Project *Nasah*

An investigation into the HIV treatment information and other needs of African people with HIV resident in England

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Original Research Report

Acknowledgments

The idea for this research originated with Colin Nee (then of NAM) and was initially developed in collaboration with Susie McLean (of the National AIDS Trust). Ultimately the research was developed, designed and conducted by four collaborating agencies – the African HIV Policy Network (AHPN), NAM, the National AIDS Trust (NAT) and Sigma Research (contact details for these agencies is provided on the outside back cover).

The Steering group for the project comprised individuals from each of the four collaborating agencies. These were Tom Lawson and Anna Poppa (both of NAM), Susie McLean (NAT), Max Sesay (African HIV Policy Network) and Peter Weatherburn (Sigma Research). It also included the interviewer co-ordinator, Winnie Ssanyu-Sseruma who was employed by Sigma Research, and a range of key stakeholders from African communities – Baltazer Mutuli (from Organisation of Positive African Men), Moono Nyambe and Mary Okoth (of Perikoth Consultancy).

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1 Introduction and methods

1.1 AFRICAN PEOPLE LIVING WITH HIV IN THE UK

There are now estimated to be more than 7,000 African people living with diagnosed HIV infection in the UK (PHLS, 2002a). In addition several thousand more African people living in the UK probably have undiagnosed HIV infection, since a recent survey of African people in London found that 66% of men and 70% of women had never had an HIV test (Fenton, *et al.*, 2002).

HIV prevalence is many times higher among African people in the UK than among the White British majority. Among attenders at London GUM clinics in 2001, 4.8% of African-born men and 7.7% of African-born women had HIV compared with 0.2% of UK-born men and 0.2% of UK-born women (Unlinked Anonymous Surveys Steering Group / Department of Health, 2002, p.21, henceforth UA Survey, 2002). Furthermore, it is widely thought that at diagnosis, African people present with significantly more advanced HIV disease than non-Africans, and that they have had their infection on average for a longer period of time at diagnosis (Burns *et al.*, 2001).

Data on the ethnicity of people diagnosed with HIV infection has been collected by the Public Health Laboratory Service for diagnoses made since 1995. Since 1995 the number of African people living in the UK who are newly diagnosed with HIV infection has increased every year. These diagnoses will include people infected with HIV before they lived in the UK, and people who acquired their infection while living here. New HIV diagnoses made among Africans in the UK are shown in Figure 1.1.

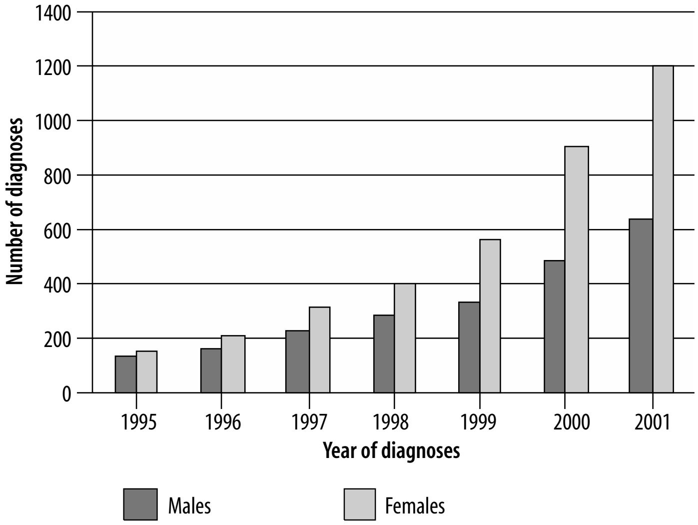

Figure 1.1: Diagnoses of HIV infection among African people in the UK, 1995 to 2001 (Source: PHLS, 2002a)

In the mid-1990s a similar number of men and women were newly diagnosed with HIV every year. However, the past six years has seen an average increase in new diagnoses of 30% each year for men and 42% each year for women. In 2001 there were two African women diagnosed for every African man diagnosed.

This is partly due to the increases in opportunities for HIV testing for women with the introduction of widespread antenatal HIV testing, giving women more opportunities to test than men. However, as almost all HIV infections will eventually be diagnosed this difference in access to testing should not show a sustained difference in the number of diagnoses. In London at least, the proportion of heterosexuals with HIV who remain undiagnosed after an GUM clinic visit was similar for men and women (71%: UA Survey, 2002). The difference in access to testing may have increased the inequality in duration of undiagnosed infection, with men remaining undiagnosed on average longer than women, but almost all will eventually be diagnosed.

Instead of access to testing, it is likely that the differences in diagnoses in Figure 1.1 reflects differences in the incidence of HIV among men and women. Diagnoses in the UK include both migrants with HIV and acquisitions while living in the UK. Among migrants from Africa we would expect to see more HIV diagnoses among women than men if more women with HIV migrate than do men with HIV. This itself may be because (i) more women than men migrate from Africa (cannot establish this); and / or (ii) a higher proportion of women in Africa have HIV than men (this is almost certainly true, Glynn *et al.* 2001); and / or (iii) women with HIV in Africa are more likely to migrate to the UK than men with HIV in Africa (no evidence for this).

The reason HIV prevalence in Africa is higher among women than among men is almost certainly because HIV incidence is higher among women than among men (not because incidence is equal and mortality is higher among men). The reasons incidence is higher among women are multiple and are the same reasons we suspect HIV incidence among Africans living in the UK is higher among women than among men.

Incidence will be higher among women than men if women are heterosexually exposed to HIV more frequently than men. However, exposure is not higher because women have more sources of sexual infection than men. The reverse is the case: both in Africa and in the UK there are more women than men with diagnosed HIV (among African women GUM attenders in London HIV prevalence in 2001 was 7.7% compared with 4.8% among men; UA Survey, 2002). It may be that a higher proportion of HIV infected men have intercourse with uninfected women than HIV infected women have intercourse with uninfected men. It is also possible that HIV infected men who have HIV sero-discordant unprotected vaginal intercourse (sdUVI) do so more frequently than do HIV infected women.

Even if the number of '+ve man / -ve woman' intercourse events is the same as the number of '+ve woman / -ve man' intercourse events, there are strong reasons for thinking the proportion of those events that feature condoms might vary. For example, it is feasible that uninfected men engaging in intercourse with infected woman are more likely to wear a condom than are infected men engaging in intercourse with uninfected women. Compared to men, women have a higher relative vulnerability to exposure because as a group they have less control over what happens in heterosexual intercourse than do men. This is a reflection of the relative positions of social and institutional power of men and women more broadly and is why many people feel that addressing gender inequalities is vital to addressing heterosexual HIV epidemics.

In addition to their social vulnerability, women are also more biologically susceptible to HIV when they engage in (receptive) sdUVI with infected men than uninfected men are when they engage in (insertive) sdUVI with infected women. It is likely that during sdUVI a greater average quantity of seminal fluid is passed to women than vaginal fluid is passed to men. It may also be possible that the average viral loading in semen is higher than that in vaginal fluids, and that the lining of the vagina is more susceptible to HIV penetration than the cells of the urethra.

Together, differences in social vulnerability and biological susceptibility mean that both HIV incidence and HIV prevalence are higher among African women than among African men. In addition to high incidence and prevalence of HIV, African people resident in the UK face a range of other challenges to their health and well-being.

Some African people with HIV resident in the UK have uncertain immigration status' and are faced with a media and, arguably, a range of government policies, broadly hostile to their residence in the UK. Whether or not such adult migrants are aware of their HIV infection when they settle in the UK, they face substantial challenges in accessing HIV diagnosis, treatment and care. For example, there is anecdotal evidence that the ways in which some African people negotiate their pathways to sexual health clinics are complex, often involving informal or lay-referral systems that depend on friends and other social contacts to facilitate access.

For some African people with HIV the potential difficulties of gaining access to a range of medical and social support interventions are exacerbated by the Home Office policy of dispersal of asylum seekers which places people in a variety of geographic locations without taking account of their potential HIV treatment needs and the local areas infrastructure to meet such needs.

In addition to African ethnicity being stigmatised within Britain, HIV is a highly stigmatised disease within African communities (Goldin, 1994; Bhatt, 1995), despite the comparatively high HIV incidence and prevalence. HIV stigma can act as a powerful barrier to accessing services, to disclosure of HIV status in personal and social settings and to enjoying the same rights and freedoms as those who are not HIV infected. The challenges faced by African people with HIV need to be understood as existing *within* African settings in addition to mainstream settings.

1.2 BACKGROUND TO THE RESEARCH

This action research project was a partnership between Sigma Research, The African HIV Policy Network, National AIDS Trust (NAT), NAM and a range of individuals with a concern for African people with diagnosed HIV. It was designed both to gather information from African people with HIV and to provide information to them.

The study arose from discussions between NAM and NAT concerning how little was known about the anti-HIV treatment information needs of African people with HIV. These agencies felt that, even in London, there were relatively few treatment information interventions aimed exclusively at this audience and that these had been developed on the basis of limited – and largely anecdotal – understandings of need. It was also felt that these interventions might have a relatively low uptake, perhaps because they were not acceptable or appropriate to their intended audience.

Finally, it was recognised that the broader social and personal contexts in which anti-HIV treatments were understood and experienced were also poorly understood.

This research project started with the observation that African people with HIV are not so large a group nor so disparate that interventions and services cannot be developed and targeted effectively. While African people with diagnosed HIV come from a wide-range of geographical backgrounds with a variety of cultures and languages, it was assumed that many of the problems and challenges they face in the UK are common to all. In this context, the collaborating agencies agreed that there was an urgent need to understand what HIV treatment information interventions would be most appropriate to enable African people with HIV to develop better dialogues with health care professionals, and hence get the health care they need.

The choice to focus specifically on anti-HIV treatment information needs was based on the interest and expertise of NAM whose original idea the project was. However, given the marked absence of research on African people with HIV resident in the UK we recognised the need to gather some baseline data on the broad social care needs of the population.

That we know so little about African people with HIV probably reflects the lack of priority this group has historically received, especially for research. Funding for the study was very difficult to negotiate and ultimately the £43,000 needed took longer to raise than the actual project took to undertake. Finally, funding was pieced together from 7 sources, including 4 pharmaceutical companies, 2 individual health authorities and a consortium of London Health Authorities (see Acknowledgments). When the entire HIV sector remains obsessed with evidence, and so little is known about African people and HIV, it is very hard to explain why this project was so very difficult to fund.

Finally, it is worth recognising that this research report also exists in something of a policy vacuum. There remains no nationally agreed framework for undertaking targeted HIV prevention or care with African people resident in the UK, though the National AIDS Trust and the African HIV Policy Network has developed such a framework on behalf of the Department of Health. In addition, the changing pattern of migration to the UK from Africa ensures that the voluntary sector infrastructure – through which targeted work might occur – is relatively under-developed. The data that follows indicates that, in population terms, African people with HIV need more (than other populations with HIV). The gaps and absences described here suggest some of the reasons they probably get less.

1.3 AIMS OF THE RESEARCH

Recognising that there is a direct relationship between anti-HIV treatments information interventions and adherence, this research project had one main aim:

- **to determine the anti-HIV treatments information intervention needs of African people with diagnosed HIV.**

Since so little is known about the challenges faced by African people with HIV living in the UK, we took a broad approach to the study design. That is, we asked sufficient questions to describe the demographic profile of the sample and their experience of living with HIV and the problems and needs this created in their lives. We also asked a range of questions regarding their previous engagement with anti-HIV treatments information interventions and their preferences for future interventions.

In summary the questionnaire covered:
- demographic profiles;
- recent experience of a broad range of social and medical problems;
- HIV history, including use of anti-HIV treatments;
- measures of current adherence and existence of barriers to adherence;
- satisfaction with relationships to clinical staff;
- levels of HIV treatment information knowledge;
- perceived need for greater knowledge concerning HIV treatments;
- preferences for future methods of receiving anti-HIV treatments information;
- other HIV health promotion needs.

1.4 METHODOLOGY AND RESEARCH DESIGN

The study was community-based and used an action research methodology. It was based on the substantial learning of three specific studies. The first study, *What do you need?* (Weatherburn *et al.*, 2002), showed us what did not work with African people with HIV. It was a national needs assessment of people with HIV conducted across the UK in the summer of 2001. It used 'traditional' research techniques: self-completion questionnaires, distributed by service providers to individuals for Freepost return. While we recruited 1830 people with HIV, only 6% were Black African. The other two studies (Nodfor-Tah, Hickson, Weatherburn *et al.*, 2000; Chinouya, Davidson & Fenton, 2000) demonstrated that African peer-based methods were likely to be an effective means of researching African people with respect to HIV and sexual health. Since neither of these studies recruited only people with HIV, nor even asked about HIV status, we were not certain that these methods would be a success with an HIV infected population. That this was not only possible, but relatively straightforward undermines previous arguments that this population is 'hard to reach' and teaches us much about how future research should be funded and undertaken.

The study had a steering group that included representatives from the four collaborating agencies, two of the peer interviewers, and two African people from HIV agencies. The process of questionnaire development was undertaken by collaboration within the steering group. It was agreed that a relatively short and simple questionnaire should be developed that interviewers would administer to people with HIV wherever they encountered them. After initial meetings to discuss topic areas, a draft questionnaire was developed and reflected back to all parties. After feedback this was modified and shared again. The process was inclusive and reflexive with all parties involved in discussions regarding prioritisation of question areas and topics. The interview was designed to last about 20 minutes, excluding any discussion at the end.

The questionnaire was also designed as an HIV treatments information intervention. Every care was taken to ensure that respondents were not misled or confused by the questions, and were not too embarrassed to answer them directly and honestly. The anti-HIV treatments knowledge section consisted of giving respondents nine true statements and asking them if they already knew these were true. This allowed the interviewer to state a number of 'facts' about anti-HIV treatments, hence minimising confusion, and made addressing errors at the end of the interview easier. In these ways the research process also served as a simple educational intervention which could develop into a longer discussion if the respondent wanted. All interviewers were briefed to defer any questions arising during the interview until the end. All interviewers were trained to answer basic queries after interviews were completed, and distribute appropriate written materials including a referral sheet which listed the contact details for a range of HIV services.

