.4	8	6	8	11	9
1-3 years	29.6	25	33	24	32	32
3-5 years	22.6	30	27	20	17	23
5-10 years	19.3	15	18	20	28	18
10+ years	14.8	17	12	23	13	12
What proportion of that job is concerned with HIV?						
None or little	8.1	27	12	8	4	4
less than half	19.1	33	33	30	17	9
about half	9.6	20	12	11	7	7
more than half	8.7	10	12	12	7	7
most or all	54.5	10	30	39	65	74
How long have you been working in the 'HIV sector' overall?						
<6 months	1.7	3	3	1	0	2
6-12 Months	3.4	0	3	1	4	5
1-3 years	19.4	23	30	15	21	18
3-5 years	13.8	15	18	13	19	12
5-10 years	26.2	20	24	31	32	25
10+ years	35.5	40	21	39	23	39

3 Commissioning HIV services

Seventy eight survey respondents stated that they commissioned HIV services. Eight of these also took part in follow-up telephone interviews. In the first section of this chapter we consider the context of commissioning using the follow-up interviews. In subsequent sections we consider the commissioning of HIV social care, support and information in the authorities surveyed.

3.1 HIV COMMISSIONING IN CONTEXT

We have seen in chapter 2 that commissioners have a range of professional competencies and backgrounds and hold very different positions within their organisations. Our interview respondents included senior commissioners with many years of experience, former sexual health/HIV coordinators, public health and health promotion professionals and those from voluntary sector, education and social services backgrounds. Respondents discussed the desirability of long standing local knowledge on HIV versus extensive commissioning expertise.

> **There are two schools of thought that it's like commissioning apples and pears, it doesn't make much difference, it's the commissioning that matters. However, with an issue like HIV, [it's better] to have some kind of context within which to put one's decisions.**

However, some were concerned that local knowledge and familiarity with social and political issues surrounding HIV was sometimes seen as a replacement for commissioning expertise.

> **HIV / sexual health is [often] given to inexperienced commissioners. It's better to have the commissioning experience because ultimately if you know about commissioning you should be able to commission anything in an equitable and effective way.**

Commissioners' wide range of backgrounds, skills and perspectives was seen to inhibit the development of common practice or understanding around HIV commissioning. Moreover, the ways in which commissioning was organised in different English PCTs exacerbated this problem.

> **Commissioning is [an] odd structure that hangs between service delivery and finance [...] The differences between PCTs and commissioning structures make it difficult for people to talk to each other.**

Some whose remit was voluntary sector commissioning relied on colleagues who commissioned acute services for vital information on their budgets or to wield influence on their behalf.

> **...we've established a very strong relationship and it works. She commissions the acute trust and I commission from the voluntary sector. [...] She is very experienced in contract management, the agreements, how we influence them and how to deal with the acute trust. [...] To complement that, I am aware of our service users' issues. I do more of the qualitative performance management. I rely on her to influence.**

However, this type of commissioning support, joint working or access to expertise was not universal.

> **The people who [...] negotiate contracts with the acute trusts are not my immediate line managers. So we don't have anyone experienced we can go to, to tell us about looking at contracts, legalities** *etc.*

Differences in skill, seniority and perspective influenced the ways in which budgets were managed. Budgets were rarely set for the beginning of the financial year and an ability to anticipate a budget was considered essential, especially when social care, support and information budgets were derived from the remainder of acute HIV budgets. As social care budgets were often linked to (and threatened by) much larger HIV treatment and care budgets, those commissioners who had responsibility for both found it easier to negotiate and safeguard social care services.

> **The problem with social care is that the level of commissioning you are at is really important. Because I deal with the Chief Exec., I can say: 'If I bring [treatment and care] in on budget than I want 20K for that'. Very junior commissioners get told to make savings and don't argue back and you need to argue back quite strenuously.**

In contrast, others reported having insufficient access to information about overall budgets and little guidance either in the form of written policy or through professional structures.

> **Recently there's been an £18K underspend and I negotiated the use of that with finance. [But] the way that budgets are allocated is largely historical. We don't have a commissioning strategy or a local sexual health strategy. How do you know what your next priority is?**

HIV social care, support and information services were often commissioned jointly between a number of Local Authorities and NHS bodies. Because such services were difficult to describe and evaluate they were often seen as easy to cut. This was particularly common in consortium arrangements, so commissioners leading on joint commissioning arrangements were acutely aware of the need to maintain the 'buy-in' of their commissioning partners.

> **A lot of PR is necessary to keep [partner commissioning] agencies on board. More recently PCTs have become more aware of the amount of money they are spending. [...] If your treatment and care budget is out of control, you're going to have to cut your social care because politically you can't say: 'I'm not going to treat somebody'.**

The quality of joint commissioning depended on the relationship between NHS and LA commissioners and how Local Authorities managed their AIDS Support Grant (ASG), especially whether they chose to provide services internally, commission services externally or allow the NHS commissioner to manage the budget. Joint commissioning arrangements often influenced how HIV social care, support and information was commissioned. For example, some perceived it to be dependent on, or even coterminous with primary prevention.

> **We joint commission with social services for social care. [...] Social support is commissioned by social services [and] we put together social support and prevention because you can't do one without the other.**

Other NHS commissioners attempted to limit Local Authorities to providing social care and based decisions on social support and information interventions more clearly on local HIV epidemiology.

> **When I came into post, the Local Authority commissioned a counselling service that was faith-based and a women's and children's service primarily focussed at teenage work. Now I probably have one teenager in my borough and also in terms of counselling, the faith based aspect. I have 95% of my population as White Gay male.**

Others had tried to bring greater accountability into the process of Local Authority funding. The extent to which Local Authorities provided designated social care for people with HIV impacted NHS commissioning. Moreover, the increasing tendency of Local Authorities to 'mainstream' their HIV services into Adult Social Services and Housing services raised the interest of NHS commissioners. Respondents had a range of responses to mainstreaming. Some NHS commissioners worked to ensure that it did not happen.

> **I [got] the manager of [social services] to say that they would definitely be appointing an HIV social worker and housing officer because we know they are using the AIDS Support Grant for services and we need to see those services.**

Others were working to put interim services in place.

> **There's a proposal here to get rid of the specialised [HIV] team [in social services]. We would like to have a link worker who works with the generic team. We don't want to lose the specialism.**

There was considerable concern about how Social Services were responding to the increasing numbers of asylum seekers and migrants with HIV in the UK. The capacity of Local Authorities to respond to the needs of these groups was seen as very limited.

> **There are very strict guidelines [...] and sometimes the social worker is stuck and needs to refuse clients with great needs. This also causes conflicts with other support agencies because a nurse can say that someone needs to be assessed and Social Services comes back [...] saying that the legal status of this person doesn't allow us to do that.**

There was also a perception that generic Social Service departments were not sensitive to the complex needs of people with HIV who were asylum seekers or were destitute.

> **We're having a lot more disputes with Social Services about challenging them when they are not accepting people they would have in the past. [...] Obviously from health we have a different perspective on a whole group of people who Social Services feel they have no responsibility for but who have very complex needs.**

Some NHS commissioners expressed frustration at the attitudes of Social Services personnel to people with HIV and their lack of attention to the problem. NHS commissioners often saw the voluntary sector as stepping into the service gap left by Local Authorities.

> **[We are] pushing things to the voluntary sector for which the statutory sector is too rigid. Also voluntary sector can respond quicker and don't have to ask so much questions. For instance we had an underspend [and] we set up an emergency [hardship] fund. That has to sit within the voluntary sector.**

Others were attempting to counteract this dependency on the voluntary sector which they saw as inappropriate and / or propping up a system that was unfair or did not meet the actual levels of need that existed in the local population.

> **[Named charity] now have so many asylum seekers on their books, they now have the name as the agency that deals with the failed asylum seekers. I'm trying to quash that because it means they get dumped and they can't refer on.**

Most respondents were working towards rationalising social care, support and information services in order to ensure seamless delivery across clinical, statutory social and voluntary sectors. This was seen to benefit the user and to be more cost effective.

> **What we are doing locally [...] is to integrate all [...] HIV social services, all mental health, community support, voluntary sector – everything into one team with one management structure and one budget [which will] probably exist within community nursing within the new PCT. You will have one core team who will get referrals from three clinics.**

Although there was support for rationalisation and consortium commissioning, some were aware of the need to coordinate commissioning in order to maintain parity, equity and investment. This respondent talks of his PCT that has a large HIV positive Gay population, but a small BME / African population.

> **I would more than happily chip into a social care provision scheme for BME African people but it would have to be a small contribution because I have a small budget. For Gay men I would expect to contribute significantly more than [a PCT with a low Gay population]. We need equity of funding but also a methodology as to why you funded something to a certain level.**

We asked respondents about their relationships with and opinions of the charities they funded. Some were very supportive saying that the agencies had been the proactive partner in bringing about innovation.

> **We do have innovation but it's down to workers. We now have an adherence clinic run by our community nurse at our voluntary sector organisation. That innovation was from the community nurse and the organisation and the PCT agreeing it...**

However, some were critical both of charitable providers and other funders that commissioned them. Charitable providers were criticised for not offering services that (NHS) commissioners considered to be demonstrably effective.

> **Providers need to get real. They have to ensure that their services have throughput. They have to ensure that service users access their service as and when they need it rather than being a constant throughout their life. [...] They have to become a lot clearer about what their outcome is [and] do things in an evidence-based way.**

> **Sometimes the voluntary sector don't help themselves. Some of them don't grasp the necessity of being performance managed.**

Charitable providers were sometimes criticised for being overly dependent on statutory funding, although some commissioners acknowledged that this has been caused by the commissioning process itself.

> **...providers are so concerned about their own positions, they rarely produce a united lobbying front and I think that's a retrograde step and the commissioning process has caused that kind of fragmentation.**

However, others were critical of charities that sought other funding. They expressed a tension between seeing the charitable sector solely as providers of NHS services, or seeing them as community organisations with an independent voice and agenda.

> **They'll go off and get additional funding and they don't tell you anything about it and then you find that they're not delivering the service because they're so busy trying to deliver the other work.**

Some respondents described quite paternalistic relationships with charities.

> **I have a good relationship with providers. They come up with ideas and I listen to them but they don't always get what they want.**

Others try to avoid this role while attending to the need to improve charitable provider capacity and viability.

> **I refuse to do the 'Come to me with all your problems, I'm the fairy godmother'. Rather it's making commissioning procedures clear [...] For example [charities] have always been underfunded. [...] So what we've done is get them to a place where they don't need to come year on year. Everything they currently do is now costed and [...] they sit around the table like anyone else, so they're not treated like the poor relation.**

Although this is a small sample and information was obtained using a relatively brief interview, it gives us an idea of the conditions under which HIV social care, support and information services are being commissioned. The task of describing what these interventions are, the nature and extent of interventions commissioned and developing consensus on priorities was made difficult by huge variation in the ways in which commissioning worked. There are no standard job descriptions nor job titles for HIV commissioners. The position and perspective of the commissioner, internal pressures within the commissioning unit and the relationship between local commissioning agencies influenced the types of services commissioned. Moreover, there was a concern that the services that exist were not sufficient or appropriate to meet the growing social care, support and information needs of fast changing local populations of people with HIV. In the remainder of this chapter, we examine these issues in greater detail through the survey results.

3.2 BACKGROUND TO COMMISSIONERS' SURVEY RESPONSES

Seventy eight survey respondents stated that they commissioned services for people with HIV. Forty-four of these worked in the NHS and 34 for a Local Authority. In all that follows it is important to bear in mind that compared to providers, commissioners had both been in their current job and in the HIV sector a similar length of time. However, compared to providers (especially those in charities) commissioners were significantly less likely to be HIV specialists. Only 20% of NHS commissioners and 42% of LA commissioners stated that more than half of their job was concerned with HIV.