While the interview schedule was being agreed, AHPN contracted with a well respected training and consultancy agency specialising in health issues relating to African communities. That agency provided a list of 30 potential interviewers who were African (by birth or descent) and had declared an interest in working on the project. As far as possible the list included a mix of genders, countries of birth and linguistic abilities. All potential interviewers were also vetted for their levels of familiarity with HIV issues including anti-HIV treatments knowledge. There was no requirement for interviewers to have diagnosed HIV infection themselves.

After a telephone conversation with the research co-ordinator the majority of potential interviewers were invited to the interviewer training day. Some additional potential interviewers were also invited after they were recommended by existing recruits or volunteered after hearing about the project from friends.

When the final draft of the questionnaire was ready, Sigma Research facilitated a one day training event for interviewers. Ultimately 26 potential interviewers attended the training day in May 2002 and 22 subsequently recruited and interviewed respondents. The training event focussed on recruitment and interviewing skills, community ethics and confidentiality. We judged that all potential interviewers had sufficient grasp of HIV and its treatment to allow us not to have to spend training time on these issues.

It was agreed that the interviewer would conduct all surveys (rather than allow self-completion) and that the interview would be in English unless the participant was not comfortable with this. Interviewers suggested they concentrate on recruiting respondents from their own communities, which also allowed them to use whatever alternative language was shared. All interviewees were recruited directly by interviewers from within their personal and service-use networks. This meant that some individuals who worked or volunteered for AIDS service organisations recruited at that agency. With permission, others used the support groups or drop-ins they attended as a service user to recruit other service users. Others simply recruited via social, family and other networks, people who they knew had diagnosed HIV.

Ultimately there were 22 active interviewers from a variety of community and ethnic groups. When they collected the printed questionnaires, they were provided with a written briefing reminding them of the key points of the training day. They were also given laminated identity cards, referral sheets to give to any respondent that wanted to access HIV services and a range of NAM leaflets to help them answer very specific queries. Interviewers were paid £15 for each interview they completed and returned. Respondents were paid £10 for their participation.

All interviewers were supported by a research co-ordinator, who debriefed with interviewers when they returned completed schedules and collected more. She was also available by mobile phone in the event of any emergency. The research co-ordinator was a well respected member of the Ugandan community who was open about living with HIV and was involved in a range of HIV related organisations and activities. At the end of interviewing the interviewers were invited to attend a feedback and debriefing session, where issues of concern were addressed and where they could compare experiences.

We intended to recruit approximately 400 people with HIV from African communities across England. For three substantial reasons the sample is biased towards London. First, 60% of the 500,000 African people resident in England are resident in 10 of London's 32 Local Authorities (London Research Centre, 2002). Second, about three quarters of African people with HIV in England are also resident in Greater London (PHLS, 2002b). Finally, the vast majority of interviewers lived in London.

In order to recruit some African people with HIV resident outside London we undertook specific recruitment in Manchester and Leeds / Bradford. In these sites, we liaised with local service providers and sent interviewers to recruit at specific drop-in or support group sessions run by those services. Some 'snowballing' also occurred when people who had been interviewed called their friends and encouraged them to participate. In addition to Manchester and Leeds / Bradford a number of other potential sites for recruitment were investigated including Birmingham, Edinburgh, Luton, Stoke-on-Trent and Reading. However, in none of these was it possible to gain access to a sufficient density of potential respondents to make trips to those sites viable.

Within the budget we chose not to use HIV or GUM out-patients clinics to recruit to the study. This decision was taken for two reasons. Practically, engaging with clinics as a potential recruitment site brings substantial extra administration costs. Conceptually, using clinics for recruitment is problematic. First, those African people with HIV that could be recruited at an HIV clinic were not likely to be the most needy in respect of treatment information, because clinic use will meet many of these needs. Also, the methodology prioritises personal contact for peer recruitment into the study and it was our view that relatively few clinics would allow peer researchers direct access to their patients even if they agreed in principle to collaborate with the study.

Ultimately we recruited and interviewed 438 African people with HIV. Three of these interviews were excluded on the basis that less than half of the schedule was completed, leaving 435 respondents in the final sample. The majority of interviewers felt that they could have recruited more respondents had our budget allowed.

1.5 THE INTERVIEWERS

The energy and optimism that the interviewers brought to this research project was the single most important reason for its success. Of the 26 people who were trained as interviewers, 22 subsequently completed any interviews. Of these 22, 13 were male and 9 female. While the 13 male interviewers conducted more interviews (60%, n=259) than the 9 female interviewers (40%, n=176), all interviewers averaged about 20 interviews each. Of the 22 interviewers, 20 carried out 10 interviews or more.

The 22 interviewers had seven different countries of birth: Uganda (8 interviewers), Zambia (6), Nigeria (2), Kenya (2), Zimbabwe (2), Angola (1) and UK (1). However, no single interviewer conducted interviews solely with respondents from their own country of birth and most respondents were not interviewed by someone of the same country of birth as themselves. More than half (58%) of all Zambian-born respondents were interviewed by an interviewer born in Zambia and just under half (48%) of Ugandan-born respondents were interviewed by a Ugandan-born interviewer. However, the match between the countries of birth of the interviewer and respondent was less substantial for the less common countries of birth: 33% for Nigeria, 20% for Kenya, Zimbabwe and the UK. There were no respondents born in Angola.

The language skills of the community interviewers were a key to our success in involving such a diverse range of respondents. While 90% of all interviews were conducted in English, 11 other languages were used including (in order of frequency): Luganda, French, Kiswahili, Swahili, Nyanja, Kikuyu, Bemba, Ndebele, Krio, Luo and Lingala.

In investigations in which the needs of the researchers are uppermost, multiple interviewers are often seen as a drawback. They result in greater variation in interview technique so data validity is more often questioned. However, in terms of participant-led recruitment where the research process itself can be thought of as an intervention, more interviewers enable you to collect more data from a wider range of respondents. In addition, community members undertaking the research interviews averted the credibility problems that have been associated with 'outsiders' carrying out research on black and minority ethnic groups. In a very tangible way the interviewers have begun the process of changing the perception within and outside African communities that research is something done by white people to black people, where the latter are relatively powerless. Our methods help overcome some of the substantial barriers that other research projects have struggled with: especially access to the population of concern via culturally sensitive and linguistically appropriate researchers. The project itself also built social capital – it trained 26 African people in research skills and engaged them in a process of needs assessment and policy and practice development that will be useful for the individuals themselves and the communities they are drawn from.

1.6 CONTENT OF THE REPORT

This is a report on the findings of the survey. The next chapter describes the broad characteristics of the respondents we recruited. The third chapter looks at their experiences of living with HIV. The fourth chapter reports data about their needs. Chapter five presents survey findings concerning both the appropriateness and effectiveness of those anti-HIV treatment information interventions they have already experienced, and their future preferences for interventions. Chapter six concludes the report with a range of broad policy and practice recommendations.

2 Description of the sample

The Survey of Prevalent Diagnosed HIV infection (SOPHID, PHLS 2002b) estimated there were 6,924 African people with diagnosed HIV infection living in England and in touch with services in 2001. Our sample of 435 African people with diagnosed HIV infection represents 6.3% of this entire population.

This chapter describes the sample using ten key variables: gender; age; country of birth; length of time living in the UK; current area of residence; current partnership status; having children and living with them, formal education level; employment status and religious affiliation. We compare the sample across these characteristics and, where possible, with what else is known of the population.

2.1 GENDER

The sample was two thirds female (65%, n=278) and one third male (35%, n=154) (gender was not recorded for three participants).

2.2 AGE

Respondents were asked in which year they were born. Their age ranged from 18 to 65 with an average (median) of 37 (mean = 37 years, 3 months; standard deviation (sd) = 7 years). The majority of all respondents were in their thirties (60%) or forties (32%).

As a group, the men (median 38 years) were older than the women (median 35 years), with 44% of the men aged 40 years or older compared with only 25% of the women.

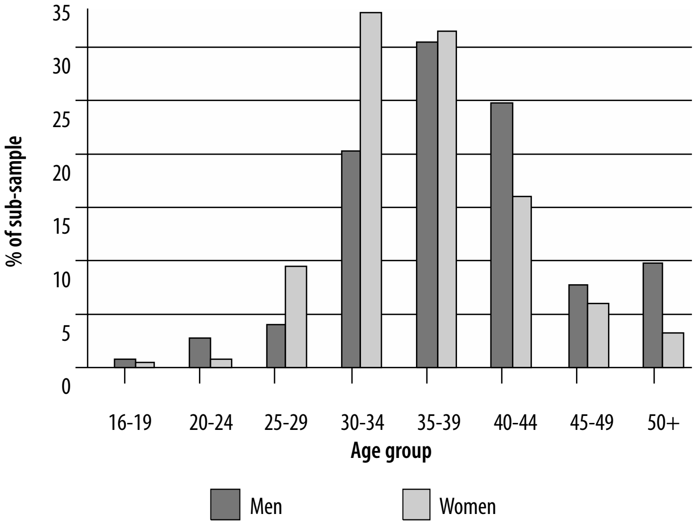

Figure 2.2: Proportion of the male and female sub-samples falling into each five year age band (N=1,1; 4,2; 6,26; 31,92; 47,87; 38,44; 21,16; 15,9)

Compared to the MAYISHA (Fenton *et al.* 2002) sample of African people in London (where the median male age was 31 years and the median female age was 27 years), our sample of Africans with HIV is older but with a similar age difference across gender.

2.3 COUNTRY OF BIRTH

Respondents were asked the open-ended question *What county were you born in?* Together they listed 26 African countries and six others. The table below shows the 13 countries where more than 1% of all our respondents were born. Almost two thirds of all respondents were born in **Uganda** (28%) or **Zimbabwe** (23%) or **Zambia** (14%). The thirteen countries listed in the table account for 92% of all respondents.

Whole sample (N=433, 2 missing)	Number born there	% born there	% who are FEMALE	% who are MALE
Uganda	119	28	69	31
Zimbabwe	99	23	69	31
Zambia	59	14	73	27
Kenya	29	7	55	45
Rwanda	14	3	64	36
Congo	13	3	42	58
Somalia	13	3	46	54
Republic of South Africa	12	3	67	33
Tanzania	10	2	60	40
Democratic Republic of Congo (Zaire)	9	2	22	78
Nigeria	9	2	67	33
Malawi	8	2	57	43
United Kingdom	5	1	40	60

The rest of the respondents were born in Namibia (4 respondents); 3 each from Botswana, Burundi, Cameroon and Côte d'Ivoire; 2 each from Ethiopia, Gambia, Ghana and Senegal; and 1 each from Burkina Faso, Eritrea, France, Jamaica, Lesotho, New Zealand, Papua New Guinea, Sierra Leone, Swaziland, and Trinidad & Tobago. While the vast majority (98%) of all respondents were born in Africa, some qualified by descent (their parents or grandparents were born in Africa).

In the sample overall, men account for only 35% of all respondents, but this was higher among the sub-samples born in the Democratic Republic of Congo (78% were male), Congo (58%) and Somalia (54%). We found no evidence for relationships between country of birth and respondents' age.

2.4 LENGTH OF RESIDENCE IN THE UK

Respondents were asked *How long have you lived in the UK?* Responses ranged from 2 months to 44 years with an average (median) of 4 years (mean = 5 years, 1 month; sd = 4 years, 3 months). In the rest of this report we sometimes compare groups of respondents who have lived in the UK for different lengths of time using the following bands: Under two years (30% of the sample); between two and four years (28%); between four and seven years (24%); and more than seven years (19%).

We found no evidence for relationships between length of time in the UK and gender or age. Among recent arrivals there were a very wide range of ages.

Respondents born in Uganda (mean = 5 years, 8 months) and Zambia (mean = 5 years, 8 months) had been resident in the UK significantly longer than those born in Zimbabwe (mean = 3 years, 2 months).

2.5 CURRENT AREA OF RESIDENCE

Respondents were asked the open-ended question *Which Local Authority do you live in? T*hey were asked to supply the first half of their postcode if they did not know the Local Authority, or the name of the area they lived in. Local Authority of residence was supplied by 97% of respondents.

England is divided into 28 Strategic Health Authorities (SHA) including five for Greater London. The following table shows the Local Authority and SHA of residence of the entire sample. The table shows only those Local Authorities where more than 1% of the entire sample were resident.

SHA of residence (N=422, 13 missing)	LA of residence	Number	% of sample
London North Central	**Total resident in SHA**	**133**	**32**
	Haringey	41	9
	Barnet	30	7
	Camden	23	5
	Enfield	21	5
	Islington	18	4
London North East	**Total resident in SHA**	**90**	**21**
	Waltham Forest	35	8
	Newham	25	6
	Hackney	19	4
London North West	**Total resident in SHA**	**46**	**11**
	Brent	24	6
	Westminster	11	3
London South East	**Total resident in SHA**	**44**	**10**
	Southwark	21	5
	Lambeth	14	3
	Lewisham	6	1
London South West	**Total resident in SHA**	**31**	**7**
	Croydon	15	3
	Merton	8	2
Greater Manchester	**Total resident in SHA**	**40**	**9**
	Manchester	20	5
	Salford	8	2
	Bolton	5	1
West Yorkshire	**Total resident in SHA**	**17**	**4**
	Leeds	13	3
Elsewhere	**Total**	**21**	**5**
	Oxfordshire	5	1

More than four fifths of the sample (81%) were resident in Greater London. Respondents lived in 28 of London's 33 Local Authorities. Recent research suggests that about 60% of the 500,000 African people living in the UK live in the ten London boroughs of Southwark, Newham, Lambeth, Haringey, Hackney, Lewisham, Brent, Islington, Barnet and Waltham Forest (London Research Centre, 2002). In our sample, 55% of Africans with HIV are resident in these 10 London boroughs, with a further 26% resident elsewhere in London. The majority of the remainder of the sample came from Greater Manchester (9%) or West Yorkshire (4%, Leeds / Bradford). These were the two sites specifically targeted for recruitment outside London.

Respondents resident elsewhere include 5 from Oxfordshire; 4 from Wolverhampton; 3 each from Lancashire and Luton; 2 from Hertfordshire; and 1 each from Birmingham, Staffordshire, Surrey and West Sussex.

In the rest of this report we sometimes compare groups of respondents depending on where they currently live in the UK. When we do we use the following areas: Greater London, Greater Manchester and West Yorkshire.

We found no evidence for associations between current Strategic Health Authority of residence and gender, country of birth or length of residence in the UK. However, the sub-sample resident in Greater Manchester were significantly younger than those living in London.

2.6 PARTNERS AND CHILDREN

Respondents were asked *Do you have either a husband or wife, or partner?; Do you have any children?* and (if they had children) *How many of your children live with you?*

Just under half of all respondents (48%, n=208) had a partner, husband or wife at the time of interview. Men were more likely to have a partner (59%) than women (42%) but the proportion with a partner was similar across the age range (those with a partner were not significantly older or younger than those without a partner).

There was no evidence for partnership varying by country of birth or length of time living in the UK. However, where respondents lived was significantly associated with whether they were partnered or not. The London sub-sample were most likely to be partnered (52%), followed by those resident in West Yorkshire (41%), while those resident in Greater Manchester were least likely to be partnered (18%). We tentatively suggest this is related to the size of the African communities in these different areas.

Three quarters (77%, n=333) of respondents had children and half (53%, n=230) were living with children at the time of interview. Among those who lived with children the majority lived with one (48%) or two (34%). Far fewer lived with 3 (6%) or 4 (8%) or 5 or more (4%) children.

While the majority of both men and women were parents, women were more likely to be (81% compared with 69% of men). Parenthood also significantly increased with age, with neither of the respondents under 20 being parents, 66% of those in their twenties; 76% of those in their thirties; 80% of those in their forties; and 95% of those fifty or older.

We found no evidence of a relationship between country of birth and whether respondents were currently living with children. However, Ugandans were more likely to have children (89%) than Zimbabweans (80%) or Zambians (69%).

We found no evidence of a relationship between length of residence in the UK or current (SHA) area of residence and having had children, or currently living with children.

2.7 EDUCATIONAL QUALIFICATIONS

Respondents were asked *What is your highest educational qualification?* and asked to indicate one of the five options in the table below.

Employment status **Whole sample (N=432, 3 missing)**	**Number in sample**	**% of sample**	**Grouping**	**% of sample**
No educational qualifications	19	4	Low	41
O-level, GCSEs, CSEs or equivalent	159	37		
A-level or equivalent	98	23	Medium	36
Vocational qualifications	57	13		
Degree or higher	99	23	High	23

With only 4% having no formal educational qualifications and almost a quarter (23%) having a degree this sample is not poorly educated. However, this sample of African people with HIV had less education than, for example, the MAYISHA sample of African people living in London (for which HIV status was not asked). In that study, 54% of men and 47% of women had a University education, compared with 35% of men and 16% of women in this study.

For further analysis and comparisons the five education groups were collapsed into three (*low*, *medium* and *high* education) as shown in the table.

Men were significantly more likely to have been educated to degree level (35%) than were women (16%) and, of the three largest country of birth sub-samples, the Zambians were most likely to have a degree (27%) compared to the Ugandans (23%) or Zimbabweans (15%). These differences were independent of each other.

Many Africans acquire educational qualifications in the UK and being educated to degree level was less common among those who had lived in the UK for less than 2 years (11% had a degree), rising to 20% among those resident for 2 to 4 years, 25% of those resident between 4 and 7 years and 38% of those living in the UK for over 7 years. However, education was not related to where respondents now lived.

The probability of being currently partnered increased with higher levels of education. Of those with *low* education 42% were partnered, compared with 48% of those with *medium* education and 60% of those with *high* education. However, we found no evidence of a relationship between education and being a parent.

2.8 EMPLOYMENT STATUS

Respondents were asked to indicate their current employment status using the categories listed in the table below, of which they could indicate more than one, although very few respondents indicated more than one term to describe their employment status.

For comparisons, responses were grouped into six categories exclusively, shown on the right of the table (*'signed off' long-term sick* and *retired* were merged as there were so few in these categories, as were *self-employed* and *in part-time employment*).

Employment status **Whole sample (N=428, 7 missing)**	**Number in sample**	**% of sample**	**% Grouping**
In full-time paid employment	46	11	11
In part-time paid employment	47	11	14
Self-employed	15	4	
Unemployed	217	51	51
'Signed off' long-term sick	22	5	6
Retired	2	< 1	
On a training scheme / Back-to-Work type activity	38	9	9
Student	41	10	10

Compared with the women, the men were more likely to be employed (either full-time, part-time or self-employed) while the women were more likely to be unemployed (61% of women compared with 44% of men).

Employment status varied by age with the students being youngest (mean = 35 years, 2 months) and those retired or 'signed off' long term sick being oldest (mean = 41 years, 8 months).

Employment, particularly full-time employment increased with increasing length of time living in the UK. Among those living here for under 2 years, only 3% were in full-time employment, compared with 8% (2 to 4 years), 16% (4 to 7 years) and 18% (over 7 years) among the longer resident groups. Unemployment decreased in a similar pattern.

Respondents with *high* levels of education were more likely to be in full-time employment (29%) compared to those with *medium* (6%) or *low* (5%) levels of education. Predictably those with *high* education were less likely to be unemployed (33% compared to 55% and 57%). It remains noteworthy, however, that a third of Africans with a university degree and diagnosed HIV were unemployed.

All the respondents who reported being on a training scheme / back to work type activity lived in London. Excluding these, there is no relationship between current area of residence and employment status. Current employment status was not associated with country of birth, partnership status, or having children.

2.9 RELIGIOUS AFFILIATION

Respondents were asked *What is your religious affiliation?* They were offered the options in the following table, which also shows the proportions indicating each answer and the list of other answers given.

The majority of respondents (87%) were of a Christian religion, with over a third (37%) being Catholics.

Men were significantly more likely to be Muslims (13%) or of another non-Christian religion (7%) than were the women (6% and 3% respectively). Also, significantly more of the Ugandans were Muslim (12%) than the Zambians (2%). None of the Zimbabweans were Muslim.

Religious Affiliation Whole sample (N=435)	**Number of sample**	**% of sample**
Roman Catholic	160	37
Protestant	109	25
Anglican	63	14
Other Christian denominations, including: Apostolic, Baptist, Born Again, Evangelical, Jehovah's Witness, Methodist, Orthodox, Pentecostal, Seventh Day Adventist, United Church of Christ	48	11
Muslim	36	8
Other including: Spiritualist, Believer, Cole, Latter Day Saints	19	4

We found no evidence of a relationship between religion and age, length of residence in the UK, current area of residence, being partnered or having children, highest education qualification or employment status.

2.10 COMPARISON WITH NATIONAL DATA

The difference between our sample and the English-resident population of African people with diagnosed HIV can be estimated by comparing sample demographics with the National Survey of Prevalent Diagnosed HIV Infections (SOPHID), conducted annually by the Communicable Diseases Surveillance Centre (PHLS, 2002b). SOPHID data was only available for 2001, the year before our survey was undertaken.

During 2001, SOPHID contained reports of 6,924 individuals with diagnosed HIV who reported their ethnicity as Black African. We exclude from our comparison those SOPHID respondents that were under 15 years of age (n=602) and those resident in Wales (n=19) or Northern Ireland (n=5). SOPHID does not include Scottish residents.

	This study	**SOPHID 2001**
Number (N)	435	6,298
% female	65%	65%
% male	35%	35%
Age Groups		
15-24	2%	6%
25-39	67%	69%
40-54	29%	23%
55 +	2%	3%
Resident in Greater London	81%	74%
Currently taking anti-HIV treatments	73%	66%

This comparison reveals that our sample was remarkably similar to what (little) is known about the national profile of (Black) African people with diagnosed HIV. We have an identical gender split and similar age ranges – though our sample has too few under 25s and too many over 40s. Our sample is also somewhat biased towards people resident in Greater London and on anti-HIV treatments.

3 Context of living with HIV

The preceding chapter described the sample using a number of standard demographic variables. This chapter looks at their experience of HIV infection and how it varied by the demographic characteristics previously described.

3.1 LENGTH OF TIME SINCE FIRST HIV DIAGNOSIS

Respondents were asked *When were you diagnosed with HIV?* They were asked to specify the year and month of diagnosis, from which we calculated time since diagnosis.

The range of time since first diagnosis was between 1 month and 16 years with an average (median) of 2 years 10 months (mean = 3 years, 8 months; sd = 3 years, 1 month). Figure 3.1 shows the number of years respondents had been living with diagnosed HIV at the time of their interview.

More than half (56%) of all respondents had been living with diagnosed HIV for 3 years or less. Two thirds (68%) had been living with HIV 4 years or less. Less than 6% had been living with HIV 10 years or more.

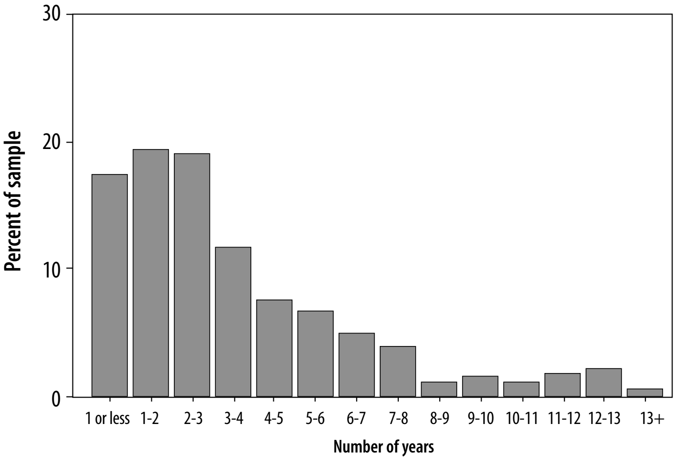

Figure 3.1: Years living with diagnosed HIV

In the rest of the report we sometimes make comparison between those diagnosed one year or less (17% of the sample), between one and two years (19%), two to five years (39%) and over five years (25%).

We found no evidence of a relationship between length of time since first diagnosis and gender, age, partnership status, having or living with children, or religious affiliation. However, length of time since diagnosis was associated with highest levels of educational achievement. Those with *high* levels of education had been diagnosed with HIV longest (mean = 4 years, 10 months) compared with those with *medium* (mean = 3 years, 10 months) and *low* levels (mean = 2 years, 11 months).

Respondents born in Uganda (mean = 4 years, 7 months) and Zambia (mean = 3 years, 11 months) had been diagnosed with HIV significantly longer than those born in Zimbabwe (mean = 2 years, 5 months). In addition, there was a strong positive relationship between length of time resident in the UK and length of time since first diagnosed with HIV. Those that have been in the UK longest have also been diagnosed with HIV longest.

There was a relationship between current SHA of residence and time since diagnosis: London residents (14%) were far less likely to report having diagnosed HIV a year or less compared to residents of Greater Manchester (30%), West Yorkshire (29%) and elsewhere (25%). While this may be one consequences of the Home Office's recent policy of dispersal of asylum seekers there is no way of confirming this.

Those that had been diagnosed longest (over 5 years) were more likely to report being in full-time (19%) or part-time (21%) employment compared with those who had been diagnosed less time.

- The majority had not been living with diagnosed HIV for very long – a third (37%) had been diagnosed less than 2 years; half (56%) less than 3 years; two thirds (68%) less than 4 years.

3.2 SETTING OF HIV DIAGNOSIS

It is widely thought that at diagnosis, Africans with HIV present with significantly more advanced disease than non-Africans, and that they have had their infection on average for a longer period of time (Burns *et al.*, 2001). This may be changing, not because Africans are being diagnosed earlier, but because the clinical and immunological parameters of HIV disease among White people at diagnoses are worsening while those among Africans remain constant (Barry *et al.*, 2002). Currently though, the difference in disease stage at diagnosis will partly be because migrant communities could not have their infection diagnosed in the UK before they lived here (ie. their recorded first diagnosis of HIV infection in the UK may not be their actual first diagnosis). It may also be because Africans with undiagnosed HIV infection are less likely to encounter or seek HIV testing services. Testing for HIV among Africans has been shown to be associated with use of STI services (unsurprisingly since that is where HIV tests are often offered) and with perceptions of HIV risk (Fenton *et al.*, 2002). Among one sample of people diagnosed with HIV, 28% of Africans had suspected they were positive compared with 45% of White people (Erwin *et al.*, 2002).

All respondents were asked *Where were you first diagnosed with HIV?* And given 5 options: *GUM, HIV or STD clinic; at your GP (family doctor); in a hospital (on a ward); ante-natal clinic (during pregnancy)* or *other*. Those that answered *other* were asked to specify a place of diagnosis.

The majority of all respondents were diagnosed in a hospital setting, either as an out-patient via a GUM, STD or HIV clinic or while on a ward as an in-patient. One in twelve (8%) were diagnosed in an ante-natal clinic and one in twenty (5%) via a GP. Other settings for diagnosis included: private clinics (3 people) and one each via blood donation and psychiatric services.

Where were you first diagnosed with HIV? **Whole sample (N=428, missing 7)**	**Number**	**%**
GUM / STD / HIV clinic	206	48
in hospital (on a ward)	161	38
Ante-natal clinic (during pregnancy)	34	8
at your GP (family doctor)	22	5
Other	5	1

All 34 respondents diagnosed in ante-natal settings were female. If we compare the other three potential sites of diagnosis (also excluding *other* as it was too small) then we find no evidence of a relationship between site of first diagnosis and gender, age, length of time resident in UK or country of birth, current SHA of residence, partnership status, living with children, educational achievement, employment status or religious affiliation.