The majority (79%) of commissioners considered the geographic remit of the organisation they worked for to be local, though some considered that they commissioned regionally (21%). Considering their geographic remit to be regional was more common among NHS commissioners (30%) than among LA commissioners (10%). Those NHS commissioners that considered their geographic remit regional were more likely to work in NHS Boards in Scotland or across multiple PCTs in England. Those LA commissioners that reported commissioning regionally tended to work for County rather than City Councils.

3.3 PRIORITY TARGET GROUPS FOR COMMISSIONING

All commissioners were asked: *Is the organisation you work for concerned with the needs of particular groups of people with HIV?* Overall 38% said YES, including 35% of NHS commissioners and 42% of all LA commissioners. While NHS and LA commissioning bodies might be considered to have a statutory responsibility to attend to the needs of all groups of people with HIV equitably, answering yes to this question was not necessarily at odds with this responsibility.

Those commissioners who said the organisation they worked for was concerned with the needs of particular groups of people with HIV were asked: *Which specific groups of people with HIV is the organisation you work for concerned with?* The table below shows percentages of the entire sample giving each answer.

The third (38%) of commissioners that said they were concerned with particular groups of people with HIV usually rehearsed their priority population groups. These were based on HIV epidemiology and on the core responsibilities of the commissioning authority. The most common priority group was ethnic minorities with the majority citing *all ethnic minorities,* though some cited Black African or African people with HIV. The next most common priority was sexuality groups which always encompassed Gay men and Bisexual men but sometimes included other sexual minorities and / or heterosexual men and women. These priority population groups were firmly based on national HIV epidemiology.

Which specific groups of people with HIV is the organisation you work for concerned with?	% ALL commissioners	% NHS commissioners	% LA commissioners
specific ETHNIC groups	31	35	26
specific SEXUALITY groups	28	35	19
Carers of people with HIV	24	19	29
Drug users (and/or ex-users)	22	22	23
Sex workers (and/or their clients)	21	24	16
specific MIGRANT groups	21	22	19
specific AGE groups	19	16	23
Prisoners (and/or ex-prisoners)	15	16	13
a specific GENDER	12	11	13
Trans-people	6	5	7
other groups (say which)	2	0	3

While the differences between the responses of LA and NHS commissioners were not statistically significant, they remain instructive. In rank order the five most common priorities of NHS commissioners were: ethnic minority and sexuality groups (predominantly Gay men, equal first); sex workers (third); and migrant groups and drug users (equal forth). All five of these groups figure prominently in national epidemiology and are the groups most likely to acquire HIV.

Among LA commissioners the five most common priorities were carers of people with HIV (first); specific ethnic groups (second); drug users and specific age groups (mainly young people, equal third); and migrants and specific sexuality groups (equal fifth). This rank order reflects a fundamental concern for social (rather than medical) care and is not based so clearly on the epidemiology of HIV. Prioritising first, carers of people with HIV was especially instructive, as this is not a group that receives much HIV-specific service provision (especially from charities). It is also notable as the question asked directly for priorities among the population of people with HIV and technically their carers was not an appropriate answer.

3.4 INVESTMENT IN HIV SOCIAL CARE, SUPPORT AND INFORMATION

All commissioners were asked a range of inter-linked questions concerning their investment in HIV social care, support and information over the last three years generally and in 2005-06 specifically. To contextualise reported changes in commissioning, we also asked all commissioners a single question on changing investment in HIV clinical care over the previous three years.

All commissioners were asked: *Thinking about your authority's commissioning over the last 3 years, how has the total spend on HIV clinical care services changed?* Among NHS commissioners more described an increase (57%) in investment in HIV clinical care than a decrease (6%) over the last 3 years, though a further third (38%) described no change. The disparity between these proportions is large and significant. It is worth noting that no NHS commissioners said they *didn't know* or failed to answer this question. No definition of clinical care was provided, and as a consequence Local Authority commissioners did not respond to this question in a uniform way. More than half (53%) felt the question was not appropriate as Local Authorities were only concerned with social care. Among the remainder the same number reported a decrease (10%) and an increase (10%) in investment in HIV clinical care over the last 3 years, but the most common answer (21%) was investment *stayed the same.*

Change in investment in HIV CLINICAL CARE in the last 3 years	% NHS commissioners	% LA commissioners
Increased dramatically	19	5
Increased somewhat	38	5
stayed the same	38	21
decreased somewhat	3	5
decreased dramatically	3	5
DON'T KNOW	0	5
NOT APPLICABLE	0	53

Turning to HIV social care, support and information all commissioners were asked: *Thinking about your authority's commissioning over the last 3 years, how has the total spend on social care, support and information services for people with HIV changed?* Among NHS commissioners more described a decrease (22%) in investment than an increase (17%) over the last 3 years. However, the most common answer (46%) was investment stayed the same. It is worth noting, however, that a sixth of NHS commissioners either said they didn't know (8%) or failed to answer (8%). While some of those that did not know or did not answer had been in post less than 3 years, most had been in their current job considerably longer.

Among Local Authority commissioners less described a decrease (16%) in investment than an increase (19%). However, the most common answer (45%) was investment *stayed the same.* Almost a fifth of LA commissioners either said they *didn't know* (3%) or failed to answer (16%).

Change in investment in HIV SOCIAL CARE, SUPPORT and INFORMATION in the last 3 years	% All commissioners	% NHS commissioners	% LA commissioners
Increased dramatically	3	3	3
Increased somewhat	15	14	16
stayed the same	46	46	45
decreased somewhat	16	19	13
decreased dramatically	3	3	3
DON'T KNOW	6	8	3
NOT ANSWERED	12	8	16

There was no significant difference between the answers of LA or NHS commissioners. More surprising perhaps, there was no substantial trend towards reductions in investment in HIV social care, support and information (at least not among respondents to this survey). The proportion of all commissioners who chose not to answer questions on changes in investment (12%) or stated they did not know (6%) was also worthy of note.

We also asked all commissioners: *In 2005-06 how many agencies did you commission HIV social care, support and information services from?* More than a quarter (28%) of all commissioners could not or would not answer this question, including 22% of NHS commissioners and 36% of LA commissioners. The table below highlights the number of contracts awarded by all commissioners and the number awarded by NHS and LA commissioners separately.

In 2005-06, on average, NHS commissioners contracted for HIV social care, support and information services from 3 agencies (mean 5.5, standard deviation = 5.5, range 0-20). On average LA commissioners contracted for HIV social care services from 2 agencies (mean 4.6, standard deviation = 6.3, range 0-20).

Number of contracts awarded to provide HIV social care, support and information in 2005-2006	% ALL commissioners	NHS % commissioners	% LA commissioners
DON'T KNOW or NOT ANSWERED	28	22	36
NO agencies contracted	4	5	3
1 contract	15	14	16
2 contracts	13	8	19
3 contracts	12	19	3
4 contracts	3	3	3
5 contracts	4	5	3
6 - 10 contracts	10	11	10
11 - 15 contracts	5	5	3
16+ contracts	6	8	3

The table demonstrates that the majority of HIV commissioners contracted for HIV social care with relatively few agencies. In 2005-06, 4% awarded no such contracts; 15% awarded one; 13% awarded two; and 12% awarded three. If we exclude those commissioners that did not or could not answer, 60% contracted with three or less agencies to provide HIV social care, support or information in 2005-06. While the sample sizes were not sufficient to demonstrate this unequivocally, it appears that those commissioners in more rural areas, and in areas of lower HIV prevalence contracted with substantially fewer providers compared to those in larger metropolitan areas and areas of higher HIV prevalence. In Inner London, in particular, commissioners contracted with considerably more agencies.

We also asked all commissioners to: *Please list those agencies you commissioned HIV social care, support and information services from in 2005-06. Where possible, please give an approximate yearly contract value (£000s) for those services.* Answers to this question were limited and of very variable quality. In particular those commissioners with a higher number of contracts answered it with limited detail or not at all. Those involved in consortium purchasing often found it impossible to disaggregate precise costs and contract values. Some cited their overall spend, others their overall spend in the voluntary sector. A few included investment in Hospital Trusts or Genito-Urinary Medicine (GUM). No commissioner with more than five contracts actually listed the contract holders and precise values and on this basis a robust analysis of individual contracts was not possible. Given that answers were so limited and the data quality was so poor, we undertook no further analysis.

3.4.1 Services LOST in the last three years

All commissioners were asked: *What HIV social care, support and information services were your authority commissioning 3 years ago that are <u>NO LONGER</u> being commissioned today?* Among NHS commissioners, 19 of 44 did not answer the question, including 11 who had been in their current job more than 3 years. Of the remaining 25, more than half (52%, n=13) reported no changes in services commissioned over the previous 3 years. Two others stated that while no major changes had occurred to date, they were in the process of reviewing commissioning strategy or policy and that changes were likely in the near future. Some commissioners reporting no change did reflect that there had been major changes in the commissioning of clinical care during that time period.

> **No great changes in services. Main changes have been the rise in the treatment cost as increasing numbers of people are receiving treatment (and more complex and expensive treatment). The increase in treatment costs has been met by taking money from the prevention budget (how crazy is that!).**

Of the other half (48%, n=12) of NHS commissioners who described reductions in services in the last three years, two thirds (n=8) mentioned cutting all funding to specific charities or cutting specific interventions or types of service provision. Contracts cited as having been cut included:

- Body Positive support service.
- Services of local positive support group.
- Numerous local community organisations that provided prevention and support services.
- HIV prevention work via local Gay Switchboard.
- Voluntary sector help-line.

Reasons given for withdrawal of all funding from an organisation often concerned perceptions of substandard or inappropriate service provision and poor management of contracts.

> **Failure to provide adequate and quality services over a period of time led to withdrawal of funding.**

In some cases commissioners explained that similar contracts had been negotiated with other agencies or services had been otherwise re-configured. Cuts to specific services included: a transport service for BME service users of a drop-in service; an African Forum; a buddying programme; and domiciliary care. In these cases reasons tended to concern limited or falling demand. However, one commissioner reflected that it was not cost effective to commission many organisations delivering the same intervention to different community groups. Another re-iterated that changes had been made:

> **Following community consultation and a review of commissioning intentions [the] current programme is designed to best meet emerging need.**

In summary, about half of NHS commissioners reported their authority had made cuts or changes in social care, support and information services for people with HIV in the previous 3 years. No NHS

commissioner expressly mentioned the need to save money as a rationale for service cuts. Reasons for reduced service provision fell into 3 broad categories: changes in need usually resulting in a lack of demand for existing services; rationalisation / restructuring to reduce duplication and improve planning; and substandard or unacceptable service provision.

Among Local Authority commissioners, 18 of 34 did not answer the question on cut or lost services at all, including 10 who had been in their current job more than 3 years. Of the remaining 16, more than two thirds (69%, n=11) reported no changes in HIV social care, support and information services commissioned over the previous 3 years. Two of these reported current reviews of social care that might impact future commissioning.

Of the five commissioners offering substantive survey responses regarding services that had been reduced or cut only two mentioned cuts to grants for specific charities – one LA reported that a reduced grant offer was refused by a large charity they had previously supported; and another transferred funding away from a national agency as local capacity improved and demand increased.

Three others mentioned changes in the way interventions had been commissioned – one LA had previously funded nursing care, responsibility for which had now been transferred to the local PCT, as per NHS PCT Regulations. Another had recognised that a specific African faith group they had funded was using the money to undertake HIV prevention which they supported but felt was an inappropriate use of their AIDS Support Grant. Another LA had cut support for a housing association concerned with HIV when their own Supporting People Team was formed to take responsibility for housing support to vulnerable groups, and they prioritised people with HIV.