As we have previously reported the average (median) time since first diagnosis was 2 years 10 months (mean = 3 years, 8 months) and the average (median) length of time respondents had been resident in the United Kingdom was 4 years (mean = 5 years, 1 month). If, for each respondent, we subtract one of these figures from the other we can establish (very) approximately whether respondents were first diagnosed with HIV in the United Kingdom or not. We find that just over a fifth of all respondents (n=88, 21%) were probably first diagnosed with HIV prior to their residence in the UK and another 5% (n=22) were probably first diagnosed at about the time they became resident in the UK. This leaves just under three quarters (n=303, 73%) who definitely were resident in the UK prior to their first HIV diagnosis.

- More than a third (38%) were first diagnosed in an in-patient hospital setting.
- Less than half (48%) were first diagnosed in an HIV/ GUM out-patients setting.

3.3 ILLNESS RELATED TO HIV

A majority of respondents (n=238, 55%) had been ill because of HIV (not including anti-HIV treatment side effects) at some point since their diagnosis.

Since your diagnosis, have you been ill because of HIV (not including treatment side effects)? **Whole sample (N=429, 6 missing)**	Number	%
No illness	191	45
Illness	238	55

Respondents' that had been ill were, on average older (mean = 38 years) than those who had not (mean = 36 years, 5 months). Since the men in the sample were older, on average, than the women it was not surprising that men (62%) were more likely than women (52%) to have ever been ill as a consequence of their HIV infection.

There was also a relationship between length of time diagnosed and having ever been ill because of HIV. On average, respondents who had been ill had been diagnosed longer than those who had not (mean 4 years, 2 months compared to 3 years, 1 month). Respondents resident in West Yorkshire (13%) were far less likely to report ever having been ill because of their HIV infection compared to respondents in Greater Manchester (45%), London (59%) or elsewhere (62%). This finding was not simply a consequence of differing age profiles but it was related to the length of time respondents had lived with diagnosed HIV (see also 3.1).

We found no evidence of a relationship between ever having been ill because of HIV and country of birth, length of residence in UK, partnership status, having or living with children; highest educational qualifications, employment status or religious affiliation.

There was a relationship between place of diagnosis and having ever been ill because of HIV. Predictably, those diagnosed in hospital were most likely to have been ill (68%) followed by those diagnosed at their GP (59%). Those diagnosed at GUM/ HIV out-patients (47%) and in ante-natal settings (41%) were considerably less likely to have ever been ill because of HIV. This suggests that interventions promoting HIV testing and early diagnosis are especially important.

- Just over half (55%) had been ill as a consequence of their HIV infection (not including treatment side effects).

3.4 USE OF ANTI-HIV TREATMENTS AND SIDE EFFECTS

The majority of all respondents (79%) had taken anti-HIV treatments at some point since their HIV diagnosis. The majority of those who had ever taken anti-HIV treatments were currently doing so (or 73% of the whole sample were currently taking anti-HIV treatments).

Have you ever taken any anti-HIV treatments? Are you taking any anti-HIV treatments at the moment? **Whole sample (N=435)**	Number	%
Never used anti-HIV treatments	91	21
No current treatment but previously taken them	25	6
Currently taking treatments	319	73

We found no evidence of a relationship between anti-HIV treatment taking and gender, country of birth, length of residence in the UK, current SHA of residence, educational qualifications or religious affiliation.

There is a strong and consistent relationship between anti-HIV treatment taking and age. The older respondents were, the more likely they were to currently be taking anti-HIV treatments: 50% of those in their twenties currently took treatments; 71% of those in their thirties; 82% of those in their forties; and 96% of those fifty or older.

Respondents who had children were more likely to currently be on anti-HIV treatments (77%) and less likely to have never taken them (17%) compared to those that did not have children (62%

currently taking treatments, 32% never taken). A similar effect is observed for respondents living with children but it only approaches statistical significance. Similarly, respondents with a current partner were more likely to currently be on anti-HIV treatments (78%) and less likely to have never taken them (16%) compared to those that did not have a current partner (69% currently taking treatments, 26% never taken them). We tentatively suggest that close personal relationships might be associated with health-seeking behaviour including treatment taking.

The relationship between current employment status and treatment taking was less straightforward. Students were least likely to be currently taking treatments (61%) followed by those in *full* (63%) or *part-time employment* (68%). Those who were *unemployed* (77%) or *retired* or *'signed off' sick* were most likely to be on treatments (83%). Clearly, this is partly a consequence of the relationship between treatment taking and age but it was also the case that those whose health was least problematic also had most opportunity to work or study.

Respondents that have been diagnosed with HIV for the shortest time were least likely to currently be on anti-HIV treatments and treatment taking increased as length of time since diagnosis increased (diagnosed 1 year or less, 65% currently on treatments; diagnosed 1-2 years, 70%; diagnosed 2-5 years, 75%; diagnosed 5 years or more, 78%).

There was a relationship between place of diagnosis and treatment taking. Those diagnosed in hospital were most likely to currently be on treatments (88%) followed by those diagnosed at their GP (77%). That those diagnosed in ante-natal settings (68%) and at GUM/ HIV out-patients (64%) were considerably less likely to be currently taking treatments suggests that interventions promoting HIV testing and early diagnosis are especially important for long-term health.

Predictably, there was also a relationship between treatment taking and ever having been ill because of HIV. Respondents that had ever been ill were more likely to be currently on treatments (83%) and less likely never to have taken them (12%) compared to those that had never been ill (61% of which were on treatments and 32% had never taken them). Of course having HIV-related symptoms is a clinical indicator of the need for treatment.

Of those currently taking anti-HIV treatments the vast majority did so twice (84%) or three times a day (14%). We found no evidence of a relationship between doses of treatments taken per day and any of the demographic or HIV related variables reported here or in Chapter 2.

The majority (86%) of those who had ever taken anti-HIV treatments had, at some point, experienced side effects. We found no evidence of a relationship between experience of treatment side effects and any of the demographic variables reported in Chapter 2.

- Just under three quarters (73%) were currently taking anti-HIV treatments.
- Almost all those currently on anti-HIV treatments took two (84%) or three (14%) doses per day.

3.5 WHO KNOWS YOU HAVE HIV

HIV infection is substantially stigmatised within African communities both within the UK and elsewhere. As a consequence, there is a widespread belief that disclosure of HIV infection is relatively uncommon among African people with HIV. Indeed recent research has suggested Black African people with HIV are less likely to have told friends and family about their diagnosis than are White people with HIV (Erwin *et al.*, 2002). This poses a range of serious problems including the absence of support from family and friends and obstacles to uptake of services for fear of the stigma associated with being known to have HIV.

Respondents were asked who knew they had HIV and given a choice of four individuals (GP, partner, mother and father) and five groups of people (friends, brothers / sisters, children, work colleagues and others who they lived with). For each category respondents were asked whether that category was applicable and whether the person knew or not. For group categories they were asked if none, some or all of those people knew. Respondents for whom the category was not applicable have not been included in the table.

Who knows that you have HIV?	**Number**	**% Does not know**	**% Knows**		
Partner	200	15	**85**		
GP (Family doctor)	405	23	**77**		
Mother	280	59	**41**		
Father	236	70	**30**		
	Number	**% None know**	**% Knows**		
			% Some	**% All**	**% Any Know**
Friends	402	16	72	12	**(84)**
Brothers / sisters	394	35	33	32	**(65)**
Other people living with	313	46	37	17	**(54)**
Children	281	64	14	22	**(36)**
Work colleagues	189	64	22	14	**(36)**

Respondents were most likely to have their status known by their partner (85%) and at least some of their friends (84%). While disclosure to GPs was relatively common (77%) it was probably less common than medical staff would hope. That is, almost a quarter of respondents with a GP had not disclosed their HIV infection to them.

Siblings were more likely to have been told than parents. A third of respondents (32%) had told all their siblings and another third (33%) had told some of them. Less than half of parents knew of their HIV diagnosis but mothers (41%) were more likely to know than fathers (30%). Almost two thirds (64%) had told none of their children and less than a quarter (22%) had told all of them. We found no evidence of a relationship between disclosure to any of these individuals or groups and gender, age, or country of birth.

- Respondents were most likely to have their status known by their partner (85%) and at least some of their friends (84%).
- Just over three quarters (77%) had disclosed their HIV infection to their GP.

3.6 SUMMARY

- The majority had not been living with diagnosed HIV for very long – a third (37%) had been diagnosed less than 2 years; half (56%) less than 3 years; two thirds (68%) less than 4 years. Compared to the others, those who had been diagnosed less than 2 years had:
    - lower levels of formal education,
    - were more likely to have been born in Zimbabwe,
    - were more likely to live outside London,
    - were least likely to be in full- or part-time employment.

- More than a third (38%) were first diagnosed in an in-patient hospital setting.

- Less than half (48%) were first diagnosed in an out-patients setting.

- Just over half (55%) had been ill as a consequence of their HIV infection (not including treatment side effects). Compared to the others, those that had been ill as a consequence of HIV, were:
    - more likely to be men and, on average, older,
    - more likely to have been diagnosed longer,
    - more likely to have been first diagnosed in hospital.

- Just under three quarters (73%) were currently taking anti-HIV treatments. Compared to the others, those that were not currently taking treatments were:
    - younger, on average,
    - less likely to have children,
    - less likely to have a current partner, husband or wife,
    - less likely to have ever been ill because of HIV,
    - more likely to have been diagnosed relatively recently,
    - more likely to have been diagnosed at HIV out-patient or ante-natal settings.

- Respondents were most likely to have their status known by their partner (85%) and at least some of their friends (84%).

- Just over three quarters (77%) had disclosed their HIV infection to their GP.

4 HIV health promotion needs

This chapter considers a number of HIV related behaviours and needs which social and health care programmes for people with HIV may wish to address. In generating this data for planning HIV health promotion in relation to African people with HIV, we are building on previous research investigating the needs of people with HIV which has delineated a number of overlapping spheres of need (Anderson & Weatherburn 1998, 1999; Anderson *et al.*, 2000; Weatherburn *et al.*, 2002).

Although there is currently no widely-agreed national framework for health promotion with people with HIV, let alone African people living with HIV, the collaborators involved with this research are in consensus that all people living with HIV in the UK should:

- Live in adequate and secure housing
- Have privacy if and when they want it
- Have enough money to live on
- Have access to training for employment and job opportunities
- Have self-confidence
- Be able to sleep soundly
- Be able to eat and drink adequately
- Be able to maintain adequate home- and self-care
- Be able to look after and keep their children with them
- Be able to get about and to use public services
- Be able to make, maintain and resolve problems with friendships
- Be able to access appropriate support if they experience relationship or sexual problems
- Be able to access appropriate support if they experience anxiety and depression
- Be able to access appropriate support if they experience alcohol and drug problems
- Have access to and be able to engage with health professionals
- Have access to their optimum anti-HIV treatments
- Be knowledgeable about anti-HIV treatments
- Be able to adhere to their prescribed treatment
- Find taking anti-HIV treatments easy
- Know about and have access to aide memoires to taking treatments
- Have clarity over their immigration status
- Not experience discrimination due to their HIV status, ethnicity, sexuality, gender, disability, religion or nationality

Evidence that these goals are not being met suggests needs that may be addressed though interventions. In this chapter we look across the range of needs broadly, before focussing specifically on the problems associated with taking anti-HIV treatments. Finally we examine respondents' knowledge and understanding of treatments. Findings about respondents' previous experience of interventions intended to address these problems are presented in chapter five.

4.1 PROBLEMS LIVING WITH HIV

In this first section we look at the broad context of day-to-day problems experienced by people with HIV. We ask two questions: what are the common problems of African people with HIV?, and which of these are particularly common when we compare African people with other ethnic groups?

4.1.1 Which areas of life are commonly a problem for African people with HIV?

To gain an initial idea of the relative prevalence of problematic areas of living, all respondents were asked to indicate which areas they had problems with in the last year. The following table gives the list of areas, the overall proportion of the sample indicating that area to have been a problem to them and the proportion of men and women separately. These problem areas, and the questions asked about them, are identical to those used in our 2001 national needs assessment of all people with HIV (*What do you need?*, Weatherburn *et al.*, 2002). That report also provides additional detail on the model of need used and its relationship to problems as investigated here. It also outlines how each of these problems are experienced by individuals and the kinds of interventions that they would prefer to address them.

Where there is a significant difference between men and women, the higher (ie. more problematic) is in **bold**, while the lower is underlined.

Whole sample (N=435) ***In the last 12 months, have you had any problems (for ANY reason) in relation to:***	**% all**	**% men**	**% women**
Money – getting enough to live on	77	78	76
Anxiety and depression	71	67	73
Sleeping	57	63	53
Self-confidence	56	52	59
Immigration status	55	57	54
Housing and living conditions	54	51	56
Relationships	51	52	51
Skills, training and job opportunities	48	47	49
Household chores and self care	42	44	40
Mobility - ability to get about	41	41	41
Sex	40	45	37
Discrimination	38	40	37
Looking after children (of those living with children only)	38	38	38
Eating and drinking	37	37	37
Taking anti-HIV treatments regularly (of those currently on treatments only)	37	33	38
Friendships	35	36	34
Dealing with health professionals	28	26	30
Knowledge of anti-HIV treatments	27	29	27
Drugs and alcohol	7	**14**	4

These figures suggest the broad priority areas for agencies concerned with the health and well-being of Africans living with HIV in England.

One area of living was problematic for over three quarters of all respondents (77%): getting enough money to live on. Since having insufficient money exacerbates the majority of other needs, interventions concerned with maximising income should be central to health promotion for African people with HIV.

The next most common problem was anxiety and depression (71%), which was exacerbated by problems in all other areas of life and also reduced individuals' abilities to address their other needs. Also, major depression has been found to be more common among African than White people with HIV although they are three times less likely to be referred for specialist mental health care (Malanda, Meadows & Catalan, 2001). As the second most commonly experienced problem among this sample, interventions to address anxiety and depression and the factors that contribute to them should be part of any health promotion programme and providers of all interventions to Africans with HIV should be aware of the likely impact of anxiety and depression on their service users.

The six next most common problems were experienced by about half (57-48%) of all respondents. These were problems with: sleeping, self-confidence, immigration status, housing and living conditions, relationships, and access to skills, training and job opportunities. Interventions addressing all these areas should feature prominently in health promotion programmes for African people with HIV.