> **[...] conditions have changed in acute [services] over last few years as medical support and treatment has changed – now [HIV is] a more chronic condition – not appropriate or practical for one worker to know all parts of social work and therefore to take on all cases.**

3.4.2   NEW services commissioned in the last 3 years

All commissioners were also asked: *What HIV social care, support and information services are your authority commissioning NOW that they were not commissioning 3 years ago?* Among NHS commissioners, 23 of 44 did not answer the question at all, including 15 who had been in their current job more than 3 years. Of the remaining 21, two thirds (62%, n=13) reported no changes in services commissioned over the previous 3 years. Again some of those that reported no change were keen to emphasize the adequacy of their current commissioned work.

> **No new services, we have just expanded and developed the services we already commissioned.**

Just over a third (38%, n=8) of NHS commissioners cited a new service or HIV social care, support or information contract that had arisen in the last three years. Among these, two concerned new commissioning of *living well* services; and another three concerned increased provision for Black African people with HIV (including children and families). All these new services were commissioned from the voluntary sector. Three other commissioners reported increased investment in HIV-specific posts within their PCT- one in domiciliary care and another in mental health support. The third reported investment in an HIV-specific community nurse specialist to work with positive patients regarding treatment information and compliance and positive prevention.

Among those NHS commissioners that described new services commissioned in the last 3 years only two identified the reason being "changes in need" or "new needs arose". The remainder described changing structures, new strategies or changing patterns of funding as drivers for service innovation or service development. No NHS commissioner cited increasing investment as the reason for commissioning additional services.

Among LA commissioners, 12 of 34 did not answer the question on new services commissioned in the last three years including 8 who had been in their current job more than 3 years. Of the

remaining 22, half (50%, n=11) reported no changes in HIV social care, support and information services commissioned and one was unsure as they had only recently come into post.

There was very little substantive information on new services commissioned by Local Authorities. Ten commented on specific new commissioned services over the last three years. Of those who highlighted new services, 4 mentioned commissioning charities to deliver increased levels of social care, support and information. Expansion of existing service was mentioned by three respondents. New services included additional written information (on treatments information); increased peer support and individual advice and support. A small number of LA commissioners (n=2) described increased user involvement in the planning and delivery of services and one described new services based on a regional needs assessment. Unlike NHS commissioners, LA commissioners rarely mentioned an increase in services for particular target groups.

3.4.3 Commissioners' wish list

All commissioners were also asked: *What additional services would you commission if your budget allowed?* Among NHS commissioners, 19 of 44 (43%) did not answer the question and 2 answered *none* or *nothing*. Among the remaining 23 (52%) NHS commissioners the most common response was a desire for additional targeted services (n=7). Five mentioned the need for more and better services for African people and two mentioned specific services for Gay men (especially those not on the commercial scene) and one for increased support for young people living with HIV.

Other aspirations for more social care for people with HIV, included general and specific social worker support, peer support and specialist advice (n=5). Some mention was also made of *living well* programmes, back-to-work projects and provision of immigration advice, as well as the provision of transport for those who needed it. A couple of NHS commissioners aspired to more mental health related provision and more clinic-based workers. There was no obvious pattern or over-riding theme to these requests and it is worth noting that a number of NHS commissioners aspired to education interventions more commonly associated with primary HIV prevention, especially outreach and schools-based work. Only two NHS commissioners mentioned structural interventions – one referring to anti-stigma and discrimination and the other aspired to a better evidence base and changes in NHS policy.

Among LA commissioners, 13 of 34 (38%) did not answer the question concerning the additional services they would commission if their budget allowed. Among the remaining 21 (62%) the two most common responses (n=7 in each) referred to provision of services for particular target groups, and increasing capacity in pre-existing services. Unlike the NHS commissioners the most common specific target group where more services were considered necessary was women/ family/ children and youth services (n=4). Three LA commissioners mentioned Black African people with HIV (or asylum seekers) and one mentioned men who have sex with men.

Of those who mentioned overall increases to capacity, three mentioned support groups, and four mentioned individual support through advocacy, advice and social work. Other areas mentioned included a desire to fund more *living well* and complementary therapy programmes, welfare and benefits advice provision, employment and training programmes and respite provision. The remaining aspirations concerned expansion of existing services and interventions.

As with the NHS commissioners there was no dominant theme among the aspirations of LA commissioners. Priority targets pre-dominated with women, family and children's services proving more common an aspiration than among NHS commissioners. There was some consensus that Black African and BME people with HIV required additional and specialist services, perhaps especially refugees, those seeking asylum and those with no legal right to remain in the UK. Gay men with HIV did not figure in the aspirations for service development of either NHS or LA commissioners of social care, support and information to people with HIV.

3.5 SUMMARY: COMMISSIONING HIV SERVICES

- **HIV is not a political or policy priority, either nationally or locally.**

There is no government target against which NHS or Local Authority performance is measured that has any direct relationship to HIV prevention or social care, support or information for people with diagnosed HIV. Local targets concerning HIV are very rare as a consequence.

- **The NHS is (always) in crisis.**

Many NHS commissioners feel their priority is to save money not spend it – PCT deficits and HIV treatment costs figure prominently in commissioning decisions – more prominently than need in many cases. However, large scale decreases in the scale of funding for HIV social care, support and information were not proven.

Some NHS commissioners were far more actively involved in the monitoring and removal of contracts than commissioning new services. Many report pressure from finance departments to reduce overall HIV spend at a time when drug costs and rising prevalence make this impossible.

The ending of ring-fenced HIV funding is now having a profound effect as the NHS undergoes restructuring. The priority among commissioners is to safeguard services they have historically funded.

HIV social care, support and information services are often seen as secondary to larger treatment and care budgets. They are constantly under threat and their survival depends on the negotiating powers of commissioners.

Charitable service providers are under increasing pressure to fill the service gap caused by increasing mainstreaming of Local Authority services.

- **Unitary concepts of HIV commissioners or HIV commissioning are not helpful.**

"HIV commissioners" occupy a range of job roles, have a range of backgrounds and skills and are rarely HIV specialists. Many have multiple other priorities and roles.

Many "HIV commissioners" care passionately about HIV and see themselves as advocates for services in a hostile political environment.

- **HIV commissioning is neither art nor science.**

Many commissioners have a background in HIV services rather than commissioning.

Few have received any formal training and many receive no ongoing support.

Expertise in service development is not a common skill among commissioners – nor is it a priority – many feel that it is the job of providers to innovate.

Many commissioners struggle to describe what they purchase and simply revert to describing the agencies that they fund rather than the interventions.

The most common reason for funding a service is historical precedent. Funding roles forward year-to-year unless poor performance (or fall in demand) allows it to be cut. On average, commissioners had 3 contracts for HIV social care, support and information in 2005-06.

While many commissioners are trying to move away from grant-giving to commissioning services that are needed, monitoring of services is often absent and usually poor when it is present.

Needs-led commissioning against strategic aims and objectives is very rare. Most commissioners fund what agencies offer to provide. Tendering of services is rare.

4 Providers of social care, support and information

4.1 HIV SERVICE PROVISION IN CONTEXT

Our follow-up telephone interviews with managers of charitable organisations were intended to help us describe the funding environment and challenges with strategic planning of HIV social care, support and information to people with HIV. The consensus among the ten charitable providers interviewed was that it was becoming increasingly hard to manage an HIV charity because of pressure on income combined with rising HIV prevalence. Some also noted that HIV was slipping down national and local agendas as its political profile receded.

> **Well generally the feeling is that it is becoming harder and harder to manage an HIV organisation mainly because the support infrastructure for HIV services is crumbling very fast. There is unsaid complacency which you can almost feel, that people think that HIV is not a problem anymore. We know that is not the case, because people are still dying. You know just last week I buried one of my clients. So HIV is still a problem especially within the African communities.**

Some felt that the lack of attention to HIV was caused not so much by an absence of national policy, but an absence of priority for HIV within policies that existed to address broader issues.

> **If you look at a lot of the policy in place and the rhetoric given by the government and the Department of Health we should be quid's in. You know the whole stuff around communities taking responsibility for their health, doing something for themself *etc*. being evidence based, user involvement – the whole, kind of, volunteer agenda, blah, blah [laughs]. One would expect, given that we do all of that, that any applications or contracts that we go for would fall in our lap and they don't.**

Others felt that existing (Department of Health) policy was adequate but that its implementation was not a priority for PCTs.

> **... I'm 99% sure that the problem is that whilst policy is issued, there is no method which ensures the policy is being followed.[...] The major issue is that there is no method by which either the government or the NHS or the Department of Health can enact their strategy. Their strategy is fine, looks great!**

This lack of political priority attached to HIV was perceived to be caused (or compounded) by the assumption that the need for HIV social care, support and information interventions had substantially receded with the advent of successful anti-HIV therapies. Respondents were at pains to counter this perception, especially since prevalence was rising and as a consequence they were struggling with an ever larger number of service users.

> **... in 2000 we had just under 500 service users, around five years later we had about 1,500, you know what I mean? The number keeps rising, so even if the funding is relatively stable, the demand is more high.**

This rise in prevalence also includes service users with complex care and support needs.

> **I am getting really pissed off with the growing assumption, amongst statutory funders anyway, that everyone with HIV is OK now and they are all going back to work or going to the gym [...] But there's a hard core of 10-20% that have other issues that compound the HIV stuff, like mental health issues, self-esteem, social exclusion, blah, blah, blah. And I don't know, a lot of statutory people seem to be forgetting about them and think it's all about moving people through and getting them back to work.**

Organisations still experience the death of service users as a consequence of illnesses arising from their HIV infection. In addition to this, the range of social care, support and information interventions that agencies were able to receive funding to provide could not, and did not, meet all the needs of all their potential service users.

> So it is particularly hard, and some of our, certainly in our African counselling service we have had at least one client a month who dies. And that is very difficult for everyone. And it's a different kind of thing, the experience of that today, and the experience of that in memory from kind of 20 years ago, because we don't want to think anyone should die today.... and that the answer somehow is to give them an expert patient course and they'll be fine. It is just very strange, and I think all those expert patient things, that is all a move in the right direction, but there are people really left behind and left out, actually.

Faced with a changing epidemic and in the absence of major public priority being attached to HIV, many respondents felt that funding for their organisation was getting more difficult to obtain and retain. Many felt that the long-term sustainability of their organisation was currently under threat.

> What we have at the moment is a realistic fear that we, unless some kind of miracle happens, that we might not survive for the next two years, and that is a realistic fear. [...] Because the last three years, we experienced a massive cut, especially in our core funding... And despite the best efforts we had done by cutting back on our expenditure from rent to management costs to deleting posts, still we have a problem, and that problem has refused to go away.

Financial difficulties were particularly acute for those agencies that historically had received the bulk of their funding from NHS commissioners. While some felt that the wider funding crises in the NHS was the root cause of this problem, others were experiencing severe disruption to on-going contracts because of the current round of re-structuring in both the NHS and Local Authorities. These problems were exacerbated by the historic loss of ring-fenced HIV monies and changes to AIDS Support Grants, both of which made HIV organisations more at risk from financial crises among their funders.

Respondents were concerned and irritated about the amount of time they spent attending to constantly changing commissioning requirements rather than their client's needs.

> The procurement and commissioning processes for our services are incoherent, nobody's managing the process. There are multiple funders. The funders from the health care and social care sectors keep having massive re-organisations of one kind or another... And examples of those re-organisations would be formation and reformation of PCTs, and the re-organisations of social services departments into social care departments, and then the split between adult care and child care services. And every time one of those re-organisations happens, we are on the receiving end of it, having to repackage, rebrand, reshape, reprice, redescribe our services in response to changes on the part of the commissioning or procuring body. And the changes happen really quickly, and several of them happen at the same time. We have eleven different local funders, each of them has a different agenda, a different pot of money with a different description and [...] different restrictions on it.

Since NHS (and LA) voluntary sector budgets had reduced, many were also finding NHS commissioners were increasingly specific about the kinds of social care, support and information they would fund for people with HIV. While this might be justifiable in strictly economic terms, it was perceived to be a significant shift in attitudes to funding from a few years previously.