Only one of the nineteen problems showed a significant difference by gender. Men were more likely than women to have experienced problems with drugs and alcohol (14% versus 4%). Interventions to address drug or alcohol problems should expect to see a higher proportion of men than interventions for other areas of concern.

The three areas that concern anti–HIV treatments were problematic relatively infrequently and all three were equally common among men and women. Taking treatments regularly was more commonly problematic than dealing with health professionals, which was slightly more commonly problematic than knowledge of treatments. Given the high prevalence of most of the practical and mental health problems, interventions addressing treatment-taking should not dominate a health promotion agenda. However, for agencies whose area of concern is treatment information needs, these findings demonstrate sufficient unmet need to warrant on-going interventions.

The nineteen problems demonstrated a high degree of association. No two problems were negatively associated and all problems were associated with at least half of the others. Four problems were positively associated with every other problem. These were: anxiety and depression; self-confidence; mobility; and dealing with health professionals. Having any of these four needs unmet, makes it more likely that you have all the other problems outlined.

Age and problems

Mobility was a more common problem among the older age groups. While 31% of those in twenties had experienced mobility problems in the last year, this figure was 39% for those in their thirties, 46% of those in their forties and 79% of those aged fifty and over.

Conversely, problems dealing with health professionals were less common among older respondents. While 31% of those in their twenties and 33% of those in their thirties had these problems, only 20% of the forties and 17% of those fifty or older had.

One other type of problem varied with age but not in a straightforward way. Experience of discrimination was most common among respondents in their thirties with 44% experiencing it in the last year. It was lowest among those in their forties (28%) and in-between for the twenties (32%) and fifty plus (33%) age groups.

Length of time in the UK and problems

Experience of nine of the nineteen problems was significantly associated with length of residence in the UK. The following problems were most common among those who had lived in the UK for the shortest period, and declined with increasing length of residence: money; anxiety and depression; immigration status; housing; (access to) skills, training and job opportunities; eating and drinking; knowledge of anti-HIV treatments. Overall, these findings suggest that health promotion programmes concerned with the health and well-being of African people with HIV should prioritise those who have been living in the UK for the shortest time, as they are the group most likely to be in need.

Two further problems varied by length of residence but were highest among those who had been in the UK between two and four years: problems with discrimination and problems with friendships.

4.1.2 Which problems are disproportionately experienced by Africans?

The preceding section considered the data from the perspective of an agency concerned with the health and well-being of African people with HIV. This section considers the perspective of a service for all people with HIV or a specific service that addresses a particular problem (eg. housing, treatments information, etc.). While the profile of service users will (probably) approximate the profile of all people with HIV, we argue it should be biased towards those groups who more commonly experience that problem. To approach this we need an idea of how problems are divided between people with HIV.

The following table compares the proportion of African people in this survey experiencing each problem in the last year, with the proportion of a larger group of White British people with HIV taken from our *What do you need?* survey from 2001 (Weatherburn *et al.*, 2002).

The following is based on multinomial logistic regressions treating each problem (individually) as the dependant variable and holding African versus White British as the factor. The following variables were entered into the model as co-variates: gender; age; currently partnered; currently live with children; University degree or not; currently in paid employment; ever taken anti-HIV treatments; ever been ill because of HIV; ever had side effects from treatments; currently on anti- HIV treatments; current number of doses of anti-HIV treatments per day. Hence, the differences described here between African and White British people with HIV, control for all variation in the co-variates described above.

In the last 12 months, have you had any problems (for ANY reason) in relation to:	% African (n=435)	% White British (n=1403)	Difference (scale of)
Immigration status	55	not applicable	
Money – getting enough to live on	77	29	10 times
Knowledge of anti-HIV treatments	27	4	8 times
Housing and living conditions	55	18	7 times
Discrimination	38	19	3 times
Relationships	51	29	2 times
Mobility - ability to get about	41	29	2 times
Friendships	35	24	1+ times
Skills, training and job opportunities	48	34	1+ times
Looking after children (of those living with children)	38	29	no difference
Household chores and self care	42	35	no difference
Taking anti-HIV treatments regularly (of those currently on treatments)	36	31	no difference
Self-confidence	56	48	no difference
Anxiety and depression	71	66	no difference
Dealing with health professionals	28	27	no difference
Sex	40	52	no difference
Sleeping	57	60	no difference
Eating and drinking	37	42	no difference
Drugs and alcohol	7	15	no difference

This sample of African people with HIV more commonly indicated problems in 8 of the 19 areas of daily life. Dealing with the Immigration Service was a huge and specific problem for at least half of all these Africans with HIV. For them, it is likely that their uncertain immigration status undermines ever other aspect of their life – their access to money via work or benefits and consequently their access to reasonable housing and other essentials for everyday life.

Since we cannot compare these population groups on their experience of immigration problems, the three problems with the greatest differences between these populations were: getting enough money to live on, knowledge of anti-HIV treatments and housing and living conditions. These problems were seven to ten times more likely among African people with HIV than white British.

The largest difference between these populations was with problems getting enough money to live on – which was also the most common problem for the whole sample of African people with HIV. Since having insufficient money exacerbates most other needs, interventions concerned with maximising income should be central to health promotion for African people with HIV. Addressing problems with income would also undermine problems with housing and living conditions. More surprising perhaps was the proportion who had problems with their knowledge of anti-HIV treatments. This was not a very common problem among the white majority but was eight times more common among African people with HIV. This suggests that interventions intended to improve knowledge of treatments should be heavily biased towards African people with HIV.

Problems in five other areas of life were considerably more common for African rather than white British people with HIV, especially: experience of discrimination, relationship difficulties and mobility problems. Interventions addressing these problems among people with HIV should also both expect a greater proportion of African people among their users than in the general population of people with HIV, and actively target African people to ensure this is the case.

In ten areas of living, there was no significant difference between African people and white British in the likelihood of experiencing problems in the last 12 months. For no single problem area were white British people with HIV significantly more likely to experience a problem compared with African people with HIV.

In the comparison above, the largest differential between African and White British people with HIV was the extent to which (basic) practical needs were problematic. This does not mean African people with HIV did not have mental health problems – they were just as likely to. However, they were profoundly more likely to have basic practical needs unmet – including access to housing, money and employment. Clearly, African people with HIV should be a priority for specific services offered by specialist support agencies that deal with single issues (such as financial support or housing advice). Moreover, generic HIV support agencies should prioritise Africans with HIV on a range of practical needs such as support with getting enough money to live on, getting about etc. That discrimination was also more likely to be a problem for African than White British people suggests one of the reasons that this population was so needy in other respects. It appears that, in very many ways, African people with HIV need more and get less.

- In the last year, between half and three quarters of all respondents had experienced problems with the following practical and emotional needs:
  - getting enough money to live on (77%),
  - anxiety and depression (71%),
  - sleeping (57%),
  - lack of self-confidence (56%),
  - immigration status (55%),
  - housing and living conditions (54%),
  - relationships (51%),
  - access to skills, training and job opportunities (48%).

- Many of the above problems were especially common among respondents who have lived in the UK for the shortest time, especially those resident in the UK for less than a year.

- Compared with White British people with HIV this sample of African people with HIV more commonly indicated problems, in the last year, in 8 of our 18 areas of daily life. Significantly more common were problems with:
  - getting enough money to live on (10 times more likely),
  - knowledge of anti-HIV treatments (8 times more likely),
  - housing and living conditions (7 times more likely),
  - experience of discrimination (3 times more likely),
  - relationships (twice as likely),
  - mobility – ability to get about (twice as likely),
  - friendships,
  - access to skills, training and job opportunities.

4.2 PROBLEMS TAKING ANTI-HIV TREATMENTS

We saw in the last section that while problems associated with taking treatments were less common than many other problems for African people with HIV, they were common enough to warrant continuing intervention. In the following section we look at findings from more specific questions about taking anti-HIV treatments.

4.2.1 How problematic is access to anti-HIV treatments?

All respondents were asked *In the last 12 months, have you had any problems getting access to anti-HIV treatments?* Only 3% of those who felt they had needed treatments reported problems accessing them. Although this is a broad measure of problems with access, the question revealed few problems, suggesting access to anti-HIV treatments was not a major problem for this group.

IIn the last 12 months, have you had any problems getting access to anti HIV treatments? **Whole sample (N=434)**	**Number**	**% of all**	**% of those needing treatment**
Not needed any	74	17	–
No	348	80	97
Yes	12	3	3

4.2.2 How problematic is adherence?

Respondents were asked about how many doses of prescribed anti-HIV treatment they had missed taking in the last two weeks.

How many doses of anti-HIV treatments have you missed in the last two weeks? **Of those currently taking treatment (N=318)**	**Number**	**% of those taking treatment**	**% of those missing any doses**
None	209	66	–
One or two	87	27	80
Three or four	16	5	15
Five or six	4	1	4
Seven or more	2	<1	2

A third (34%) of those currently taking treatments had missed one or more doses in the preceding fortnight. This is similar to the 30% indicating a problem in the last year with regular treatment taking. However, while missing doses was associated with indicating a problem with regular treatment taking in the last year, they were not the same groups: half (50%) of those who indicated having missed a dose in the last fortnight did not say they had a problem in the last year, while 29% of those who indicated they had missed no doses did indicate they had a problem regularly taking treatment in the last year. This suggests both that many people with HIV do not see missing doses as a problem, and many people who do not miss doses do find treatment-taking a problem.

We found no evidence of a relationship between missing doses and gender, age, country of birth, length of residence in the UK, current area of residence, currently being partnered, having children or living with children, highest education qualification, employment status, religious affiliation or length of time since HIV diagnosis.

4.2.3 Common reasons for missing doses – what are adherence needs?

All respondents who reported missing doses (in the question about informing their doctors about missed doses – see section 5.3.3) were asked: *What are the most common reasons for you missing doses of anti-HIV treatments?*

What are the most common reasons for you missing doses of anti-HIV treatments? **More than one response possible (N=225)**	**Number**	**%**
I just forget sometimes	159	70
My social life interferes (hard to take them when I am out with friends / family)	90	40
Side effects make it difficult (vomiting, sleeping etc.)	60	27
I have no privacy to take them (people around me don't know my status)	49	22
I have physical difficulty in taking them (swallowing, pill size etc.)	32	14
My working life interferes	20	9
Other	20	9

Most commonly, doses were missed because they were forgotten or other activities related to the respondents social life interfered. Over a quarter of those missing doses did so because of difficulty with side-effects, and a fifth missed doses because they could not take them in private. Of those who gave an *other* response the most common (n=8, 4%) was tiredness with taking treatments and the need for a break or rest. Less (n=4, 2%) said they did not take them due to depression and the same proportion (n=4, 2%) said they had other activities such as college or immigration office appointments took precedence. Individuals also reported running out; being late for a dose; having difficulty explaining taking drugs to others; finding the strict regimen difficult; and not taking them because they were 'happy'.

Adherence to chronic therapy is always challenging and complex, but anti-HIV therapy is unusual in that very high levels of adherence are necessary for success. These findings suggest that simply forgetting, especially in a varied life-style or work context, is the most common contributor. Simple cognitive-behavioural interventions may help here, including memory aids which are considered especially helpful in establishing treatment-taking routines. However, the finding that 'I just forget sometimes' needs further investigation – using more in-depth research techniques. It remains unclear the extent to which forgetting is influenced by motivational as well as more straightforward cognitive factors. Adherence to drug regimens would also be improved by reductions in side-effects and the physical difficulty in taking them (which requires better designed drugs). Also, interventions to undermine the stigma associated with HIV disease could make drug taking easier.

- Among people who need anti-HIV drugs, access to them was rarely problematic.
- A third (34%) of those currently taking anti-HIV treatments had missed one or more doses in the preceding fortnight.
- The main challenge in adhering to complex drug regimens was simply remembering to take them (at least twice a day, every day).

4.3 KNOWLEDGE OF ANTI-HIV TREATMENTS

One of the central focuses of this research was to establish the knowledge and understanding of anti-HIV treatments among African people with HIV. Such understanding is assumed to arise from a range of treatment information interventions including written information and discussion with, and information from, HIV clinical staff. This project arose from anecdotal evidence that there were insufficient treatment information interventions which were appropriate to African people with HIV. Having access to appropriate HIV treatment information is essential because high adherence levels require that people understand the requirements of the regimen and have a basic understanding of the rationale for their anti-HIV treatment (Anderson *et al.*, 1999; Tuldra *et al.*, 2000).

We saw in section 4.1.1 that 27% of this sample indicated they had experienced some kind of problem with regard to knowledge of treatments in the last year. The following section looks at treatment knowledge in greater detail.

4.3.1 Measured knowledge

All respondents were given nine statements about anti-HIV treatments and told that they were all true. They were asked, for each statement, to indicate whether*: you already knew this; you weren't sure about it; you didn't know this already*. We used this method, rather than a true / false test both to ensure we did not mislead respondents and to maximise the educational benefit of the survey. The following table shows the 'facts' they were presented with, and the proportions indicating they *did not know this* and the proportion who were *not sure*. Topics are ordered by the largest proportion *who did not know*.

Whole sample (N=435) ***All the following statements are true ...***	**% didn't know**	**% not sure**
Some anti-HIV treatments cause cholesterol levels to rise	33	30
Neuropathy means damage to the nerves	28	16
Drug resistance is an important reason why HIV treatments may fail	9	21
Anti-HIV treatments can stop many pregnant women with HIV passing it to their child	7	15
Missing doses of anti-HIV treatments can allow drug resistance to develop	7	11
Undetectable viral load does not mean that HIV has been eradicated from the body	7	11
At present, combinations of at least 3 anti-HIV drugs provide the best chance of reducing the amount of HIV in your blood to very low levels	6	22
Anti-HIV treatments prevent HIV from damaging your immune system, and so prevent ill health	3	13
A woman with HIV can pass it to her child during breastfeeding	2	7

A lack of understanding of the impact of some treatments on cholesterol was relatively common (63% did not know or were uncertain) but this is one of the more recent developments asked about. Almost half (44%) were uncertain about the meaning of neuropathy, and almost a third (30%) were uncertain of the relationship of drug resistance to treatment failure. However, most other items were unknown (or uncertain) to about a fifth of respondents. Whether, these levels of knowledge are good, bad or indifferent is largely a matter of opinion but all these figures should be seen as lower estimates of unmet need, because the way we asked the question probably led some people to not admit their lack of knowledge.

4.3.2 Satisfaction with current knowledge

Our second approach to judging unmet needs for anti-HIV treatment knowledge was to ask about satisfaction. All respondents were asked: *Overall, are you satisfied with what you know about anti- HIV treatments?* Overall, just over a third (36%, n=153) said no they were not satisfied with what they knew, and just under two thirds (64%, n=272) said yes they were satisfied (10 respondents did not answer this question).

Satisfaction with current knowledge about anti-HIV treatments was not associated with gender, age, educational achievement, or length of time resident in UK. However, it was associated with country of birth: respondents born in Zimbabwe were much more likely to be satisfied with what they knew about anti-HIV treatments (81% were satisfied) compared with respondents born in Zambia (63% satisfied) or Uganda (57% satisfied).

Those who were currently taking treatment were asked the additional question: *Do you feel you know enough about the anti-HIV treatments you are taking, at the moment?* One in seven (14%) of those on treatments indicated no, they did not know enough about their current treatment and a further 32% were unsure.

4.3.3 Topic areas for which more knowledge is desired

All respondents were also asked: *More specifically, are you satisfied with what you know about* ... and given a list of HIV treatment related topic areas. This list was very diverse and included aspects of HIV medicine (viral load, CD4 tests and counts, clinical trials etc.), likely side effects (lipodystrophy etc.) and broader topics such as pregnancy, nutrition and HIV prevention. The table below shows the proportions *not satisfied* or *not sure* about their current knowledge of each topic. Later in the schedule, respondents were offered the same list and asked which they would like more information about. Topics are ordered by the largest proportion not satisfied with their current knowledge.

More specifically, are you satisfied with what you know about... (N=435) *What specific area/s would you like to have more information on?*	% not satisfied	% not sure	(of those wanting to know more about anything) % wanting to know more about that (n=396)
Lipodystrophy (body fat changes)	33	30	80
Clinical trials of anti-HIV treatments	28	37	76
Looking after children (of those living with children only)	20	17	46
Pregnancy and HIV	17	18	47
Side-effects of anti-HIV treatments	14	24	82
Viral load	12	15	62
Illnesses related to HIV	11	26	68
Resistance to anti-HIV treatments	11	27	85
Nutrition / dietary advice	10	18	56
CD4 tests and counts	9	19	62
Adherence (taking treatment as prescribed)	8	22	67
Availability of anti-HIV treatments	6	16	58
Preventing HIV transmission	1	6	46
Other topics	[not asked]	[not asked]	10

For all topics, more respondents indicated they would welcome more information than said they were dissatisfied with what they currently knew. The ranking of topics by satisfaction was not the same as the ranking by wanting to know more.

While 10% of respondents specified other specific areas on which they would like more information, only half of these specified what they were. Most commonly respondents requested information on progress towards a "cure for AIDS", with others wanting information on microbicides, mutation of HIV, complementary therapies and support groups.

- The majority of respondents knew many of the most basic facts about anti-HIV treatments but many could benefit from a more secure footing for their knowledge.

- A third (36%) of respondents were not satisfied with what they knew about anti-HIV treatments.

- A seventh (14%) of respondents did not feel they knew enough about the anti-HIV treatments they were currently taking and a further third (32%) were unsure whether they knew enough.

4.4 SUMMARY

- In the last year, between half and three quarters of all respondents had experienced problems with the following practical and emotional needs:
    - getting enough money to live on (77%),
    - anxiety and depression (71%),
    - sleeping (57%),
    - lack of self-confidence (56%),
    - immigration status (55%),
    - housing and living conditions (54%),
    - relationships (51%),
    - access to skills, training and job opportunities (48%).

- Many of the above problems were especially common among respondents who have lived in the UK for the shortest time, especially those resident in the UK for less than a year.

- Compared with White British people with HIV this sample of African people with HIV more commonly indicated problems, in the last year, in 8 of our 18 areas of daily life. Significantly more common were problems with:
    - getting enough money to live on (10 times more likely),
    - knowledge of anti-HIV treatments (8 times more likely),
    - housing and living conditions (7 times more likely),
    - experience of discrimination (3 times more likely),
    - relationships (twice as likely),
    - mobility – ability to get about (twice as likely),
    - friendships,
    - access to skills, training and job opportunities.

- Among people who need anti-HIV drugs, access to them was rarely problematic.

- A third (34%) of those currently taking anti-HIV treatments had missed one or more doses in the preceding fortnight.

- The main challenge in adhering to complex drug regimens was simply remembering to take them.

- The majority of respondents knew many of the most basic facts about anti-HIV treatments but many could benefit from a more secure footing for their knowledge.

- A third (36%) of respondents were not satisfied with what they knew about anti-HIV treatments.

- A seventh (14%) of respondents did not feel they knew enough about the anti-HIV treatments they were currently taking and a further third (32%) were unsure whether they knew enough.

5 Interaction with interventions

5.1 SETTING OF CLINICAL MANAGEMENT INTERVENTIONS

Respondents were asked which HIV (GUM) clinic they usually went to. Answers were missing for twenty three respondents (5%) and a further twenty four answered none (6%) meaning there was not a clinic they usually attended. While the latter answer is perfectly reasonable if respondents had recently been diagnosed or moved home, we suspect that some of the respondents' answered none (or refused to answer) so as not to disclose information that they perceived might threaten their identity. That is, of those that said none or refused to answer: a third (33%) subsequently said they went to a clinic at least monthly, 27% went every 3 months, 23% every 6 months and 7% went less often. Hence, only three respondents both did not list a clinic they usually went to and also stated that they never went to a clinic (see section 5.2 below).

The remainder gave the name of either a HIV (GUM) out-patients clinic or hospital (388, 89%). The table below lists the name of the hospital usually attended, in order of their popularity. Hospital names are used because many respondents did not name the actual clinic used, although these are usually easily inferred. Hospitals outside London are in **bold**.

Which HIV (GUM) clinic do you usually go to? **Of those listing a usual clinic (N=389)**	**Number**	**%**
The Royal Free Hospital	35	9
St Mary's Hospital (London)	33	9
St George's Hospital	30	8
North Middlesex Hospital	29	7
King's College Hospital	27	7
Newham General Hospital	22	6
St Thomas' Hospital	22	6
University College Hospital (Mortimer Market Centre)	19	5
North Manchester General Hospital	19	5
Homerton University Hospital	18	5
Manchester Royal Infirmary	15	4
Chelsea & Westminster Hospital	13	3
Mayday University Hospital	12	3
Royal London Hospital	10	3
Central Middlesex Hospital	10	3
Leeds General Hospital	9	2
Whittington Hospital	7	2
St Bartholomew's Hospital	5	1
Northwick Park Hospital	5	1
St Hellier's Hospital	5	1
Royal Bolton Hospital	4	1
Radcliffe Royal Hospital (Oxford)	4	1
Kingston Hospital	4	1
Whipps Cross University Hospital	4	1
Other clinics (listed by less than than 1% of respondents)	27	7

Only clinics used by more than 1% of respondents are in the table. Others included: Seacroft (Leeds) (3 respondents); Lewisham, Barnet, Burnley General, Churchill (Oxford), Ealing, Luton & Dunstable (2 respondents each); Hillingdon, Baille Street Health Centre, Queen Mary's, Royal Oldham, St Ann's, St Luke's, Staffordshire District General, Barking, Watford General and West Middlesex University (1 respondent each). Also one each for 'private GP' and 'private clinic'.

The degree to which respondents attended HIV (GUM) out-patients clinics in the same Primary Care Trust (PCT) as they lived varied considerably between cities and especially within London. Outside London the vast majority of respondents attended clinics in the PCT in which they lived: in Leeds 92% (12 respondents of 13) did; in Manchester 95% (19 respondents of 20); and in Oxfordshire 100% (5 of 5).

However, in London considerably more variation was observed with an absolute maximum of two thirds of respondents staying in the PCT they lived for routine HIV care. Indeed, in London, if we consider whether respondents stayed within their Strategic Health Authority of residence for their HIV care, the proportion that did so varies between 58% and 87%. With the exception of London South West (87%) the other London SHAs see about two thirds of their residents for routine HIV care. The table below illustrates (for London residents) the percentage receiving care in their PCT and SHA of residence. Only PCTs where more than 1% of the sample live are shown.

SHA of residence (London residents listing usual clinic, N=344, 4 missing)	LA of residence	Number of Residents	% getting HIV care in SHA / PCT
London North Central	**Total resident in SHA**	**133**	**66**
	Haringey	41	3
	Barnet	30	10
	Camden	23	50
	Enfield	21	60
	Islington	18	28
London North East	**Total resident in SHA**	**90**	**58**
	Waltham Forest	35	0
	Newham	25	56
	Hackney	19	61
London North West	**Total resident in SHA**	**46**	**65**
	Brent	24	35
	Westminster	11	56
London South East	**Total resident in SHA**	**44**	**68**
	Southwark	21	53
	Lambeth	14	8
	Lewisham	6	25
London South West	**Total resident in SHA**	**31**	**87**
	Croydon	15	33
	Merton	8	0

- Outside London the vast majority attended HIV clinics in the PCT in which they lived (Leeds 92%, Manchester 95%). In London, less than half (0-60%) stayed in the PCT they lived for their routine HIV care.

5.2 FREQUENCY OF CLINICAL MANAGEMENT INTERVENTIONS

All respondents were asked *How often do you go to your HIV (GUM) clinic?* They were allowed six options for their answer, as outlined in the table below.

How often do you go to your HIV (GUM) clinic? **Whole sample (N=415, 20 missing)**	**Number**	**%**	**Cumulative %**
More than once a month	47	11	11
Every month	112	27	38
Every 3 months	218	53	91
Every 6 months	17	4	95
Less often (than every 6 months)	18	4	99
Never	3	<1	100

More than one third (38%) of all respondents reported attending HIV (GUM) out-patients at least every month and the vast majority (91%) attended at least every three months.

Three respondents (less than 1%) reported *never* attending HIV (GUM) out-patients services and all of these answered *none* to the previous question on which HIV (GUM) clinic they usually went to. Of these three, two had never taken anti-HIV treatments but neither reported difficulties accessing them and both reported discussing anti-HIV treatments with medical personnel in the last twelve months. The remaining respondent was currently on anti-HIV treatments suggesting he might receive medical support in another context (privately perhaps) or share treatments with someone who was prescribed it directly.

- More than one third (38%) reported attending HIV out-patients at least every month and the majority (91%) attended at least every three months.

5.3 RELATIONSHIPS DURING CLINICAL MANAGEMENT INTERVENTIONS

All respondents currently on anti-HIV treatments were asked a range of questions on their relationships with HIV clinic staff, and their satisfaction with those relationships.

5.3.1 Understanding of anti-HIV treatment information from HIV clinic staff

All those respondents currently taking anti-HIV treatments were asked *How often do you understand what HIV clinic staff tell you about your anti-HIV treatments?*

How often do you understand what HIV clinic staff tell you about your anti-HIV treatments? **Current treatment takers (n=314, 5 missing)**	**Number**	**%**
Always	129	41
Usually	177	56
Never	8	3

The majority of all current treatment takers either *usually* (56%) or *always* (41%) understood the information given to them by HIV clinic staff. A small proportion (<3%) never understood what HIV clinic staff told them about the anti-HIV treatments they were currently taking.

Respondents who reported that they did not *always* understand information on anti-HIV treatments given by HIV clinic staff were asked *How often do you ask HIV clinic staff questions when you don't understand what they are saying about your anti-HIV treatments?* Over a third (39%) reported *always* asking HIV clinic staff questions when they did not understand what they were saying about treatments and over a half (56%) *usually* asked. Of more concern were a minority of respondents (5% of those that did not *always* understand, 3% of all those currently on treatments) who did not always understand what HIV clinic staff told them about their treatments and never asked HIV clinic staff questions about their anti-HIV treatments.

5.3.2 Satisfaction with joint decision making with HIV clinic staff

All of those respondents currently taking anti-HIV treatments were asked *How satisfied are you about the way you and the HIV clinic staff make decisions together, about your anti-HIV treatments?*

How satisfied are you about the way you and the HIV clinic staff make decisions together, about your anti-HIV treatments? **Current treatment takers (N=314, 5 missing)**	**Number**	**%**
Very satisfied	140	45
Somewhat satisfied	160	51
Not at all satisfied	14	4

The vast majority (96%) of respondents who were currently taking treatment were *somewhat* (51%) or very *satisfied* (45%) with the way decisions about anti-HIV treatment were made between themselves and HIV clinical staff. Only a small minority (4%) were *not at all satisfied.*

5.3.3 Informing doctors of missed doses

All respondents currently taking anti-HIV treatments were asked *Do you tell your doctor when you miss doses of anti-HIV treatments?*

Do you tell your doctor when you miss doses of anti-HIV treatments? **Current treatment takers (N=312, 7 missing)**	**Number**	**%**	
I never miss doses	85	27	%
Yes	140	45	62
Sometimes	51	16	22
No	36	12	16

More than a quarter (27%) of respondents reported that they never miss doses of their anti-HIV medicine. Of those that reported any missed doses, the majority *always* (62%) or *sometimes* (22%) informed their doctor. However, one in six (16% of those who miss doses, or 12% of those on treatments) did not inform their doctors when they missed doses.

- The majority of all current treatment takers either *usually* (56%) or *always* (41%) understood the information given to them by HIV clinic staff.
- The vast majority (96%) of respondents currently taking treatments were *somewhat* (51%) or *very satisfied* (45%) with the way decisions about anti-HIV treatment were made between themselves and HIV clinical staff.
- Of those respondents currently on treatments that reported any missed doses, the majority *always* (62%) or *sometimes* (22%) informed their doctor.