> ...some funders are [...] sort of cherry picking: *I would like this, I want that, but I don't want this, and I want it done in this particular way.* And that sometimes might be at odds with your ethos and the way that you would want to work as well. So to a certain extent the power base is imbalanced, really.

In this context some organisations remained able to fundraise for the specific costs of interventions but found it difficult to cover the core costs of their agency.

> Core costs. That is a fundamental, we face that issue of being able to get project costs, and, what was that term? 'whole cost recovery' ... Is still a major issue, because you can't keep an organisation going without that infrastructure, and often that infrastructure is not fundable under a lot of project costs.

In the midst of such anxiety about NHS (and LA) commissioning of social care, support and information services, relationships with individual commissioners were very variable. Some respondents reported a close and supportive relationship with their key commissioning contacts, whereas others had little contact and even less meaningful dialogue.

> I think they are my closest allies. That is how I think of them. It can be very frustrating, the relationship, I think at the moment a lot of them are quite powerless. I think within London there's only a handful that are effective, so I can have a very good relationship with a very nice person who really cares and knows and is interested in what we're doing and in what clients are saying, and they are completely ineffective. And so it's not an effective relationship but it's a good one.

> Pretty poor is the nature of the communication... and then either just roll things over.... And then on the other hand they just suddenly pull something when they say they're not interested. You know it's not based on much evidence really. That's the truth of it ...

Others complained about delays in the agreement of ongoing funding or the lack of Service Level Agreements, when funding had been agreed.

> [It was] July before we were informed what our funding levels were [...] Three months into a 12 month programme. And now we find out that we haven't got all the money we thought we had, we can't do all the outputs so we have to re-plan. It's just ridiculous, frankly. [...] And I think where it really hurts is that because we went through a competitive tendering process, all our margins were slashed anyway... That's really frustrating when you try and do stuff to maximise output to be as efficient as you can, and then you have to throw all of that out of the window. Nobody cares.

Where funding continued to be agreed and received, there were substantial and common concerns about the burden of monitoring attached to contracts from a range of sources.

> ...if it carries on like this, it won't be very long at all before we spend 50% of our money on admin and monitoring and only 50% on direct service provision, in fact less than 50% on direct service provision once you take off overheads.

> For the 10 grand or so we get off [our Local Authority], the monitoring requirements are a joke! [...] and sometimes I am tempted to tell them to stick the money.

In addition to an ever growing burden of monitoring some respondents reported commissioners using the lack of evidence as an excuse to avoid decisions about proposed service development.

> The commissioner says, well, where is the evidence? And yet, [research has produced] masses of evidence. That there is so much needs for African communities which are not being met. You have got a commissioner saying where is the evidence? Come on! Every day we are generating the evidence! ... although this evidence is out there, I would just say it is a lack of political will.

The survey data suggests that major service development and innovation emerges mainly from the providers of HIV social care, support and information. While some respondents bemoaned their own (and others) lack of a strategic over-view of all services available, this was especially problematic in London.

> We do I think still have lots of duplication, and we have unequal access, and unequal provision. And yet we have no kind of comprehensive overview. I think there is a problem for innovation because I don't know, when I get a good idea, am I innovating or is that actually already being provided around the block by somebody else brilliantly?

Ideas for major service innovations emerge from formal research, from providers' understanding of the services offered by others and from discussing the needs and views of pre-existing service users. Many respondents outlined their long-term commitment to understanding the needs of their service users, through regular service user forums and intermittent service user consultation. Some recognised that they needed to invest more time in ensuring the voices of their users were heard and made a difference to service provision. Others recognised this posed a particular challenge as funding restrictions made it difficult to meet all the needs articulated.

> **I would say it is service user need and what we can realistically provide. Because there is no point, I mean we can, service users can request for any number of things to be provided. It is being realistic about what you can provide and what will benefit them and the organisation.**

Service user consultation without the capacity to respond meaningfully to articulated needs was considered especially problematic when commissioners insisted on consultation processes but then were not interested in implementing the outcomes.

> **When you ask clients what they want and their feedback is about services, and involve them in the planning of services that rarely meets what comes from the other direction of what commissioners or charities have decided their priorities are for funding. And even though they all want service users' involvement, it is very difficult to respond to that in terms of resources. I find that a big challenge, in terms of keeping people involved when they say: 'What is the point of saying this? We said it before and nothing ever happens'.**

Linked to these concerns many respondents reported frustrations about their capacity to innovate and improve service provision in response to users' need. Some complained that commissioning processes were not designed to foster innovation, as NHS (and LA) funders were more willing to roll-over and sustain pre-existing agreements than they were to consider service development. Conversely "non-statutory" funders were willing to invest in innovation and pilot interventions but less willing to invest in their subsequent sustainment.

> **The statutory funders are keen to support some things that you get into a bit of a treadmill of wanting to sustain all the time because the income is good, and the non-stats pull the funding very quickly because they have sort of funded it once, and you are sort of caught in between the two sometimes, and that can be a bit problematic.**

The need for innovation that was most often cited as problematic was in relation to asylum seekers, especially those who had failed in their asylum application. Here, in particular, many respondents had recognised the need to develop new and challenging interventions but most core funders (especially from Local Authorities) were unwilling to fund these interventions.

> **15% of our service users are living on nil income. And [...] 25% are seeking asylum, so they have got multiple complex needs. [...] Our funders are saying: *we will not pay for any services for those people. You are gonna have to do that through your own fundraising.* So they're actually asking us to, and this is where the monitoring gets more complicated, find ways of proving to them that none of them individually are paying for services for these people, and we're magic-ing the money from somewhere else.**

Some organisations had re-prioritised their services and strived to ensure that charity fundraising supported the activities that the NHS or Local Authorities could not.

> **We structured our services quite a few years ago so that there are some, like the hardship fund and the food bank and complimentary therapies, where we've never had any statutory funding, we don't expect any statutory funding. Those particular services are entirely run on donations, fundraising and mainly charitable trust fund applications. And that is sustainable, if everything else fell away, we could keep on doing that.**

Others had shifted the entire balance of funding for their organisation away from NHS and Local Authority sources and felt considerably more secure as a consequence.

> **I think agencies need to think creatively [and] not expect the same old funding from the same old places. We don't do that and we seem to do OK. [But] we are very specialist, so it's easy for me to say. I've never restrained myself to purely HIV funding. I have always looked beyond that to funding that had BME priorities, or older people priorities, or women priorities, or whatever. And you know, HIV falls into that great social exclusion catch-all. [...] I would imagine we are one of the least statutory funded HIV organisations in the country now.**

4.2 BACKGROUND TO PROVIDERS' SURVEY RESPONSES

164 respondents to our online survey worked for a charity providing social care, support or information to people with HIV. Of those that worked in the HIV sector, 32 also volunteered, including 21 people who volunteered for an organisation other than the one they worked for. In addition 8 people volunteered for an organisation but did not work in the HIV sector. Including both workers and volunteers, 111 different charities were represented as providers of HIV social care, support and information. In the remainder of this chapter the unit of analysis is the organisation providing service rather than the person completing the survey. Hence, responses from charitable workers and volunteers are presented together and, for the 23 organisations represented by more than one staff member or volunteer, answers have been merged. That is, one answer has been extrapolated from all the information received from that organisation. Where there was any conflict between the answers received from a single organisation the answer from the most senior staff member (or volunteer) was used. This problem was unusual – in most cases multiple responses from the same organisation were in consensus. Where multiple text-based answers were received, duplication has been removed but additional detail has been retained.

The majority of NHS and Local Authority organisations represented in the sample of providers considered the geographic remit of their organisation to be local (76% of NHS providers and 92% of LA providers). Among the charities a third (31%) considered their remit local and a similar figure (29%) considered it regional. However, 36% of the charities considered their remit national, though many of these also worked at a regional and local level.

What is the geographic remit of the organisation you work (or volunteer) for? (% of all provider organisations)	% NHS providers	% LA providers	% ASO providers
Local only	76	92	31
Regional only	12	8	29
Local & regional	8	0	<1
National only	2	0	20
Regional & National	0	0	6
Local & regional & national	2	0	2
International only	0	0	3
International & national	0	0	4
International & national & regional & local	0	0	4

4.3 PRIORITY TARGET GROUPS FOR PROVIDERS

All providers of HIV social care, support or information were asked *Is the organisation you work for concerned with the needs of particular groups of people with HIV?* Overall 42% of all providers said YES, including 30% of NHS providers, 39% of all Local Authority providers, and 50% of those working or volunteering in a charity providing services. Those providers who said the organisation they worked for was concerned with the needs of particular groups of people with HIV were asked *Which specific groups of people with HIV is the organisation you work for concerned with?* The table below shows percentages of the entire sample giving each answer.

Which specific groups of people with HIV is the organisation you work for concerned with? (% of all provider organisations)	% ALL providers	% NHS providers	% LA providers	% ASO providers
specific ETHNIC groups	23	24	20	23
specific SEXUALITY groups	22	25	20	22
Carers of people with HIV	14	13	13	15
specific MIGRANT groups	14	19	17	10
specific AGE groups	12	13	11	11
Drug users (and/or ex-users)	11	13	9	10
Sex workers (and/or their clients)	11	19	7	7
a specific GENDER	10	8	13	11
Prisoners (and/or ex-prisoners)	7	13	7	3
Trans-people	4	5	4	5
other groups (say which)	7	2	11	9

The majority of *other* responses concerned families, especially families with children, though a range of other populations were mentioned including people with haemophilia, people with mental health problems and those with alcohol and drug dependancy problems.

Those 42% of providers that said they were concerned with particular groups of people with HIV usually rehearsed their priority population groups. The two most common groups were ethnic minorities and sexuality groups (both cited by more than half of those that prioritised any groups). The majority of providers citing specific ethnic minorities described the group as *all ethnic minorities,* though some cited African people with HIV. Others cited "mostly Black African with increasing numbers of African Carribean" people; South Asian people were also cited by a couple of providers. The next most common priority was sexuality groups which always encompassed Gay men but sometimes included other sexual minorities and / or heterosexual men and women. These priority population groups were firmly based on national HIV epidemiology.

In rank order the next three priorities were carers of people with HIV (third); migrant groups (forth) and specific age groups (fifth). Those citing migrant groups usually referred to all migrants, though some mentioned refugees and asylum seekers (and some cited people with no legal right to be in the UK). Those citing age groups usually mentioned young adults and / or children, though mature adults were sometimes considered a priority.

The majority of differences between the responses of providers types were not statistically significant, though two were (highlighted in bold in the table). Compared to Local Authority and charitable providers, those within the NHS were significantly more likely to prioritise sex workers and prisoners, with charitable organisations particularly unlikely to prioritise prisoners with HIV.

4.4 INCOME TO PROVIDE HIV SOCIAL CARE, SUPPORT AND INFORMATION

All providers were asked a range of inter-linked questions concerning the income of their organisation for HIV social care, support and information over the last three years generally, and in 2005-06 specifically.

Change in investment in HIV social care, support and information over the last 3 years (% of all provider organisations)	% NHS providers	% LA providers	% ASO providers	% ASO providers who answered
NOT ANSWERED or DON'T KNOW	90	77	45	
Increased dramatically	1	0	8	15
Increased somewhat	0	4	11	20
stayed the same	7	10	11	21
decreased somewhat	1	6	9	17
decreased dramatically	0	2	15	27

Providers based in NHS or LA organisations did not or could not usually answer this question. Since LA and NHS staff rarely have to fundraise to provide service we expected less of their staff to be able to answer this question – however, with 90% of NHS providers and 77% of LA providers not answering no meaningful interpretation of this data is feasible.