5.4 ACCESS TO TREATMENT INFORMATION INTERVENTIONS

All respondents were asked *In the past 12 months, have you had any problems getting information about anti-HIV treatments?* Overall, **81%** (n=353) said NO they had not had any problems and another **10%** (n=43) said they had not needed any anti-HIV treatments information. This leaves **9%** (n=38) of the whole sample who said they had problems getting anti- HIV treatments information in the previous 12 months.

We found no evidence of a relationship between having had problems getting information about anti-HIV treatments and gender, age, partnership status, living with children, educational achievement, country of birth or length of time resident in UK.

5.4.1 Experience of treatment information interventions

All respondents were given 13 (learning) options and asked: *Thinking about what you already know about anti-HIV treatments, which of the following activities have you done in the last 12 months?* The full list of options offered and the proportion of respondents who had done each one in the last 12 months is indicated in the table below.

Thinking about what you already know about anti-HIV treatments, which of the following activities have you done in the last 12 months? **Whole sample (N=434, 1 missing)**	**% done it**
TALKED with medical staff like doctors or nurses etc.	96
READ leaflets and pamphlets	93
READ newsletters and the HIV-positive press	90
TALKED with workers from HIV organisations	87
TALKED informally with other people with HIV	84
TALKED with other people with HIV at support groups	84
TALKED with workers from Black organisations	76
READ mainstream newspapers and magazines	75
TALKED with my friends	64
ATTENDED presentations (seminars) from positive people	63
ATTENDED presentations (seminars) from medical staff	43
READ medical journals	42
READ web-pages / the internet	34

With regard to anti-HIV treatments, the vast majority of respondents had engaged in some form of talking (99%) and / or reading (99%) intervention in the last 12 months. Two thirds (66%) had attended some form of presentation about anti-HIV treatments in the same period.

The majority of respondents who reported attending presentations (seminars) on anti-HIV treatments from medical staff had also attended presentations from people with HIV in the last 12 months. All respondents who reported attending either type of presentation had also experienced other talking interventions and almost all had done reading interventions, in the last 12 months.

In some form or another, talking interventions were almost universally used in the last 12 months. Talking with medical staff like doctors and nurses was the most common of all interventions engaged with (96% had done this). Having talked about anti-HIV treatments with workers from HIV (87%) and Black or African (76%) organisations was also very common, as was talking with other people with HIV either informally (84%), or via support groups (84%). Finally, two thirds of all respondents (64%) had talked with friends about anti-HIV treatments at some time in the last 12 months.

Of the six respondents that had not experienced any of the talking interventions in the last 12 months, five had read about anti-HIV treatments. Only one respondent had experienced none of the types of interventions listed in the table above, in the last 12 months. He had never taken anti-HIV treatments, and although he was asylum seeker he reported no recent problems in getting information about anti-HIV treatments, and no interest in knowing any more about them.

In the last 12 months, reading interventions were almost universally used in some form or another. Reading pamphlets or leaflets (93%) and specific newsletters and the HIV-positive press (90%) were especially common. Mainstream newspapers were mentioned by three quarters (75%), though their use was limited to keeping 'an eye out' for new information. Reading medical journals (42%) and web pages and the internet (34%) were less common.

Engagement with written resources for learning about anti-HIV treatments was prioritised over talking interventions in the remainder of the questionnaire both because of NAMs collaboration in this research, and the widespread assumption that the current range of written resources for people with HIV may be less appropriate to African audiences.

5.4.2 Settings of reading interventions

All those respondents who reported reading any HIV publications in the last 12 months (N=422, missing 1) were asked *How do you usually get hold of the publications you read?* The vast majority collected written materials at their HIV (GUM) clinic (83%) and / or from support groups and HIV organisations (80%). Indeed, not only had almost all respondents (99%) read some form of HIV publication in the last 12 months, but 96% had either collected such materials from a GUM (HIV) clinic or from support groups and HIV organisations.

A quarter (27%) subscribed directly to written resources on treatment information, that is had them delivered directly to their home. Similar proportions received them from friends (26%) or accessed them via the internet (25%). Just 4% of respondents listed *other* sources of written material (N =14, 5 missing). These included picking them up from seminars and conferences or during presentations and collecting them from the place they worked or volunteered. A couple of respondents buy newspapers when they see a caption on HIV but only one had collected written material on HIV from their GPs surgery.

All respondents who read anything about anti-HIV treatments in the last 12 months were asked: *Do you take any publications you read home with you?* Overall, 86% (n=362) stated that they had taken home with them some reading matter concerned with HIV treatments and only 14% (n=60) had not. Those respondents (14%) who had not taken any reading materials home with them were asked *Why do you not take them home with you?* (n=55, 5 missing). The vast majority (80%) of those who did not take home anti-HIV treatment related publications were concerned about privacy and confidentiality. That is, they worried that the publications would make it more likely that their HIV status would be guessed or discovered by other people in their home including family, friends, relatives or people they shared accommodation with. A minority did not take HIV publications home because they did not have time to read, were generally disinterested, read them where they found them (in clinics and ASOs), were homeless, felt they were only for gay men or were unaware of their existence.

5.4.3 Acceptability of reading interventions

All respondents were asked: *Generally speaking, are you satisfied with the information you read about anti-HIV treatments?* A third (33%, n=138) were *very satisfied* and two thirds (63%, 262) were *somewhat satisfied.* Just one respondent in 25 (4%, 18) was *not at all satisfied.* Satisfaction with information read about anti-HIV treatments was associated with country of birth: respondents born in Zimbabwe were much more likely to be very satisfied with what they read about anti-HIV treatments (54% were very satisfied) compared with respondents born either in Uganda (28%) or Zambia (24% satisfied).

Those respondents (n=15, 3 missing) that reported being not at all satisfied were asked: *How could written information about anti-HIV treatments be improved?* Almost all their answers related to the difficulty of understanding the information presented, particularly it being too technical, medical, jargonistic or not clearly explained. Some also felt that there were such a range of publications (leaflets, newsletters) dealing with the same topics at the same time that written information seemed repetitive. A couple of people suggested improvements to the distribution of written materials so that they could access them more easily, for example via community gatherings or (GUM) HIV out-patients clinics, the latter being seen as particularly confidential places to access HIV information.

- 9% (n=38) of respondents had experienced problems getting information about anti-HIV treatments in the previous 12 months.
- Talking with medical staff like doctors and nurses was the most commonly used of all treatment information interventions in the last 12 months (96% had done this). Talking with workers from HIV (87%) and Black or African (76%) organisations was also very common, as was talking with other people with HIV, either informally (84%), or via support groups (84%).
- The majority reported attending presentations on anti-HIV treatments from medical staff (43%) or other people with HIV (63%) in the last 12 months.
- Almost all (99%) had read some information on treatments in the last 12 months, usually in leaflets (93%) and / or newsletters and the HIV-positive press (90%).
- Most respondents collected written materials from their HIV (GUM) clinic (83%) and / or from support groups and HIV organisations (80%). A quarter (27%) subscribed directly to written resources, received them from friends (26%) or accessed them via the internet (25%).
- Overall, 86% had taken home some reading matter concerned with treatments.
- Most respondents (96%) were broadly satisfied with the information they read about treatments.

5.5 EFFECTIVENESS OF TREATMENT LEARNING INTERVENTIONS

There are many ways to judge the success of interventions, and the preceding data gives us some insight into one of them: coverage. Coverage is the term we use to describe the proportion of the target population that is aware of, or has participated in, an intervention. The previous data shows that most broad categories of interventions concerned with anti-HIV treatment information are known and used by African people with HIV. The following data uses the same broad categories of interventions to try and demonstrate the likely effectiveness of these interventions among those people who use them.

Any respondent who reported having undertaken any of the learning activities described in section 5.4 was asked: *How important was [that activity] to your learning about anti-HIV treatments?* Responses offered were: *very important; a little important*; and *not at all important*. The following table shows the data in order of the highest ranked intervention first.

How important have the following activities been to your learning about anti-HIV treatments? **(Respondents doing each activity in last 12 months)**	**% Very Important**	**% A little Important**	**% Not at all important**
ATTENDING presentations (seminars) from medical staff (n=184)	91	7	2
ATTENDING presentations (seminars) from other people with HIV (n=268)	90	8	2
TALKING with medical staff like doctors or nurses etc. (n=413)	90	9	1
TALKING with other people with HIV at support groups (n=359)	87	12	1
READING newsletters and the HIV-positive press (n=390)	86	13	1
READING leaflets and pamphlets (n=404)	86	14	<1
TALKING with workers from HIV organisations (n=370)	85	14	<1
TALKING with workers from Black organisations (n=326)	83	16	<1
TALKING informally with other people with HIV (n=359)	82	17	<1
READING web-pages / the internet (n=140)	76	19	5
READING medical journals (n=123)	73	24	3
TALKING with my friends (n=275)	67	28	5
READING mainstream newspapers & magazines (n=314)	54	34	12

Overall, the majority of interventions are highly ranked in terms of their importance. That is, all the groups of interventions intended to inform people about anti-HIV treatments are ranked as *very important* by more than three-quarters of all respondents who had used them. Variation in the ranking of interventions is not substantial, with most ranked as *very important* by 83-91%, and *not at all important* by 1-2% of the users of that intervention.

While the broad order of the interventions is similar to that in section 5.4 (concerning use of them in the last 12 months), some differences were observed. Attendance at presentations (seminars) from medical staff and from other people with HIV is ranked at the top – these interventions are used by *only* two thirds of respondents but ranked as very important by the largest proportion of users (91% and 90% respectively).

5.5.1 Overall utility of learning interventions

Having predicted that most respondents would rate most treatment information interventions they had used as important, we also asked them *who or what has been most helpful to you in finding out about anti-HIV treatments?* The questionnaire included three blanks lines and interviewers were asked to record responses verbatim, recording also what was listed first, second and third. Among all respondents 3% (11) gave no answer; 11% (48) gave one; 30% (131) gave two answers and 56% (245) gave three or more answers.

From the actual words recorded it was possible to re-code almost all answers (about 96%) into the broad categories used in previous sections. Presenting the data in this format facilitates comparisons with other questions. The original answers that could not be categorised in this way were either so general as to be unhelpful (eg. 'reading', 'myself', 'library', 'professionals') or were simply misunderstandings of the question ('adherence' etc.). To facilitate recoding we added one category (Family) and merged presentations (seminars) from medical staff and from other positive people into one category. While some mentioned a type of speaker at presentations, most did not. The answers 'workshops' was also added to the presentations and seminars category.

The table below outlines the proportion of all respondents that mentioned each category as being most helpful to them in finding out about anti-HIV treatments. Column one shows the proportion that mentioned that category at all and the remaining 4 columns show what proportion mentioned it first, second, third and fourth. The listed fourth column was added because some respondents listed items together that were subsequently separated in the data cleaning (for example, newsletters and leaflets).

WHO or WHAT has been most helpful to you in finding out about anti-HIV treatments? **Whole sample (N=424, 11 missing)**	**% Listed AT ALL**	**% Listed FIRST**	**% Listed SECOND**	**% Listed THIRD**	**% Listed FOURTH**
(TALKING with) Medical staff: doctors / nurses etc.	86	63	16	7	<1
(TALKING with other PWHIV at) Support groups	46	11	25	9	<1
(READING) Newsletters & the HIV-positive press	27	5	8	10	4
(READING) Leaflets & pamphlets	19	2	7	8	2
(TALKING with) workers from HIV organisations	18	6	6	4	<1
(TALKING with) my Friends	11	1	3	6	<1
(READING) Web-pages / the internet	10	2	4	3	<1
(TALKING with) other PWHIV (informally)	9	1	4	3	<1
(ATTENDING) Presentations, seminars & workshops	8	2	3	2	<1
(TALKING) with Family	7	2	4	<1	0
(TALKING with) workers from Black (or African) organisations	7	2	4	1	<1
(READING) Medical journals	4	<1	2	1	<1
(READING) Mainstream newspapers & magazines	<1	0	<1	<1	0

By far the most common response overall was medical staff like doctors and nurses etc (listed by 86% of all respondents). It was also the response most likely to be listed FIRST (by 63%). While the category *medical staff like doctors and nurses etc.* is very broad, the vast majority (90%) of answers within it were *doctor* or *consultant* or *doctors and nurses*. Some respondents specified the type of doctor (eg. *clinic doctor*) or consultant (eg. *HIV consultant*) but the vast majority did not. While a few specified GP or family doctor (<2% of all who mentioned the category) the majority are assumed to have been referring to staff of HIV / GUM out-patients services. The next largest staff group included were nurses. The majority of mentions of nurses were not specific but a variety of types were alluded too (eg. *clinical nurse specialist, HIV specialist nurse*). Also included in this category (in broad order of most common first) were social workers, pharmacists, midwives, counsellors, health advisors and dieticians. Some of the responses in this category allude to *talking* with various types of medical staff but most just cite the staff type (doctor, nurse) or group (eg. medical staff, clinic staff).

The second most common response to the question *who or what has been most helpful to you in finding out about anti-HIV treatments?* was support groups (listed by 46% of all respondents). It was also the response second most likely to be listed FIRST (by 11% of all respondents) and most likely to be listed SECOND (by 25%). Most of the respondents that specified any more than just 'support groups' stated that it was talking to other people with HIV at them that was valued. A few respondents mentioned talking with staff or workers also. While not all respondents mentioned talking at support groups this is assumed for all responses.

Since peer support obviously plays a substantial part in the value attached to support groups, this category should be considered in combination with the eighth most common response, talking (informally) with other people with HIV (listed by 9% of all respondents) and the sixth most common response, talking with friends (listed by 11% of all respondents). While it is far from certain what proportion of *friends* will also have diagnosed HIV, some probably will. Talking with family was also mentioned by 7% of all respondents.