Almost half (45%) of charities represented could not or did not answer – while many of these staff (or volunteers) may not have had the experience to address questions concerning income, others seemed unwilling to reveal the information. Among those charitable organisations where an answer was provided more described a decrease (24%) in investment than an increase (19%) over the last 3 years. However, there was not a huge disparity between the numbers describing an increase or a decrease. If we only take account of those that answered the question 35% saw an increase and 44% had seen an decrease, with 21% saying that their income had stayed the same for the last 3 years.

We also asked all providers: *In 2005-06 how many agencies commissioned you to provide HIV social care, support and information services?* About half (54%) of all charitable providers did not answer this question. Senior staff members taking part were more likely to answer and those represented by volunteers (especially when they were not board members) and direct contact workers were less likely to answer. The table below highlights the number of contracts awarded to charitable organisations and the number awarded to NHS and LA providers separately.

The majority of charities were contracted to provide HIV social care, support and information by relatively few authorities. If we exclude those that did not answer, 69% of all charities contracted with three or less commissioning bodies, including 9% who were awarded no such contracts; 9% who were awarded one; 25% two; and 26% three. In 2005-06, on average, charitable organisations were contracted to provide HIV social care, support and information services by 3 commissioning bodies (mean 4, standard deviation = 3.9, range 0 to 20).

Number of contracts awarded to provide HIV social care, support and information in 2005-2006	% NHS providers	% LA providers	% ASO providers	% ASO providers who answered
NOT ANSWERED or DON'T KNOW	94	85	54	
NO agencies contracted	1	12	4	9
1 contract	1	3	4	9
2 contracts	1	0	11	25
3 contracts	1	0	12	26
4 contracts	0	0	3	7
5 contracts	0	0	2	5
6 - 10 contracts	0	0	7	14
11 - 15 contracts	0	0	<1	2
16+ contracts	0	0	2	4

Those provider charities in more rural areas, and in areas of lower HIV prevalence contracted with substantially fewer commissioners compared to those in larger metropolitan areas and areas of higher HIV prevalence. In Inner London, in particular, providers contracted with considerably more commissioners to provide HIV social care.

We asked all providers to: *Please list those agencies who commissioned your organisation to provide HIV social care, support and information services in 2005-06. Where possible, please give an approximate yearly contract value (in £000s) for those services.* Answers to this question were of variable quality. In particular those providers with a higher number of contracts answered it with limited detail or not at all. Those commissioned by consortia found it difficult to disaggregate precise contract values. Some cited their overall income, or listed their funders without attributing precise contract values to them.

What was clear was that most charities get the majority of their income for HIV social care, support and information from the NHS – by far the most common answers were the PCTs across England, Local Health Boards across Wales, Health and Social Services Boards in Northern Ireland and NHS Boards in Scotland. Local Authorities were represented, as were the Supporting People Teams within them. However, grants from LAs were outnumbered 2:1 by NHS sources and LA contracts tended to be of lower value than NHS contracts.

Other sources of funding included the Scottish Executive and English Department of Health; the European Social Fund; The Learning & Skills Council; Opportunities for Volunteering; Crusaid; Elton John AIDS Foundation; Lloyds TSB Foundation; Monument Trust; Northern Rock Foundation; Big Lottery Fund (or Community Fund or National Lottery); BBC Children in Need; Comic Relief; the YMCA and pharmaceutical companies. However, if we exclude the very large grants (usually from the Big Lottery or the European Social Fund) then all these funders collectively account for less than 10% of income.

4.5 SERVICES LOST, SERVICES GAINED AND NEW SERVICES PROPOSED

In order to assess how HIV services were developing and changing, we asked a set of questions of all providers (whether workers or volunteers).

- *What HIV social care, support and information services was your organisation providing 3 years ago that it is NOT providing now?*

- *What HIV social care, support and information services is your organisation providing NOW that it was not providing 3 years ago?*

- *What ADDITIONAL services would your organisation provide if your budgets allowed?*

Those that reported any services lost, gained or needed were asked to state the reason why. Respondents were free to give written answers of any length, but most wrote relatively little. While the responses from the charitable sector were numerous, we received very few from either PCT or LA providers. In order to get a picture of the type and scale of service change, we assigned all the charitable sector responses to a service or intervention category based on method of delivery. In the case of statutory sector providers where there were fewer and briefer responses, we make much less use of these categories. Where descriptions described target groups rather than types of services, these are briefly outlined first.

4.5.1 Charitable services LOST

Approximately one quarter of charities made no cuts in service in the last three years. These tended to be smaller and more specialist charities that had maintained (or expanded) their service provision. Where lost services were described in relation to their specific target group, the majority had been for African people with HIV (or asylum seekers, refugees or migrants) and Gay or Bisexual men (7 responses each). Four childcare / children's / young people's services had been cut. The most common types of services lost were:

Information, advice and advocacy interventions (22)

- Including general and specialised services – financial/welfare benefits, treatment information services and *living well* services.

Social support/social care services (17)

- Including drop-in services, support groups, buddying / befriending services, hardship funds, meals services and home care services.

HIV prevention interventions (14)

- The majority were aimed at African people or Gay and Bisexual men, but including 'general population' services as well as those for positive people and drug users.

Therapeutic interventions (7)

- Including complementary therapies and counselling.

Written interventions (4)

- Including web-based and printed interventions such as treatments information service directories and mass media advertising.

The vast majority of service terminations described were due to funding cuts. However, others (especially social support and social care services) were due either to falls in demand or rationalisation or restructuring of services (especially as a consequence of the changeover to direct payments systems within Local Authorities).

4.5.2 Charitable services GAINED

Four fifths of charitable organisations described new services started in the last three years. These overwhelmingly targeted Black and ethnic minorities (primarily Africans, 27), children and young people (17) and women (8). Far fewer respondents reported services for men who have sex with men (5), injecting drug users (4) or sex workers (2). The most common new services were:

Information, advice and advocacy interventions (70)

- Mainly training interventions including back-to-work and *living well* courses. Information and advice interventions included HIV treatments, personal finance / welfare benefits and specialist immigration advice. Advocacy and referral services were mentioned by a much smaller number of respondents.

Social support/social care services (57)

- Social support included support groups, user involvement services, personal development and assertiveness training, emotional support services, drop-in services and social activities. Social care services were mainly hardship funds and grants but also included housing services (floating support), home care and respite services.

HIV prevention interventions (15)

- The majority aimed at children and young people, heterosexuals, BME populations, sex workers, injecting drug users and LGBT people.

Therapeutic interventions (13)

- Including counselling / mental health support and complimentary therapy interventions.

Written interventions (8)

- Including treatment information, information for/on women with HIV, children with HIV, HIV & mental health, HIV & sex, HIV & TB, migration *etc*.

Infrastructural developments (4)

- These included developing an existing remit for training interventions targeting other workers and included an expansion from a national to an international emphasis, and from people with HIV to their partners and carers *etc*.

4.5.3 Charitable services PROPOSED

Approximately one fifth of charitable organisations did not describe any new interventions they wanted to provide. These tended to be smaller and more specialist charities.

For those who did propose additional services that they would like to provide, the target groups most often cited were Black and ethnic minorities, asylum seekers, children, young people and families while far fewer responses concerned Gay and Bisexual men and fewer still injecting drug users and sex workers. The most common new services proposed were:

Information, advice and advocacy interventions (84)

- Including specialised advice services, back-to-work interventions and proposals to meet information needs in a 'one stop' setting. A minority referred to legal advice and immigration services as well as *living well* courses.

Social support / social care services (61)

- Social support proposals predominantly related to support groups and user empowerment / involvement interventions for the most vulnerable users. Far fewer mentioned drop-in services, buddying, emotional support and social activities for children. Social care service proposals included hardship and small grants funds for asylum seekers and migrants, food distribution and the reinstatement of subsidised or free meals and transport services.

HIV prevention interventions (26)

- Including general population anti-stigma campaigns, condom distribution / STI screening campaigns and HIV prevention with positive people.

Infrastructural developments (25)

- Mainly involving investment in staffing to extend current service delivery.

Therapeutic interventions (23)

- Including mental health and counselling services and complementary therapy services.

Written interventions (11)

- The majority of which concerned general information as well as better use of the internet and other technologies for the dissemination of information.

Clinical interventions (5)

- Including service developments around treatment and care access, community sleep clinics and smoking cessation and nutrition services.

The majority of these proposals stem from a perception of increasing demand on agencies, both from increased HIV prevalence and the widespread perception that acute poverty was increasingly common among people with HIV.

Overwhelmingly, the reasons cited for service developments were changes in need with a minority mentioning changes in funding or organisational capacity. Although there appears to be a slight gain in terms of overall services, it is difficult to discern any trend in these changes. There is little evidence of a shift in approaches or priority and closures of a service by one provider is generally mirrored by another provider launching a similar service. However, we can discern two imperatives which appear to be informing service development.

The first is a clear perception that there is acute need among certain groups that is not being met by the statutory sector, especially for asylum seekers and some other African people with HIV. The increased emphasis on hardship funds and basic food provision as well as a concentration on services for families, parents and children reflects this concern. This interpretation is underlined by the relative absence of service development specifically for Gay and Bisexual men or injecting drug users. This response is informed by the increasing mainstreaming of Local Authority services resulting in an increasingly visible population of individuals who do not qualify for social care services and are liable to fall between ever-widening service gaps.

The second is a preoccupation with skills and employment interventions (such as back-to-work and vocational services) as well as an emphasis on *living well* and training around health maintenance. This indicates that services may be increasingly geared towards enabling the individual to live independently.

4.5.4 NHS services LOST

Of the 74 NHS providers, roughly half either gave no answer to the question or described having made no cuts in service in that time.

NHS losses were usually attributed to the withdrawal and 'mainstreaming' of Local Authority services. That is, Social Services were increasingly withdrawing from clinics and service provided by specialist HIV teams within LAs were being subsumed into generic services. This put pressure on home care, CNS services and respite. However funding restrictions had also led to the cessation of NHS therapeutic interventions (counselling and mental health services) as well as a dietetic advice service.

4.5.5 NHS Services GAINED

Of the 74 NHS providers, 17 gave no answer to the question on new services developed in the last three years and nine said that no new services had been developed.

Like the charitable providers, new services were primarily aimed at BME groups or migrants and children / young people while fewer were aimed at Gay men. One of the main innovations was to improve synergy between clinical and community-based services and replace social care services lost through LA mainstreaming.

Thus, new information services centred on treatments, immigration and benefits (within clinics either by, or in association with charitable providers). New social support services were divided between user involvement and group support for people with HIV and their carers. New social care services replaced lost Local Authority services or targeted asylum seekers. New therapeutic services included clinical psychology services and alternative therapy services. New clinical services aimed to enhance access to treatment and care.

4.5.6 NHS Services PROPOSED

Of the 74 NHS providers responding, 21 gave no answer while one said that they did not know what they might provide.

The target groups suggested for possible new services mirrored those of the charitable providers (Africans and BME groups, young people, women and families) with the exception of Gay men, who were largely absent from NHS priorities. The nine responses which mentioned information, advice and advocacy interventions described aspirations to develop general information services based within clinics rather than community settings along with outreach services and improved referrals between the clinic and the charitable sector. The emphasis within the seven social care interventions proposed was primarily on replacing lost social services within clinics and services such as hardship grants and peer support services. The eight therapeutic/clinical interventions were similar to the charitable response in that they called for enhanced counselling and/or clinical psychology as well as services to improve access to treatments.

4.5.7 Local Authority services LOST

Of the 47 Local Authority providers, 18 gave no response, 16 said that they had not lost any services in this period and two said that they did not know or were unsure.

The majority of service losses were ascribed to the same mainstreaming of LA services described by the NHS respondents. Some respondents were concerned that Local Authorities may be losing sight of HIV infection as a cause of social care need. For example, some reported that social care services for people with HIV were being more tightly controlled or mainstreamed into generic services. Others mentioned the subsuming of mental health services into PCTs and in a minority of cases, budgetary restrictions had led to the withdrawal of designated services (for example respite care or HIV training for staff).

4.5.8 Local Authority services GAINED

Of the 47 Local Authority providers, 15 gave no response, and 8 said that they had not developed any new services in the last three years.

The target groups for new interventions were evenly split between those for ethnic minorities, migrants and asylum seekers and those concerning gender. No LA provider reported developing any new services for Gay or Bisexual men in the last 3 years.

Although 10 responses mentioned new information, training and advocacy services, half of these were commissioned from charities and the other half were delivered at, or in partnership with charities or NHS providers (and were mainly general information as well as specific advice on benefits, education and employment). Five responses mentioned new support groups for people with HIV. New social care interventions were generally in response to mainstreaming and consisted of changes to home care provision (direct payment) and the need for specialist social services for residents with HIV (as well as generic social care). The three new therapeutic interventions (all complementary therapies) were all provided in association with the NHS or a charity.

4.5.9 Local Authority services PROPOSED

Of the 47 Local Authority providers responding, 18 gave no response to the question on new interventions they might want to provide.

While both charitable and NHS responses prioritised BME/African people over families, the LA response was the opposite. Moreover, services for Gay and Bisexual men, women, prisoners, drug users or sex workers were not on any LA respondent's wish list. Moreover, no responses mentioned information, training and advocacy services around employment. Rather, they focussed on general information, benefits and immigration, nutrition and *living well*. The majority of the nine responses calling for new social support/social care services mentioned restoring lost services (better access to respite, hardship payments, transport payments *etc*.) while three mentioned support groups. Finally, there was concern that the HIV training function of LAs had been lost and should be restored.

Assessing the development of LA services specific to HIV was difficult because of the extent to which services were delivered through charitable organisations or NHS partners. Moreover, the complexity and variability of AIDS Support Grant funding arrangements meant that some of these services were commissioned from partners. In addition, services directly provided by Local Authorities are available to all who qualify under assessment. Many found identifying which of these services were HIV specific very difficult.

4.6 SUMMARY: PROVIDING HIV SERVICES

Including both workers and volunteers, 111 different charities were represented in the survey as providers of HIV social care, support and information.

- **Many charities report growing concern about the lack of priority given to HIV in national and local policy and the impact this has on the viability of their organisations.**

- **Many charitable providers report widespread indifference and apathy towards HIV from Local Authority, NHS and larger charitable funders – while many report maintenance of their overall funding levels over the last three years the search for funding is a constant pressure on organisations and services.**

- **Many charities feel it is increasingly difficult to establish and maintain contracts to provide HIV social care, support and information.**

NHS deficits figure prominently in these difficulties, as does the mainstreaming of HIV in various forms. While many charities reported not yet receiving contracts for 2006-07, large scale decreases in funding were not proven. On average charities were awarded 3 contracts in 2005-06.

- **Approximately half of charitable organisations represented described having made cuts in social care, support and information services in the last 3 years.**
  The most common types of services lost were:
  - ▶ Information, advice and advocacy interventions.
  - ▶ General social support.
  - ▶ HIV prevention interventions.
  - ▶ Therapeutic interventions.
  - ▶ Written interventions.

- **Approximately three quarters of charitable organisations represented described having introduced NEW social care, support and information services in the last 3 years.**
  The most common types of new services developed were:
  - ▶ Information, advice and advocacy interventions.
  - ▶ General social support and social care interventions.
  - ▶ Interventions for specific target groups.
  - ▶ Therapeutic interventions.
  - ▶ Written interventions.

- **The description of services cut and new services started suggests that changing need and changing patterns of HIV infection are far less important (to services delivered) than the changing political and funding environment.**

Looking across all organisations in the UK, very similar services are simultaneously being cut and launched, and these changes are not usually a consequence of changing need. There are many disparate factors driving innovation but funding, political and organisational priorities (at NHS and Local Authority level) are key. The wish lists of service providers suggest there is no consensus about the ideal mix of HIV social care, support and information services for people with HIV, nor the key target groups and needs.

- **Charitable providers have a great deal of expertise in the planning and provision of service – many strive to innovate and develop new services in response to changing need and changing patterns of HIV infection. However, the lack of a national HIV social care, support and information strategy or framework makes the prioritising of need problematic.**
  The over-riding impression is of a high volume of aims and needs (and target groups) competing with no way of prioritising among them. Commonly, one group (or service) cannot gain without another losing.

5 Improving HIV social care, support & information

In this chapter we revert to the entire sample of 371 workers and volunteers, rather than just considering the data at an organisational level. This allows us to consider a wide range of expert opinion on the equity of current service configuration; the potential for better targeting both of services and of future funding and finally, the main challenges to delivering better social care, support and information to people with HIV.

5.1 EQUITY OF CURRENT SERVICE CONFIGURATION

All respondents were asked: *Do you think that all people with HIV are equally served by HIV social care, support and information services (in the geographic area you are concerned with)?* Overall 68% of respondents said NO, including 71% of providers and 55% of commissioners. Those who said NO were asked: *Which specific groups of people with HIV do you think are less well served by HIV social care, support and information services?* The table below shows percentages of the entire sample giving each answer.

When broken down by role (commissioner / provider) and organisation worked for (charity, NHS, Local Authority) statistically significant differences emerged. Where a row is highlighted in bold, responses significantly varied. Compared to providers, commissioners were less likely to consider services to be inequitable and were less likely to choose each specific group as less well served, even when they acknowledged the absence of equity in current service configuration. Invariably, charitable providers (workers and volunteers) considered each group least well served.

Which specific groups of people with HIV do you think are less well served by HIV social care, support and information services? (n=340, missing 31)	% ALL	% ASO providers	% NHS providers	% LA providers	% NHS commissioners	% LA commissioners
specific MIGRANT groups	**37**	**44**	**34**	**34**	**23**	**28**
specific ETHNIC groups	31	37	31	23	21	25
specific AGE groups	**22**	**30**	**19**	**7**	**21**	**9**
Carers of people with HIV	**20**	**30**	**18**	**2**	**10**	**13**
Prisoners (and/or ex-prisoners)	**20**	**27**	**16**	**9**	**13**	**16**
specific SEXUALITY groups	**18**	**24**	**18**	**9**	**13**	**6**
Drug users (and/or ex-users)	**17**	**23**	**12**	**11**	**5**	**19**
Sex workers (and/or their clients)	17	18	22	14	8	13
Trans-people	12	16	10	9	3	13
a specific GENDER	12	17	9	7	5	6
other groups (say which)	9	11	8	7	8	6

The group considered least well served by current services were migrants (mentioned by 37% of the whole sample). Among these responses more than half (20% of all) specifically mentioned asylum seekers and somewhat less mentioned refugees (14%). Fewer specifically mentioned undocumented migrants, over-stayers, students, rejected asylum seekers or those with no recourse to public funds. Others mentioned migrant groups from particular areas, such as Africans or Eastern Europeans.

The next most common response was specific ethnic groups (mentioned by 31% of all respondents). The majority giving this answer felt all ethnic minorities were poorly served, though some

mentioned specific minorities, including Black African, Black Carribean or simply Black people. Less common were specific answers concerning South Asian people, Eastern Europeans and 'non-Africans'. Migrants and ethnic minorities were mentioned by a substantially higher proportion of respondents than other groups.

The next most common answers (mentioned by between 22% and 17% of respondents) were specific age groups (mainly children and young adults); carers of people with HIV; prisoners; specific sexuality groups (mainly Gay men); drug users and sex workers. Trans-people and specific genders (mainly women) were mentioned by 12% of respondents each. 9% mentioned other groups not well served by services. The most common other response related to where the person with HIV lived. It was felt that those in rural areas or who lived in an area not covered by the agency received less and poorer services. Other answers included disability groups, including those with learning difficulties and people with HIV who were deaf, and people with health issues including mental health problems, HIV-related brain impairment, Haemophilia and HIV / Hepatitis C co-infection. Parents, families, and single men with children were also mentioned.

This question was not a test of knowledge of epidemiological priorities. It was intended to assess the extent to which experts considered current service provision to be equitable. Migrants and ethnic minorities figure substantially in national HIV prevalence figures and they were the groups considered least well served by current social care, support and information provision. Gay men also figure substantially in national prevalence but this data suggests that the majority of key stakeholders consider them relatively well served by current provision.

5.2 PRIORITISING SPECIFIC TARGET GROUPS FOR FUTURE FUNDING

Having predicted that many key informants would consider that current provision of HIV social care, support and information was not equitable across specific target groups (locally or nationally) all respondents were also asked: *Do you think the AIDS Funders Forum should prioritise specific TARGET GROUPS for future funding of social care, support and information services for people with HIV?* Overall 60% said YES, including 60% of all providers and 59% of all commissioners. Among providers of services there was no difference in likelihood of agreement by type of organisation worked for (NHS, LA and charitable workers and volunteers all at 58-61%). Among commissioners, those in the NHS were slightly less likely to agree (51%) than those working in LAs (68%). All those that said yes were asked: *Which GROUPS of people with HIV do you think should be prioritised by the AIDS Funders Forum for future funding?* The table below outlines the proportion that said specific groups should be prioritised, for the whole sample and across job roles and organisational types. Note that there are no statistically significant differences by role (commissioner / provider) and organisation worked for (charity, NHS, LA).

Which GROUPS of people with HIV do you think should be prioritised by the AFF for future funding? (n=340, missing 31)	% ALL	% ASO providers	% NHS providers	% LA providers	% NHS commissioners	% LA commissioners
specific ETHNIC groups	38	37	45	40	27	39
specific MIGRANT groups	33	33	35	40	32	26
specific AGE groups	25	27	20	26	32	16
specific SEXUALITY groups	23	28	18	21	18	10
Carers of people with HIV	20	19	25	16	21	20
Drug users (and/or ex-users)	19	20	17	19	21	20
Sex workers (and/or their clients)	19	20	23	16	21	10
Prisoners (and/or ex-prisoners)	17	19	16	14	30	3
a specific GENDER	11	14	6	14	9	10
Trans-people	7	10	3	5	3	3
other groups (say which)	9	10	9	5	6	19

The target group that respondents were most likely to consider required specific funding prioritisation was ethnic minorities (mentioned by 38% of all respondents). The majority giving this answer felt all ethnic minorities required prioritisation, though some mentioned specific ethnic minorities, including Black African, Black Carribean or simply Black people. The group next most likely to be prioritised for funding was migrants (mentioned by 33%). Among these responses more than half (17% of all) specifically mentioned asylum seekers and somewhat less mentioned refugees (12% of all). Fewer mentioned specific migrant groups such as students; asylum seekers whose claims had been rejected; those applying for leave to remain; work permit holders; or those with no recourse to public funds.

The third group most likely to be cited as requiring prioritisation of funding was age groups (cited by 25% of all), specifically young adults (21%) or children (14%). The fourth most common priority target group was sexuality groups (cited by 23% of all), among which most (21%) mentioned Gay, Bisexual or other men that have sex with men. The only other priority group cited by at least a fifth of the sample was carers of people with HIV (cited by 20%). In order of priority this was followed by drug users; sex workers; prisoners; women (or men); and Trans-people.

Other groups included those with physical or mental health problems or disabilities; people in rural, isolated or under-served locations; friends and family of people with HIV; faith communities; and 'high risk' groups.

5.3 PRIORITISING SPECIFIC NEEDS FOR FUTURE FUNDING

All respondents were also asked: *Do you think the AIDS Funders Forum (AFF) should prioritise specific NEEDS of people with HIV when considering future funding of social care, support and information services?* Overall 73% of all respondents said YES including 74% of providers and 68% of commissioners. Among providers there was no difference in the likelihood of agreement by type of organisation worked for (NHS, LA and charitable workers and volunteers, all at 74%). Among commissioners, those working in the NHS were less likely to say YES (64%) than those working in Local Authorities (72%). All those respondents that agreed that members of the AIDS Funders Forum should prioritise specific needs of people with HIV, were asked: *Which needs of people with HIV do you think the AFF should prioritise?*. Respondents were free to give written answers of any length and some wrote 50-100 words. Although we asked respondents to identify needs, they tended to identify target groups and services.