Talking with – and listening to – a range of other professional groups and individuals was also important to many respondents. The fifth most common response to the question *Who or what has been most helpful to you in finding out about anti-HIV treatments?* was talking with workers from HIV organisations (listed by 18% of all respondents) and eleventh was talking with workers from Black or African organisations (listed by 7%). Attending presentations, seminars and workshops was mentioned by 8%.

Reading interventions were also popular. The third most common response overall was reading newsletters and the HIV positive press (listed by 27% of all respondents) and fourth overall was reading leaflets and pamphlets (listed by 19%). While some respondents mentioned specific newsletters (especially AIDS Treatment Update) and magazines (especially Positive Nation) the majority did not. Similarly, specific leaflets or pamphlets were rarely mentioned though those that were, usually originated at NAM or the Terrence Higgins Trust. While a smaller proportion of respondents mentioned reading web-pages and using the internet (10%) this still ranked as the seventh most common answer. Reading medical journals and mainstream newspapers and magazines for HIV treatment information were rare.

- Attendance at presentations (seminars) is ranked as very important in their learning about anti-HIV treatments by the largest proportion of users.

- The majority of types of interventions are very highly ranked in terms of their importance to their users.

- Talking with medical staff like doctors and nurses etc. was by far the most helpful treatments information intervention (listed at all by 86% of respondents, and listed FIRST by 63% of them).

5.6 LEARNING MORE ABOUT ANTI-HIV TREATMENTS

All respondents were asked if they *would like to know more about anti-HIV treatments?* Overall **91%** (n=396) stated that they would like to know more, and only **9%** (n=39) did not. Wanting to know more about anti-HIV treatments varied according to respondents' own treatment taking history. The majority of respondents currently on treatments wanted to know more (94%), as did an even higher proportion of those who had previously taken them but were not currently doing so (96%). However, even four fifths (80%) of those respondents who had never taken anti-HIV treatments wanted to know more about them. Wanting to know more about anti-HIV treatments was associated with gender. That is, women were more likely than men to want to know more about anti-HIV treatments (93% compared to 87%).

All the respondents who wanted more information about anti-HIV treatments were asked: *How would you like to learn more about anti-HIV treatments in the future?* and given the same 13 options as earlier questions about finding out about anti-HIV treatments. Responses are outlined in the table below. Column one shows the percentage that wanted to learn more using each type of intervention, ordered from most popular first. Column two shows the proportion of respondents that had done that intervention in the last 12 months and wanted to use it to learn more. Column three shows the proportion of respondents that had NOT done that intervention in the last 12 months but wanted to use it in the future.

How would you like to learn more about anti- HIV treatments in the future? Respondents wanting to know more (n=396)	% wanting to access intervention	% of those DONE it	% ofthose NOT DONE it
TALKING with medical staff like doctors or nurses	82	82	93
ATTENDING presentations (seminars) from medical staff	76	**87**	68
READING newsletters and the HIV-positive press	74	**76**	56
ATTENDING presentations (seminars) from positive people	73	**79**	62
READING leaflets and pamphlets	73	74	65
TALKING with workers from HIV organisations	72	**74**	59
TALKING with other people with HIV at support groups	71	**76**	44
TALKING with workers from Black organisations	69	72	63
TALKING informally with other people with HIV	67	**71**	44
READING medical journals	62	**79**	51
READING web-pages / the internet	57	**70**	51
READING mainstream newspapers and magazines	55	**62**	35
TALKING with my friends	46	**60**	22

This data demonstrates the on-going acceptability and appropriateness of the range of broad types of interventions through which anti-HIV treatments information is currently delivered. The majority of interventions previously experienced, are highly valued for continuing future learning. That talking with medical staff is the first choice of the majority of respondents is in line with earlier research among Ugandans with HIV in South London who showed a mark preference for receiving health promotion interventions form medical personnel (McMunn, Mwanje, Paine & Pozniak, 1998).

Columns 2 and 3 demonstrate that, generally speaking, respondents that have experienced an intervention in the last 12 months are more likely to want to do so again in the future. For ten of the 13 categories of intervention this difference is statistically significant (denoted by **bolding** of the higher figure and underlining of the lower).

However, high proportions of respondents who have not done most of the interventions would like to access them in the future. This is especially true of attendance at presentations (seminars) of both types; reading newsletters, positive press, leaflets and pamphlets; talking with medical staff and workers from HIV and Black (African) organisations; and reading medical journals and web-based information. More than half of all Africans with HIV, that have not done these things in the last 12 months, would like to do so in the future in order to help them learn about anti-HIV treatments.

The core set of treatment information interventions which we examined appear in a similar – but not identical – order of popularity when we compare data on which respondents have already done in the last 12 months (column 1 from section 5.4); which they rate as *very important* in their previous learning (column 2 from section 5.5); and the interventions they want to access in the future, to continue learning about treatments (column 3 from section 5.6).

COLUMN 1: ***... which of the following activities have you done in the last 12 months?*** **COLUMN 2:** ***How important have the following activities been to your learning ... ?*** **COLUMN 3:** ***How would you like to learn more about anti-HIV treatments in the future?***	**% DONE in the last 12 months**	**% rating very important**	**% wanting to access intervention in FUTURE**
TALKING with medical staff like doctors or nurses	96	90	82
READING leaflets and pamphlets	93	86	73
READING newsletters and the HIV-positive press	90	86	74
TALKING with workers from HIV organisations	87	85	72
TALKING informally with other people with HIV	84	82	67
TALKING with other people with HIV at support groups	84	87	71
TALKING with workers from Black organisations	76	83	69
READING mainstream newspapers and magazines	75	54	55
TALKING with my friends	64	67	46
ATTENDING presentations (seminars) from positive people	63	90	73
ATTENDING presentations (seminars) from medical staff	43	91	76
READING medical journals	42	73	62
READING web-pages / the internet	34	76	57

If we examine these data side-by-side we see that for four of the interventions that are used by relatively few of the respondents (at the bottom of the table) – attending presentations of both types, reading medical journals and reading web-pages – then more respondents want to access these interventions in the future, than have managed to do so in the last 12 months. If there are a range of interventions where greater access is necessary then it is probably these four.

- The majority (91%) of respondents wanted to know more about anti-HIV treatments.
- All the specific types of interventions through which anti-HIV treatments information is currently delivered were acceptable and appropriate to the majority of respondents.
- The majority of types of interventions previously experienced were highly valued for continuing future learning.

5.7 SUMMARY

- Outside London the vast majority attended HIV clinics in the PCT in which they lived (Leeds 92%, Manchester 95%). In London, less than half (0-60%) stayed in the PCT they lived for their routine HIV care.
- More than one third (38%) reported attending HIV out-patients at least every month and the majority (91%) attended at least every three months.

- The majority of all current treatment takers either *usually* (56%) or *always* (41%) understood the information given to them by HIV clinic staff.
- The vast majority (96%) of respondents currently taking treatments were *somewhat* (51%) or *very satisfied* (45%) with the way decisions about anti-HIV treatment were made between themselves and HIV clinical staff.
- Of those respondents currently on treatments that reported any missed doses, the majority *always* (62%) or *sometimes* (22%) informed their doctor.

- 9% (n=38) of respondents had experienced problems getting information about anti-HIV treatments in the previous 12 months.
- Talking with medical staff like doctors and nurses was the most commonly used of all treatment information interventions in the last 12 months (96% had done this). Talking with workers from HIV (87%) and Black or African (76%) organisations was also very common, as was talking with other people with HIV, either informally (84%), or via support groups (84%).
- The majority reported attending presentations on anti-HIV treatments from medical staff (43%) or other people with HIV (63%) in the last 12 months.
- Almost all (99%) had read some information on treatments in the last 12 months, usually in leaflets (93%) and / or newsletters and the HIV-positive press (90%).
- Most respondents collected written materials from their HIV (GUM) clinic (83%) and / or from support groups and HIV organisations (80%). A quarter (27%) subscribed directly to written resources on treatments, received them from friends (26%) or accessed them via the internet (25%).
- Overall, 86% had taken home some reading matter concerned with treatments.
- Most (96%) were broadly satisfied with the information they read about treatments.

- Attendance at presentations (seminars) is ranked as very important in their learning about anti-HIV treatments by the largest proportion of users.
- The majority of types of interventions are very highly ranked in terms of their importance to their users.
- Talking with medical staff like doctors and nurses etc. was by far the most helpful treatments information intervention (listed at all by 86% of respondents, and listed FIRST by 63% of them).

- The majority (91%) of respondents wanted to know more about anti-HIV treatments.
- All the specific types of interventions through which anti-HIV treatments information is currently delivered were acceptable and appropriate to the majority of respondents.
- The majority of types of interventions previously experienced were highly valued for continuing future learning.

6 Conclusion: what does this mean for policy and practice?

At present the increasing population of African people with HIV is the most complex challenge posed by HIV and AIDS in the UK. This report seeks to begin the process of describing and understanding the reality of everyday life for African people with HIV resident in England. This should help commissioners, policy makers and health promotion practitioners to invest in, and deliver more appropriate and higher quality services. Such stakeholders have not waited for research to steer them, nor should they have, but they can use this data to begin to consider the ways in which they fund and organise future developments.

This research is fundamentally descriptive – it obviously does not answer every question or even address every area it might have. It is just the beginning of a process of describing and understanding the lives of a large portion of the population of people with HIV. However, it does undermine some of our assumptions about this group and lays the groundwork for further more detailed research. Contrary to popular belief, African people with HIV are not particularly hard to reach nor are they substantially unwilling to participate in this kind of research exercise. However, researchers (and their funders) must be willing to adapt their research methods and invest in the training and development of those individuals and organisations that already have the cultural competence to engage with this very diverse population.

The impact of migration on HIV-related need is identified clearly in this data. High levels of need are pervasive and especially common among those African people with HIV that have been resident in the UK the shortest time. This suggests an important future focus for HIV services – that those resident in the UK for the shortest periods should disproportionately benefit from interventions.

Health promotion programmes for African people with HIV should include interventions aimed at supporting people to resolve practical problems, such as: maximising their income; dealing with the immigration services; improving their housing and living conditions; managing relationships (and friendships); accessing skills training and job opportunities; looking after themselves and their children; getting around locally; and finding out about HIV treatments. They should also include interventions increasing mental health and well-being, by addressing problems such as anxiety, depression and lack of self-confidence and the factors that interact with them such as sleeplessness and sexual problems.

Levels of need are much greater for African than for white British people with HIV in many areas, especially the very practical aspects of life such as getting enough money to live on and housing and living conditions. This finding supports an on-going process, underway in many parts of the UK, to re-orient long established HIV organisations, services and organisational cultures to be more responsive to the needs of African people. This picture of need also supports the development of African-led responses to HIV and the development of African HIV community organisations.

While access to anti-HIV treatments and adherence to the regimens was not substantially more problematic among this group than the white British, problems with knowledge of anti-HIV treatments were very common. That is, African people with HIV were 8 times more likely to report problems with what they knew about treatments than their white British counterparts. This suggests that interventions intended to improve knowledge of anti-HIV treatments should be heavily biased towards African people with HIV.

The data in chapter 5 on access to, and experience of, treatment information interventions suggests that the current range of interventions is broadly acceptable to Africans with HIV. The role of the clinician as a fundamental source of treatment information is an important finding, as are the findings that a high proportion read printed information and talked about treatments with staff at HIV and African organisations, and with other people with HIV at support groups and elsewhere.

The data challenges previous notions that reading is fundamentally problematic for cultural reasons and demonstrates that printed materials (such as newsletters, leaflets and the HIV-positive press) are broadly acceptable. However, such resources probably need to be made available in a broader range of contexts and settings, including GUM / HIV out-patients clinics. There was also a high demand for seminars, presentations and workshops. While these were not the most popular interventions they were among very few where more people wanted to use them in the future than had done so in the past. Reading medical journals and using the internet were the only other interventions that followed this pattern and providing access to them is also worth considering.

The finding that treatment information need is much more common among African than white British people with HIV may seem inconsistent with the data that suggests that most Africans have access to treatment information interventions and are broadly satisfied with them. It is not – the vast majority (91%) of African people with HIV want to learn more about treatments but only one in ten (9%) had any difficulties accessing treatment information in the last year. Within this population a much higher proportion has had diagnosed HIV infection a relatively short time, certainly compared to gay men, and many are diagnosed a relatively long time after infection. As a consequence the need to learn about treatment options is immediate and pressing for much larger proportion of the population.

The challenges for African community organisations, HIV organisations, NHS services and for government – both local and national – are significant. While HIV remains so linked to social exclusion, the full benefits of both HIV treatment and care and HIV prevention programmes will not be realised. The findings on disclosure of HIV status underline this point. Many in the sample have not disclosed their HIV status to their parents, and some have not disclosed to siblings, friends, and their children. Not only does this point to a very real fear of HIV stigma and discrimination, but it also suggests a reduced likelihood of informal social support.

The picture provided by this research is just a beginning. So much of the experiences identified here require much more exploration to promote greater understanding. For example, when we identify that three quarters are taking anti-HIV treatments, many more questions emerge: what are the experiences of side effects? How are HIV treatments shaping peoples' sense of future? How do HIV treatments effect family or working lives? Similarly, when half identify problems with relationships, what does this mean? Are people having the intimate relationships that they want and need? Are the problems with relationships about their breakdown or about the pressures of HIV impacting on them?

A picture of HIV need amongst African communities resident in the UK is slowly emerging, despite the absence of a unified national policy and research framework. Many NHS providers and community organisations are already seeing and responding to the range of needs identified here. When funding and national government policy catches up with this shift, the social research agenda will become clearer. This research, funded by donations from a variety of sources and the goodwill of the partner organisations, will act as a 'way in' to understand a wide range of complex human needs that are fuelling the problem of HIV amongst African people resident in the UK.

Governments in the UK must attend to this shift by:

- developing HIV policy that responds to many of these needs both within and beyond public health;
- providing human rights protections to all people with HIV in the UK, including those from African communities, to create a supportive legal and policy environment for better HIV prevention, treatment and care; and
- re-focussing the national HIV social research agenda to answer some of the many questions raised by this, the UK's first survey of need specifically targeting African people with HIV.

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