An initial analysis yielded 14 thematic categories. In order to assess the relative importance of each category, we assigned a numeric value to each answer and re-coded every response into one or more categories (that is, where a single response fitted into more than one category, it was scored in all the relevant categories). Below, we present each category in order of numeric importance along with an analysis of the comments in each category.

5.3.1 The needs of specific target groups

By far the most frequently identified 'needs' were those concerned with target groups (with 76 responses). Respondents listed groups perceived to have greater need around social care and support, those that were more substantially threatened by social exclusion, and those that were at increased risk of contracting HIV. Two overlapping constituencies emerged as central: Black and minority ethnic (BME) or African migrants, and asylum seekers and families, children and women. Other groups (including Gay men) were given much lower priority overall.

Forty-three responses referred to (mostly African) BME populations, migrants or asylum seekers. Responses cited a range of factors which elevated need. These included lack of access to benefits, stigma from both the host and their own expatriate communities, and the fragmentation of families leading to a lack of social support. Moreover, the threat of repatriation to countries where HIV treatments were not available was seen as important.

> **Support HIV positive African asylum seekers in their fight not to be sent back to their home countries if they will not realistically be able to access treatment there.**

Respondents mentioned specific needs for language / interpretation services as well as advocacy services. Some mentioned that this group can take up a lot of clinical resources because they lack appropriate social support services.

The second most common target (24 responses) was children and / or young people. There were three ways in which need was presumed to be elevated among this group. First, children as carers of HIV positive parents were perceived to have needs that were often overlooked. Second, the period when a child with HIV reaches sexual maturity was seen as a time of elevated need.

> **Those [needs] of young people in transition to adulthood (e.g. aged 14-25) presenting with: behavioural needs (experiencing cycles of crime, low self-esteem and poor self-worth) and educational needs (paid work experience rather than voluntary work experience).**

Third, young people were generally seen to be in need of more HIV prevention interventions.

The third largest response concerned women and families (the needs of women with HIV were expressed almost exclusively in relation to their role as mothers or partners to men). As many women are diagnosed in antenatal contexts, a need for emotional support at this time was recognised. HIV positive women with children were seen as particularly in need of practical support. This need was seen to increase if their children were also HIV infected. Such support was seen as crucial to keep families functional and supportive.

Far fewer respondents (5) mentioned Gay men as a group with specific needs. These few comments suggested that the specific needs of Gay men were being overlooked as resources were increasingly oriented towards migrants and BME groups.

> **Gay men with HIV, indigenous to Britain, are invisible to most funders.**

Others said that services oriented towards migrant communities were not appropriate for Gay men.

Five responses each mentioned drug users and sex workers while three referred specifically to people living with HIV in rural areas.

> **Consideration should be given to the specific needs of people living in rural counties, where the geographic spread of service users increases their isolation.**

5.3.2   The need for social care and support

Fifty-eight responses mentioned the need for social care or support for people with HIV. Almost half of these (26) referred specifically to the need for peer support mechanisms and services in order to reduce isolation. These included drop-in services, support groups and befriending services. Many (13) referred to more generalised social support needs without either specifying the nature of those needs or the services that might meet them.

> **Support at specific times during their life with HIV: these are often 'times of crisis' such as diagnosis, emergence of symptoms, starting treatment, any illness, changing treatment.**

In addition, there was a desire for interventions to increase community participation among people with HIV. Such interventions may meet the need to reduce isolation among people with HIV. Ten responses referred specifically to the need for emotional support to deal with feelings of isolation, depression and anxiety and 2 responses each referred to the need for advocacy and the need for leisure / recreation.

Ten responses attended more directly to social care need. Some mentioned what they saw as specific needs of HIV positive clients with regard to domiciliary care while others mentioned the need for equity in access to social care for all people with diagnosed HIV.

5.3.3 The need for financial security

Financial need was mentioned in 42 responses. Roughly half of these referred to poverty. Many made a direct connection between poverty, stress and ill-health.

> **Basic survival costs – until these are met, people will not mange their health well. This will result in more people becoming more ill more quickly, higher viral loads, more cases of transmission, and also more drug-resistant transmission.**

For many the need for financial stability was paramount especially for migrants (asylum seekers). The remaining half of responses in this category referred to specific services. These included the need for hardship funds and crisis support, especially for those not entitled to welfare benefits. This included the need for help with accommodation and with basic furniture, appliances, food and clothing (12 responses). Others mentioned the need for financial assistance associated with transport costs and childcare especially for those with limited or no access to benefits. Finally four responses mentioned financial and debt advice.

5.3.4 Needs associated with education, training and employment

Thirty two responses mentioned needs for educational opportunities and employment. The majority of these referred to the need for help with finding and keeping employment. Also included was the need for back-to-work training and support, re-training and support for the long-term unemployed as well as the need for support in managing employment with a chronic health condition. Others mentioned the need for volunteering opportunities to reduce isolation. Educational and re-training opportunities for migrants or asylum seekers with HIV were also mentioned.

5.3.5 Housing need

Thirty responses mentioned the need for adequate and secure housing. Included here was the need for information around social and private housing; advice about finding better accommodation (for those living in over-crowded accommodation); the need for support in managing HIV-related illness and treatments within shared accommodation and finally, complex or specialised housing needs (such as those with immigration-support needs and those with mental health or drug dependency problems).

5.3.6 Health care needs including treatments maintenance

Twenty-seven responses mentioned needs around maintaining health and well-being. Roughly half of these mentioned help with treatment compliance and half mentioned *living well* and complementary therapies. Treatment support need included information on side effects and health, treatment 'literacy', social and peer support regarding the management of symptoms and adherence. Need around *living well* included access to complementary therapies, the need for information about nutrition, self-management and mental health maintenance.

Another 26 responses specifically mentioned the needs of those with mental health problems. Responses covered the need for ongoing support to maintain mental health including strategies for dealing with depression and anxiety, and advice on dealing with long-term or chronic illness. Other responses highlighted the need for more specialist counselling and therapeutic services for people with HIV. Responses mentioned periods of acute need (such as recent diagnosis) and needs associated with long-term survival.

5.3.7 Clinical service needs

Thirty responses referred to the need for greater access to clinical services. Among these increasing access to clinical care and treatments emerged as the top priority especially increasing access to treatments for asylum seekers and immigrants. Other answers emphasised increasing understanding for informed choices around treatments; improving treatment pathways; the need for information and advice about side effects; reducing clinic waiting times and improving primary care services for people with HIV. Two respondents mentioned the need for rehabilitation services for those with HIV-related brain impairment.

5.3.8 Legal and welfare benefits need

Twenty six responses mentioned need associated with legal or benefits issues. Roughly half of these mentioned the need for expert legal advice and representation for immigrants and asylum seekers with HIV. Others mentioned needs related to benefits advice and the increasing need for legal information on the criminalisation of HIV transmission.

5.3.9 Other needs

Fourteen responses mentioned needs associated with HIV stigma and discrimination. The majority of these concerned the need to change societal attitudes towards HIV (some also mentioned stigma around asylum seekers and migrants while others mentioned stigma attached to women with HIV). A minority of responses concentrated on the need to empower the individual with HIV to deal with stigma and discrimination.

Another 14 responses referred to HIV prevention need. This involved the need for interventions addressing risk management, support, empowerment and self-esteem, but also the need to involve people with HIV in the design of prevention campaigns. Prevention with specific target groups were also mentioned. The majority mentioned young people as targets while others mentioned prisoners and sex workers. One response mentioned prevention for (young) Gay men.

Ten responses mentioned the need to empower people with HIV for a range of reasons. First, to increase self-esteem; second, to increase patient representation for clinical and social services; third, to encourage independent living and fourth, to promote peer support and self-help. Finally, 7 responses stressed the need to ask people living with HIV what their needs were. Some said that such complex and variable needs were not amenable to summary in this form. Others said that HIV positive people should be consulted through advisory and consultation groups and user empowerment.

5.4 CURRENT CHALLENGES IN SERVICE PROVISION

Towards the end of the survey all respondents were asked: *What do you think are the current challenges in social care, support and information for people with HIV?* Responses from charitable workers, volunteers, other providers and commissioners are presented here as a whole. 301 respondents answered this question, though many gave answers that were split across two or more thematic categories below.

Responses fell into two over-riding themes, reflecting two different interpretations of the word 'challenge'. Some respondents reflected on the ways in which structural and environmental impediments such as a lack of funding, legal and political frameworks, stigma and discrimination and structural changes to funding bodies operated as impediments or 'challenges' to successful service provision. Others offered their thoughts about the 'challenging' task of ensuring high-quality service delivery by emphasising those areas of their work that were most difficult. This latter group tended to re-iterate many of the issues that related to specific responses in previous chapters.

All answers were divided fairly evenly between the two meta-themes, with 257 comments relating to environmental and structural impediments, and 241 pertaining to desired outcomes in service structure and delivery. We start with an exploration of environmental and structural issues, followed by findings related to service provision.

5.4.1 Environmental and structural (policy) impediments

Funding

One third of all comments that fell into this overall theme related to concerns about inadequate funding of HIV services (82). Many highlighted that at a time of increasing HIV prevalence funding was scarce. There was also a great deal of concern about decreasing statutory funding, as resources for HIV were spent elsewhere, or were cut because of a perception of the diminishing priority attached to HIV. Some charities were also considered lacking in their support of HIV.

> **Reduced funding which has not kept up with the increased number of patients, some of whom have complex problems sometimes related to late diagnosis *etc*.**

While a small number of respondents did make specific mention of the overall crisis in the NHS, others (7) made some mention of the impact of the loss of the AIDS Support Grant on effective service delivery. Others (8) noted that widespread funding cutbacks were necessitating prioritisation of services and more targeted delivery. This was sometimes represented as having a divisive effect amongst service users.

> **Lack of funding can mean that for some groups, those who shout the loudest get the service.**

Another common negative impact of the funding environment (14) was the extent to which significant capacity and staffing shortages were being experienced. As one individual explained, the problem of insufficient funding was being felt across statutory and charitable providers. With widespread resource shortages there was no one left to fill the gaps.

> **Social care services are stretched to breaking point and they need the capacity of the voluntary sector, but at present they too are stretched and don't have enough statutory funding to meet the daily running requirements of the charity.**

Legal and political climate

The second most common environmental or structural challenge to the provision of HIV services was considered to be the legal and political climate of the UK (73 responses). More than half these responses (43) related to the way in which asylum and immigration laws and policies in the UK were severely impacting upon service providers' ability to assist some of the most marginalised people with HIV. Although no one mentioned asylum seeker dispersal, some (14) mentioned that lack of access to public funds meant that those whose asylum application had failed were effectively blocked from accessing HIV treatment and care, while also facing destitution. Those working in care services expressed frustration at the role they were expected to play in enforcing this policy, and some actively resisted such a role.

> **African asylum seekers are fearful to come out and make contact with others because of fear of stigma and fear of being picked up by police.**

Others (3) raised concerns about the extent to which the increased policy of deportation of failed asylum seekers was having an impact on the physical and mental health of their client group. It was also clear to many that the policy environment that shaped the lives of their different client groups meant that many migrants with HIV were living in a world apart from other service users.

> **This also means that working with two groups with very different needs – the haves and have nots – benefits, work, housing and security are a dream to many [people] I work with.**

Other responses within this category related to concerns about the lack of political profile for HIV (19). Half of these comments relate to respondents' concerns that the government was not motivated to recognise the specific problems posed by HIV. As one person pointed out, to the extent that HIV was addressed within official policy, it was increasingly subsumed by other issues that were a higher priority.

> **HIV social care is not related to a performance indicator for Local Authorities therefore is not high profile any more. And in terms of health it is tacked on to the strategy for sexual health with priorities mainly around teenage pregnancy and chlamydia.**

The other group of responses that were assigned to this category related to concerns about the impact of criminal prosecutions of people for the transmission of HIV (11). While one of these respondents noted that legal liabilities in such cases remained unclear, another set out the ramifications of this situation for people with HIV, noting a concern about:

> **[the] impact of prosecutions on psychological sexual health and on levels of stigma and discrimination.**

Stigma and discrimination

The third most common environmental or structural challenge to the provision of HIV social care, support and information was HIV-related stigma and discrimination accompanied by misperceptions of the epidemic (68 responses). Most of those who mentioned stigma and discrimination did not elaborate on its causes or effects. Some did note that disempowered groups, including African migrants and Gay men, were marginalised through HIV stigma, with the effect that their ability to disclose and access support were undermined.

> **Stigma, which prevents people living openly with HIV, and prevents them accessing support.**

A small number (4) drew attention to the acute problems of challenging stigma within the government, among funders and among health professionals. Others (10) also highlighted the way in which HIV stigma reinforced racist and homophobic social attitudes. Some spoke of the way that shifting perceptions of the epidemic have impacted upon the meanings associated with it (14). One respondent noted the declining recognition of HIV as a serious condition exacerbated the stigma and discrimination still attached to HIV.

> **Due to the progress in medication and people now living longer with HIV it is not seen as a serious condition anymore. Although there is still a lot of stigma and discrimination, people tend to overlook this.**

Others expressed concern about the way that medical success had reduced the visibility of HIV, and increased complacency about social responses to the epidemic.

Structural changes

The fourth environmental or structural challenge to the provision of HIV social care, support and information were the various ways that structural change in NHS and Local Authority services presented difficulties to meeting the needs of people with HIV (34). Though some referred to the constant disruption of NHS restructuring, most commented on the re-shaping of statutory service delivery away from specialisation. Mainstreaming of HIV services (17) was depicted as a challenge to meeting the needs of people with HIV, whether mainstreaming of HIV into sexual health services in the NHS, or into 'disabilities' or 'vulnerability' models in Local Authorities.

> **HIV specialist teams are being merged into generic teams. This is driven by the fair access to care guidelines. In [name of LA], talks are taking place that will see the HIV team become part of a vulnerable adults team. There may still be some specialist workers in the team, but these specialists will still have to work with other groups, and other social workers who have not chosen to work with people living with HIV will also have to do HIV work. This will lead to a loss of specialist skills.**

Another respondent offered a means of tackling the challenge of mainstreaming.

> **HIV services are being mainstreamed. This seems an inevitable constant to the point where specific HIV services are endangered. We must not give away the gain of the sector easily. While HIV services are being mainstreamed we must also ensure that we HIV the mainstream and make sure that the quality of services that have been built up over the last two decades are not lost and diluted but are transferred to other areas.**

Others (10) reflected on the structural difficulties that clients can face when they are required to access services from across sectors. Communication between providers was highlighted as a particular challenge, and 'seamless' service provision was regarded as rare.

5.4.2 Improved services – improved service outcomes

The remainder of this section reviews the 241 responses to the question *What do you think are the current challenges in social care, support and information for people with HIV?* that related to service provision. These responses reflected a desire to provide better access to high quality services, while addressing some of the complex needs of people with HIV. We will deal with this data in less detail than the preceding section, because there has already been thorough coverage of the provision of services elsewhere in this report.

Related social care and health issues

The most common issue raised was the challenge of providing high quality support for people with HIV whose complicated lives simply meant that HIV was usually not their only support need (66 responses). To a certain extent, this related to the lack of joined up provision of complex care packages for individuals. The most common element (27) concerned the ways financial instability among service users (including unemployment and lack of access to public funds) resulted in inadequate housing, lack of nutritious food, social isolation and difficulties with mobility. Other respondents (20) voiced concerns about lack of capacity to address the long-term needs of clients on HIV medication who still required social care and support.

> **Social services appear to be focussing on short-term crisis management issues, as it easier to show that people fulfill eligibility criteria. There is a need for social services to be more proactive in supporting people over the longer-term.**

Such a shift requires that those making assessments of social care needs are able to recognise and pre-empt less acute needs relating to disclosure, isolation and well-being. These concerns also relate to the problems of mainstreaming health and social care services for people with HIV. Some respondents pointed to related health issues that can complicate the delivery of social care especially mental health issues (8), HIV-related brain impairment (4), dual diagnoses with Hepatitis C (3) and the implications of drug interactions for those who use recreational drugs while on prescription medication (2).

Targeting

The topic of targeted services for different groups of people with HIV emerged as significant again (65 responses). Some respondents (17) referred simply to the need to respond to diversity amongst service users, while others reiterated their specific priority target groups. Gender was not raised among these responses, and only three mentioned the need for improved work with Gay men. Again, most respondents (18) emphasised the need for improved work with BME, African and migrant communities in relation to accessing culturally appropriate services. Related to this were comments on the need for language-specific support (10), both in terms of translated written materials and interpreter services for those whose first language was not English. The other common target concerned children and families with HIV (15) and young people in transition into adulthood (3). The following respondent was not alone in recommending that the Children's Act (2004) should shape the provision of children's services in the HIV sector, as it did elsewhere.

> **[The] HIV sector needs to be up to speed with the 'Every Child Matters' agenda for sweeping changes in LA services and how they are being delivered.**

Although the question specifically asked about social care, support and information for people living with HIV, five responses related to the need for provision to carers, which itself can be regarded as a means of indirect support.

Improving service content and capacity

Respondents who examined the shortcomings and challenges of service delivery (53 responses) tended to focus on issues such as improving the capacity of providers (14); scaling-up of employment and training provision (13); and tailoring services to the changing needs of individual users (11). Those who made this latter point tended to be expansive, including discussions of the extent to which multi-agency care packages were inflexible in the face of changing circumstances, and the way in which non-acute issues were ignored.

> **Often services only focus on people with high health needs and forgets that investment in supportive services is a very effective way of preventing deterioration in terms of their health.**

Improving access to services

Many who suggested access was an important challenge to service delivery (45) made generalised comments about the need to ensure equality for all of those people in need. Among those who raised specific concerns about access, the most common issues were: disparity of access to high quality services within large centres and between rural and urban areas (12); equal access to information (8); and inflexible eligibility criteria (2).

Managing HIV as a chronic condition

Very closely aligned with those who made specific comments about service delivery were respondents who drew attention to the changed context of HIV infection as a long-term, chronic health condition (34). These respondents regarded the widespread availability of anti-HIV treatments as having profoundly changed the general response to HIV. They raised a number of practical issues relating to ageing, returning to employment, treatment literacy, and the long-term impact of a fast growing population of people with HIV.

> **The needs of people with HIV are different now with the advent of anti-retrovirals and the challenges for patients are much more about maintaining a good quality of life, teaching them to adjust to their diagnosis, empowerment, increasing self-esteem, and living with a chronic illness.**

Management of HIV as a chronic illness requires a particular shift in the alignment of services which can be both proactive and responsive to individuals whose long periods of social, mental and physical well-being may be punctuated by instability and ill-health.

HIV prevention

The final group of responses (31) related to the challenges of preventing the onward transmission of HIV. Those respondents who answered in this way usually made no reference either to people already living with HIV, nor to their social care, support or information needs. We should not be surprised that underlying concerns about the challenges of HIV prevention pervade the thoughts of those working in the sector, but this can be unhelpful when the focus is the lives and needs of those who have diagnosed HIV.

5.5 SUMMARY: IMPROVING HIV SERVICES

- **More than two thirds (68%) of all respondents did not think all people with HIV were equally well served by the current configuration of HIV social care, support and information services (in the geographic area covered by their organisational remit).**

About a third of all respondents felt that migrants (37%) and specific ethnic groups (31%) were less well served by HIV social care, support and information services. Less than a fifth (18%) felt that Gay and Bisexual men (and other sexuality groups) were not well served by current services. That placed them sixth in the list of groups less well served by current services after migrants; ethnic minorities; specific age groups (mainly children and young adults); carers of people with HIV; and prisoners.

- **60% of all respondents thought the members of the AIDS Funders Forum should prioritise specific TARGET GROUPS for future funding of social care, support and information services for people with HIV.**

About a third (38%) of all respondents listed ethnic minorities and migrants (33%) as the groups AIDS Funders Forum members should prioritise for future funding of social care, support and information services for people with HIV. The third group most likely to be cited as requiring funding prioritisation was age groups (cited by 25%), followed by Gay, Bisexual or other men that have sex with men (21%) and carers of people with HIV (20%).

- **Almost three quarters (73%) of all respondents thought members of the AIDS Funders Forum should prioritise specific NEEDS of people with HIV when considering future funding of social care, support and information services. Needs were prioritised in the following rank order:**
  - ► The need for social care and support.
  - ► The need for financial security.
  - ► Needs associated with education, training and employment.
  - ► Housing need.
  - ► Health care needs including treatments maintenance.
  - ► Needs around (access to) clinical services.
  - ► Legal and welfare benefits need.

Responses to our question on the current challenges in social care, support and information for people with HIV reflected two over-riding themes. Many respondents reflected on the ways in which structural and environmental factors challenged and undermined the provision of services – these included the struggle to maintain adequate funding; the UK legal, political and policy context that does not prioritise HIV; stigma and discrimination surrounding HIV; and the constant structural changes of their funding bodies. Others offered their thoughts about the 'challenging' task of ensuring high-quality service delivery by emphasising those areas of their work that were most difficult.

References

Cook PA, Downing J, Hargraves SC, Madden H, Syed Q, Bellis MA (2006)
HIV & AIDS in the North West of England 2005. Liverpool, Liverpool John Moores University.

Dodds J, Mercey D (2005) *Sexual health survey of Gay men, London 2005: annual summary report.*
London, Royal Free & University College Medical School.

Health Protection Agency Centre for Infections and Health Protection Scotland (2006)
Unpublished Quarterly Surveillance Tables No 70, 06/1.
✍ www.hpa.org.uk/infections/topics_az/hiv_and_sti/hiv/epidemiology/hars_tables.htm

Health Protection Agency Centre for Infections and Health Protection Scotland (2006)
Unpublished Quarterly Surveillance Tables No 72, 06/3.
✍ www.hpa.org.uk/infections/topics_az/hiv_and_sti/hiv/epidemiology/files/
     2006Q3(Sept)_HIV_Quarterlies.pdf

Health Protection Agency Centre for Infections and Health Protection Scotland (2006)
Survey of Prevalent HIV Infections Diagnosed (SOPHID), Data tables 2005.
✍ www.hpa.org.uk/infections/topics_az/hiv_and_sti/hiv/sophid/sophid_main.htm

The UK Collaborative Group for HIV and STI Surveillance (2005) *Mapping the Issues: HIV and other
Sexually Transmitted Infections in the United Kingdom: 2005.* London, Health Protection Agency,
Centre for Infections. Supplementary data tables: Part 1: HIV
✍ www.hpa.org.uk/publications/2005/hiv_sti_2005/pdf/MTI_ST_Part_1_HIV.pdf

The UK Collaborative Group for HIV and STI Surveillance (2006) *A Complex Picture. HIV and other
Sexually Transmitted Infections in the United Kingdom: 2006.* London, Health Protection Agency,
Centre for Infections.
✍ www.hpa.org.uk/publications/2006/hiv_sti_2006/contents.htm

The UK Collaborative Group for HIV and STI Surveillance (2006) *A Complex Picture. HIV and other
Sexually Transmitted Infections in the United Kingdom: 2006.* London, Health Protection Agency,
Centre for Infections. Supplementary data tables: Part 2: HIV
✍ www.hpa.org.uk/publications/2006/hiv_sti_2006/pdf/sup_tables/part2_HIV_st.pdf